

**I want to do something positive with
my experiences:
The Youth Involvement in Mental
Health Research project**

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Declaration

I, Rebecca Kate Randall, declare that the PhD thesis entitled: I want to do something positive with my experiences: The Youth Involvement in Mental Health Research project— is no more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. All chapters of this thesis were drafted independently and revised with input from my supervisory panel. I certify that all sources consulted are acknowledged in this thesis.

Signed:

Date:

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Dedication

Consumer and community involvement is only ever possible because people care enough to use their experiences to serve others. I have been privileged to be part of the Australian mental health consumer community for over 10 years, and during those years to have been cared for, nurtured and accepted by people who I have loved and admired.

This thesis is written for that community—to celebrate who we are, to challenge where we are at, and to help the broader research community engage with our wonderful piece of the world. I have tried to, and hope, that it does justice to a community of people who are incredibly precious to me. To my elders: thank you for being such tall giants and for so graciously letting me stand on your shoulders. To my contemporaries, and in particular to the young people of the Young and Well Cooperative Research Centre, this is my contribution to an important conversation—please take it, use it, rip it to shreds and use it as either scrap metal or building blocks.

Near the end of my time writing this, Jackie Crowe, a giant of the Australian mental health consumer community, passed away. It is with deep reverence and a lot of love that I dedicate this work to her.

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On a personal note—I am the first in my family to complete a PhD. As a young woman with a severe mental illness, this achievement is more a reflection on the people in my life than it will ever be on me. To the people who have walked this journey with me, thank you. For the gifts of emotional support, long hours of listening, endless hugs and the thousand other ways that support has been expressed I will be forever grateful. Special thanks go to two very special people: my father, Robert and my husband, Adrian.

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Abstract

Consumer and community involvement in research and health services is an increasingly well recognised area of research methodology and practice, yet one which is not well documented in the published literature (Staniszewska et al., 2017). When applied specifically to youth mental health research this absence of documentation is particularly pronounced (Mawn, Welsh, Stain, & Windebank, 2015). In the instances where it has been directly examined, it has typically been from the point of view of researchers, not young people.

The Youth Involvement in Mental Health Research project sought to investigate this issue by examining the characteristics, motivations and experiences of the young people involved in youth mental health research. The project specifically focused on the experiences of young people and researchers who were part of an Australian multi-institutional cooperative research program (the Young and Well Cooperative Research Centre (the CRC)) which involved young people in every research project and at an organisational level.

A multi-method approach was used involving five interconnected studies. Three studies used qualitative methods: focus groups, interviews and analysis of existing data; and two used quantitative methods: a longitudinal study and an online cross-sectional survey. Across these studies, four participant groups were considered: young people aged between 18 and 25 who were involved in the research projects of the CRC, including young people who were part of the youth advisory group of the CRC (the Youth Brains Trust), other young Australians aged 18 to 25, and researchers who conducted research as part of the CRC. This breadth has allowed the perspectives of a range of different stakeholder groups to be compared and contrasted.

This study is the first comprehensive description of the young people who were involved in an extensive program of youth mental health research. The current literature is predominately small-scale studies of single instances of involvement, which are mainly focused on the researcher's experience. By contrast, the current project's use of five studies which each examine different facets of the young people who are involved provides a greater level of depth and breadth.

The results of the project show that young people who are involved in youth mental health research have higher rates of mental ill health than the rest of the population. They are motivated to do this work to further their relationships with researchers and each other, and to gain new skills. Their involvement entails a wide

range of traditional and non-traditional research activities such as being involved in project design and planning, and is largely a positive experience.

The project represents an important step in the field of consumer and community involvement by highlighting the contribution of young people to this work. This group has not been consistently or sufficiently acknowledged as key informants to the work they have been involved in. Findings suggest greater effort is needed to include young people from a broader range of backgrounds such as culturally and linguistically diverse groups, and that the experiences of young people who are involved could be improved by working with young people across all stages of the research such as design, analysis and dissemination of findings.

1 Introduction

1.1 Overview

Young people around the world, including in Australia, experience high rates of mental ill health (Australian Bureau of Statistics, 2014b; Patel, Flisher, Hetrick, & McGorry, 2007), but do not seek help at commensurate rates (Bhugra, 2010). While attempts to change this are ongoing, it is a problem for which there are currently limited solutions. An important aspect of any potential solution is involving the young people who benefit from mental health research in designing and executing research, and the outputs of research, which will benefit them. This approach is known as community and consumer involvement.

Mention of consumer and community involvement in policy and practice guidelines is increasingly prominent and frequent, in both youth mental health research specifically, and in broader health research and service delivery. Despite this, there has been minimal direct examination of the young people who take part in these activities. The majority of literature on the topic either discusses the principles of youth involvement, or provides suggestions for how to involve consumers and young people. Some papers report small case studies where youth involvement processes were used in mental health research, but have limited detail about the young people who were involved.

The Youth Involvement in Mental Health Research (YIMHR) project addresses this gap. It is based on the premise that understanding the characteristics, motivations and experiences of young people involved in youth mental health research will improve the practice of youth involvement by assisting with broadening the group of people who are involved, and improving their experiences when they are involved.

The project examines the Young and Well Cooperative Research Centre (the CRC). The CRC was an Australian, multi-institutional, cooperative research program which involved young people at an organisational level in its governance, guidance and strategic direction and in all of the research projects that the CRC funded. Examining youth involvement throughout the CRC meant that it was possible to obtain a broader picture than could be achieved through investigating individual instances of involvement in one research project.

The YIMHR project comprises three aims, explored through five different research studies: three qualitative and two quantitative, with four stakeholder groups. A

multi-method approach was used, with both open-ended exploratory work and the more directed investigation of a number of facets.

The thesis describes each of the studies individually while also detailing how they contribute to the aims of the YIMHR project. The present chapter introduces the terminology used in the project. Chapter 2 provides an overview of what is known from the published literature on the topic. Chapter 3 describes the design of the project and introduces the CRC and the researcher's relationship to the topic. Chapters 4 through 8 sequentially describe each study's specific design features, results and discusses the outcomes. The thesis concludes with Chapter 9, which discusses the findings in light of the aims, suggests practical implications of these results and proposes areas for future work.

1.2 Terminology

The concepts which underpin this project are used in a range of settings to mean similar, but slightly different, ideas. Because of this, it is necessary to clarify at the outset of the thesis what is meant by each of the main terms used.

1.2.1 Research involvement, participation and engagement

A variety of terms have been developed and used to describe consumer and community involvement throughout the history of the approach (Liabo, Boddy, Burchmore, Cockcroft, & Britten, 2018; Miller et al., 2017; Morley, Norman, Golder, & Griffith, 2016). This variation has arisen from the wide range of disciplines which have used, and contributed to, the theory and practice of this approach. It can be seen in the myriad of scales and conceptualisations of consumer and community, or public and patient, involvement and engagement that exist in research, policy, and practice. As Liabo, Boddy, Burchmore, Cockcroft and Britten (2018) explain, this variety has also contributed to the confusion that many researchers and health professionals report about involvement. The term most frequently used in North America is 'engagement', in the Netherlands it is 'participation', and as described below, the United Kingdom currently uses a range of terms to describe particular activities (Liabo et al., 2018).

INVOLVE, which supports active public involvement in health services, public health and social care research in the United Kingdom uses the following definitions:

Involvement: 'where members of the public are actively involved in research projects and in research organisations;'

Participation: 'where people take part in a research study;' and

Engagement: ‘where information and knowledge about research is provided and disseminated’ (National Institute for Health Research, 2018a).

The CRC used the following terms in its organisational vision:

Youth participation: ‘Young people are critical partners in our work. Involving young people meaningfully expands the quality of our research and ensures that our work is relevant, engaging and meets the needs of young people’.

End user engagement: ‘The Young and Well CRC believes that, in the words of VicHealth, ‘together we do better.’ We believe that we can have a much greater impact by working together as a collective than we can as individuals’ (Young and Well Cooperative Research Centre, 2016b).

When the INVOLVE and CRC descriptions are contrasted, it is apparent that there are differences in how different groups use the terms ‘involvement,’ ‘engagement,’ and ‘participation.’ Because the definitions used by INVOLVE are more commonly used in the published literature they have been used in this thesis. However, because the work aimed to document what had occurred in practice, and how those who executed this work described what they had done, engagement and participation level activities were also examined. This is most apparent in the first two studies, which used qualitative methods to examine the lived experience of involvement, participation and engagement.

1.2.2 Civic participation

The term ‘civic participation’ is used to describe a situation where young people are active in their communities beyond the day-to-day activities of living. As with research involvement, considerable ambiguity and disagreement exists concerning what nomenclature should be used to describe this range of actions. Checkoway (2011), in an examination of what is known about civic participation, suggested that when ‘...people are involved in the institutions and decisions that affect them, it is participation’ (page 341; Checkoway, 2011).

Where the term ‘civic participation’ is used in this thesis, it is used as defined by Checkoway. Because the project focuses on young people, the term ‘civic’ is used instead of ‘youth’ to make a clear distinction between the two areas.

1.2.3 Research

In this thesis, the definition of ‘research’ is that used by the National Health and Medical Research Council in the Australian Code for the Responsible Conduct of Research. It defines research as: ‘an original investigation undertaken to gain knowledge, understanding and insight’ (page 1; National Health & Medical Research Council, 2007).

This definition is inclusive of research about the development of health services. It excludes investigations or research which describes the ongoing delivery of a service. For example, work which describes how young people have been involved in an advisory group or board assisting the execution of a service is not included within the definition.

1.2.4 Young people

Throughout the thesis, the terms ‘young person’ and ‘young people’ are used to describe people aged 18-25 years of age. The reason for the choice of this age range is described in Chapter 3, Section 3.7.

1.2.5 Mental health

In this thesis, the term ‘mental health’ refers to health conditions, and aspects of a person’s lived experience, which affect their emotional and mental wellbeing in both a positive and negative manner. Where the terms ‘mental ill health’ or ‘mental illness’ are used, this is as defined by the Australian Commonwealth Department of Health: ‘a health problem that significantly affects how a person feels, thinks, behaves, and interacts with other people’ (Australian Government Department of Health, 2007).

2 Literature review

2.1 Overview

The goal of the Youth Involvement in Mental Health Research (YIMHR) project is to increase the understanding of the characteristics, motivations and experiences of young people who are involved in youth mental health research. This goal is achieved through an examination of an organisation which mandated the use of youth involvement techniques in its organisational structure and the projects which it funded, the Young and Well CRC (the CRC). Section 2.2 of this chapter describes the demographic characteristics, mental health, and civic participation and volunteering of the CRC's target group—young Australians aged 18-25.

The majority of the chapter (Sections 2.3 – 2.6) focuses on consumer and community involvement in research and mental health service development. Section 2.3 describes the origin and rationale for consumer and community involvement in research and mental health service development. The ways and processes used in involvement, and an overview of contextual influences, is described in Section 2.4. What is presently known about the three key dimensions examined in this thesis: the characteristics, motivations and experiences of those who are involved in areas other than youth mental health research, is described in Section 2.5. The limited work which has specifically focused on youth involvement in mental health research is reviewed in Section 2.6. As this section demonstrates, work in the area to date is limited to a small number of papers about the principles of involvement, and a slightly larger, but still limited, number of papers which have described the involvement of young people in mental health research.

The work which informed this literature review has been drawn from a variety of sources. Section 2.2, which describes the CRC's target group, was derived from Australian sources including government databases such as the Australian Bureau of Statistics. Preference has been given to data which is nationally representative, where possible.

The majority of the chapter was informed by searches of peer-reviewed literature and grey literature which were undertaken in early 2013, the end of 2016 and March 2018. The PsycInfo, PubMed and the Web of Science databases were searched using terms including those in Table 2.1 below (inclusive of relevant combinations of these terms, e.g. 'patient and public involvement'). Where relevant, the 'young person'

terms were included or excluded in order to find the work relevant to the specific sections.

Table 2.1 *Search terms used for peer-reviewed literature*

Concept	Search terms
Young people	Young people, young person, adolescent, youth, students, young adult, emerging adult, young male, young female, volunteers, volunteer, caregivers, carer client, consumer, patient, patients, survivors, survivor, Sx, user
Forms of involvement	Involvement, participation, personal narratives, participatory design, experience based, co-design, governance
Mental health	Mental health, mental health care, social welfare, well-being, mental disorder, mental illness, mental disease, fear, mood disorder, depression, dysthymia, stress, stress disorder, acute stress, anxiety, panic, agoraphobia, social phobia, generalized anxiety disorder, GAD , obsessive compulsive, OCD, adjustment disorder, separation anxiety , post-traumatic stress, stress disorders, post-traumatic, post-traumatic, post-traumatic stress disorders, ptsd, phobia, mild depressive disorder

In addition to these searches, the grey literature was extensively searched throughout the project. Grey literature consists of reports, websites and other materials published outside the academic or peer-reviewed literature. Mental health websites, peak health and mental health consumer organisation websites and known participation sites such as INVOLVE were searched for information relevant to the topic of the thesis. This was supplemented with searches of Google and Google Scholar using a combination of the terms outlined in the table above. Finally, academic informants such as the supervisory team and researchers in the CRC were consulted and relevant papers provided by these informants.

2.2 Young Australians: their mental health, demographic characteristics and civic participation

2.2.1 Overview

The CRC worked with young Australians to improve their mental health and wellbeing through the use of digital technologies. The characteristics of the population which the CRC aimed to involve, young Australians aged 18-25, are described in order to situate the specific explorations conducted in the thesis. Specifically, what is known about their mental health, demographic characteristics and civic participation is reviewed.

2.2.2 Mental health

Mental ill health is a considerable problem worldwide, contributing to adverse economic and social outcomes including unemployment, physical illness, and lost productivity at school and work (Patel, Flisher, et al., 2007). Reported prevalence of mental ill health in adults varies worldwide, and drawing international comparisons is challenging due to the heterogeneity of measurement instruments and methods employed across studies (Patel, Araya, et al., 2007). Estimates of 12 month prevalence in developed countries vary from 8% in the Netherlands, to up to 57% within certain geographical areas in the USA (Patel, Flisher, et al., 2007). Across the countries of the Organisation for Economic Cooperation and Development (OECD), on average 20% of the working age population will experience mild to moderate disorders each year (OECD, 2014).

Mental ill health is particularly prevalent among young people. Of those who develop a psychiatric condition in their lifetime, 50% do so by 14 years of age, and 75% before 25 years of age (Patel, Flisher, et al., 2007). In Australia, estimates of the overall prevalence of youth mental ill health vary between 16.3% and 27% (Australian Bureau of Statistics, 2014b; Patel, Flisher, et al., 2007). The more recent of these figures, 16.3%, was derived from the Australian Bureau of Statistics' General Social Survey, which asked if participants self-defined as having a behavioural or emotional disorder (Australian Bureau of Statistics, 2014b).

Higher rates of psychological distress have been observed within two specific groups of young people: Lesbian, Bisexual, Transgender or Intersex (LGBTI) and Aboriginal and Torres Strait Islander young people (Australian Bureau of Statistics, 2014a, 2014c; Lea, de Wit, & Reynolds, 2014; National LGBTI Health Alliance & Rosenstreich, 2013; Robinson, Bansel, Denson, Ovens, & Davies, 2014). LGBTI young people experience psychological distress, suicidality and substance use problems, and experience abuse at considerably higher rates than heterosexual young people of a similar age (Lea et al., 2014; National LGBTI Health Alliance & Rosenstreich, 2013; Robinson et al., 2014; Smith et al., 2014). These higher rates are thought to be due to the increased presence of risk factors in this group, including internalised homophobia and perceived stigma associated with membership of the group (Lea et al., 2014; National LGBTI Health Alliance & Rosenstreich, 2013; Smith et al., 2014). Similarly, a comparison of rates of psychological distress between young Aboriginal and Torres Strait Islander Australians aged 15 to 24 and the non-indigenous population found that young Aboriginal and Torres Strait Islander Australians self-report high, or very high

rates of psychological distress at approximately twice the rate of non-indigenous Australians (Australian Bureau of Statistics, 2014a).

Worldwide, rates of help seeking are not commensurate with rates of experience of mental ill health (Bhugra, 2010). International estimates suggest that up to 60% of young people who need treatment do not receive it (Kessler et al., 2007; OECD, 2014). In any one year, fewer than 22% of Australians aged 16 to 24 with a diagnosable mental disorder access mental health services (McGorry, Bates, & Birchwood, 2013; Slade, Johnson, Oakley Browne, Andrews, & Whiteford, 2009; Yap, Reavely, & Jorm, 2013). This trend is similarly evident when intentions to seek help are examined. A study of the help seeking intentions of 15 to 24 year old Australians found that only 10% perceived no barriers to seeking help, and that 39% of males and 22% of females would not seek help from formal services for personal, emotional, or distressing problems (Donald, Dower, Lucke, & Raphael, 2000). This discrepancy is a key issue in the mental health field. As discussed in Section 2.3, one of the assumptions that underpins the use of involvement is that it can increase the likelihood that a young person will use a service. Given the discrepancy between rates of experience of mental ill health and help seeking, and this assumption, it is useful to examine what is known about what impedes young people from seeking help (barriers), and what facilitates help seeking (facilitators).

A systematic review of studies which examined young people's reported barriers to, and facilitators for help seeking for mental health problems concluded that strategies for improvement should focus on improving mental health literacy and reducing stigma (Gulliver, Griffiths, & Christensen, 2010). The first of these, health literacy, has many dimensions (Rickwood, Deane, Wilson, & Ciarrochi, 2005). These include knowledge of how to prevent mental disorders, recognition of the symptoms of mental disorders, and knowledge of the sources of help for mental ill health (Griffiths, Christensen, & Jorm, 2009; Jorm, 2011; Jorm et al., 1997). Attempts to quantify rates of mental health literacy in the population have focused on the level of knowledge that people have about depression. Examples of measures include the Depression Literacy Scale developed by Griffiths and colleagues (Griffiths, Christensen, Jorm, Evans, & Groves, 2004; Gulliver et al., 2012) which asks participants true/false questions about facts about depression; and surveys which present participants with case vignettes describing a person with a mental health condition, asking them to identify which mental health condition was described (e.g. Reavley & Jorm, 2011a). A cross-sectional survey of young Australians aged 18 to 25 years employing the latter method found that this

group has low rates of mental health literacy compared to adults (Wright et al., 2005). This finding is important in the context of the present study because, if one of the goals of the use of involvement is to improve the rates of uptake of treatments, then involving young people with comparatively high rates of mental health literacy, and thus who may have higher rates of service use, may be problematic.

Possessing negative attitudes toward mental ill health and those who experience it, which is often referred to as stigma, is considered to be a major barrier to help seeking among young people (Gulliver et al., 2010; OECD, 2014). A variety of facets of stigma have been examined, including personal stigma—the attitudes a person holds regarding others; self-stigma—the views a person has about themselves; perceived stigma—beliefs regarding the stigmatising views others hold; and, interpersonal stigma—the stigma that occurs within interpersonal communication and lived engagements (Wright, Jorm, & MacKinnon, 2011). Reavely and Jorm's (2011b) national survey of young people's stigmatising attitudes towards people with depression, anxiety disorders and psychosis/schizophrenia, found that young people associated all mental disorders with unpredictability. As above, a range of measures have been used to attempt to understand the rates of mental health stigma in the Australian population. Because of the multi-faceted nature of the concept, few studies have attempted to ascertain the magnitude of the stigmatising attitudes held by specific population groups. One exception is Calear, Griffiths and Christensen (2011), who used the Depression Stigma Scale to conclude that levels of perceived depression stigma reported by young people were statistically significantly higher than the levels of personal depression stigma reported by young people.

Sources of help for mental health difficulties available to young people in Australia, and internationally, are varied. A recent major review of Australian programs and services for mental health found that there are a myriad of sources of information and advice available for people with mental ill health (National Mental Health Commission, 2014). However, these sources are poorly coordinated and existing systems do not maximise the best outcomes for either the people who use them, or the resources used to create and maintain them (National Mental Health Commission, 2014). A key recommendation arising from the review was that the mental health system should move to a person-centred approach. This approach was defined as being one where services are designed around the needs of people, rather than people having to organise themselves around services (National Mental Health Commission, 2014).

For young people, one avenue through which this may be achieved is the use of internet-enabled technologies, often referred to as e-mental health. As noted in the next section, almost all young Australians use the internet on a daily basis (Australian Bureau of Statistics, 2009b) for a wide range of purposes (Burns et al., 2014; Kauer, Mangan, & Sanci, 2014; Muir et al., 2009). This high rate of usage has stimulated a focus on the potential of e-mental health strategies and tools for providing e-mental health services to young people. E-mental health solutions can enable and empower young people to access help for mental ill health at times and places of their choosing, including in some cases anonymously, which may circumvent some of the major barriers to help-seeking in this group. Studies of structured online programs with this group have demonstrated both high rates of acceptability and significant improvements in mental health outcomes (Calear, Christensen, MacKinnon, Griffiths, & O’Kearney, 2009; Sethi, Campbell, & Ellis, 2010; Spence et al., 2011).

2.2.3 Demographic characteristics of young Australians

The following section describes the demographics of young Australians. The specific characteristics reported were chosen based on their relevance to youth mental health research and youth involvement practices. Where available, the results of national level studies of young people aged 18 to 25 are reported; however, this was not possible for all the characteristics described.

Young people aged 18 to 25 years comprised 10.5% of the Australian population at the last census (Australian Bureau of Statistics, 2016). This figure is broadly similar to Organisation for Economic Cooperation and Development (OECD) nations, in which young people account for between 8.0% and 14.3% of the population (OECD, 2010).

Approximately half of young Australians aged 18 to 25 are female (Australian Bureau of Statistics, 2016). The majority (89%) participate in full time education, training, employment, or a combination of full time education and part time employment (Australian Institute of Health and Welfare, 2015). The General Social Survey found that they are most frequently located in major cities (75%), with 15% residing in inner regional areas and the remaining 10% living in regional areas or remote communities (Australian Bureau of Statistics, 2014b).

In the last Australian Census of Population and Housing, the proportion of young Australians aged 18 to 25 who identified as Aboriginal or Torres Strait Islander was 12.5% (Australian Bureau of Statistics, 2016). The proportion of young people who

had arrived in Australia in the last 10 years was 16.7%, and the proportion who reported that they spoke a language other than English was 25.7% (Australian Bureau of Statistics, 2016).

The proportion of young Australians aged 18 to 25 who identify as LGBTI has not been comprehensively documented at a national level. The most recent national survey of a subset of this population group, people who identify as homosexual, was a self-selecting survey which used an online survey method. It found that among the young people aged 20 to 25 who were sampled, 6.5% identified as homosexual (Roy Morgan, 2015).

The 2009 Australian Bureau of Statistics Survey of Disability, Ageing and Carers indicated that serious disability was experienced by 3.4% of young people aged between 15 and 25 years, and that 41.4% of the same age group experienced a long term health condition in any one year (Australian Bureau of Statistics, 2009a). The rates of young Australians who have a caring role is also large, with 23.2% of Australians aged 15 to 24 self-identifying as being a carer (Australian Bureau of Statistics, 2009a). Homelessness is also a significant issue for young Australians, with 11% of 15 to 24-year old people having experienced homelessness at some point in their life (Australian Bureau of Statistics, 2014b).

Finally, young people in Australia self-report high rates of internet and technology use (Burns et al., 2014; Kauer et al., 2014; Muir et al., 2009). Almost all young Australians report that they use the internet (Australian Bureau of Statistics 2009), usually on a daily basis. They do so for a variety of reasons, the most common of which is to engage in social networking activities such as messaging, online games, and emailing (Australian Bureau of Statistics, 2011). They also use the internet to access services related to healthcare (8.4%), government information services (Australian Bureau of Statistics, 2014b), and to access online mental health services (Burns et al., 2014; Kauer et al., 2014; Muir et al., 2009).

2.2.4 Civic participation and volunteering

Studies that have documented the characteristics and motivations of young people who take part in civic participation are limited. However, a related area which has been more thoroughly examined in the published literature is volunteering. Consequently, the following section describes both civic participation and volunteering.

The 2016 Australian census indicated that 3.4 million people, or 20.6% of all adults in Australia, take part in some form of volunteering work in any one year

(Australian Bureau of Statistics, 2016). Among those aged 18 to 24 years this rate drops to around 18.8% (Australian Bureau of Statistics, 2016). The proportion of young people who volunteer regularly is even lower— only 4% of young people report volunteering in any one week (Australian Bureau of Statistics, 2006a). These volunteering rates are comparable to those in other OECD countries, though reliable comparisons are difficult as definitions and collection methods differ (Australian Government, 2011). The likelihood that a young person will take part in these activities has been linked to a range of factors, including gender, education level, socio-economic status, location, and cultural identification (Hickie, Groom, McGorry, Davenport, & Luscombe, 2005; Walsh & Black, 2015).

A greater percentage of young women tend to volunteer than young men, a pattern which is evident across all types of volunteering and civic participation (Muir et al., 2009). In the five years between 2001 and 2005, the median annual hours of volunteering decreased by 12 hours among young men, whereas it increased by two hours for young women (Australian Bureau of Statistics, 2006a).

Young people who self-report that they volunteer are more likely to be enrolled in an educational program than their counterparts, with approximately 40% of students volunteering in any one year (Australian Bureau of Statistics, 2012a; McCabe, White, & Obst, Patricia, 2007). Young people who are studying and not working, or who combine study and paid work, are significantly more likely to self-report that they volunteer than young people who are engaged in paid work only (Australian Bureau of Statistics, 2006b; Australian Institute of Health and Welfare, 2015; Muir et al., 2009). However, young people who are engaged in paid work are more likely to volunteer than young people who neither work nor study (Muir et al., 2009).

A review of previous studies of the characteristics of young people who volunteer, commissioned by the Australian Federal Government, found that young people who reside outside of major cities are slightly more likely to volunteer than young people who live in major cities (Muir et al., 2009). This finding suggests that young people may be more likely to volunteer where the community is easier to access, smaller, or more familiar (Muir et al., 2009).

The final characteristic that affects the likelihood that a young person will volunteer is cultural diversity (Muir et al., 2009). Specifically, lower participation rates have been observed in groups of young people for whom English is not their primary language (Australian Bureau of Statistics, 2012a; K. Brown, Lipsig-Mumme, & Zajdow, 2013; Muir et al., 2009), and in groups of young people who identify as being

from an Aboriginal, Torres Strait Islander or Indigenous background (Mission Australia, 2013).

In addition, a range of motivations that young people have for volunteering or civically participating have been described. These are examined in the following paragraphs.

Multiple studies have found that young people are motivated to volunteer in order to contribute to society or their community (Australian Institute of Health and Welfare, 2015; Muir et al., 2009; Walsh & Black, 2015), or to contribute to a worthwhile cause (Muir et al., 2009). Many believe volunteering is linked to good citizenship (Hill, Russell, & Brewis, 2009) and the opportunity to ‘make a difference’ (Ferrier, Roos, & Long, 2004; Hill et al., 2009; Moffat, 2011).

A range of social factors may contribute to the likelihood that a young person will volunteer. These factors include a desire for social contact, perceived pressure by a social group, or personal or family involvement in the cause (Australian Institute of Health and Welfare, 2015; Ferrier et al., 2004; Hyde & Knowles, 2013; Moffat, 2011; Muir et al., 2009; Snyder & Omoto, 2008). Young people may also volunteer for the perceived social benefits that volunteering may afford them, including the opportunity to receive acknowledgement or appreciation for their contributions (Edwards, Elwyn, Smith, Williams, & Thornton, 2001; Ferrier et al., 2004).

Young people also volunteer because they believe they can learn from their participation (Australian Institute of Health and Welfare, 2015; Hyde & Knowles, 2013), and/or develop skills that could be useful in progressing or obtaining work and career opportunities (Muir et al., 2009; Snyder & Omoto, 2008). However, the latter motivation is more often cited by young men than young women, particularly when young men are pessimistic about their future work prospects (Walsh & Black, 2015).

2.3 Consumer and community involvement: origins and benefits

2.3.1 Overview

At the broadest level, consumer and community involvement is an ideological tradition, investigative method and academic discipline. Fundamentally, it aims to redistribute ‘power’ from those who ‘have it’ to those who ‘do not’ through involving those without power in the processes and structures which shape their worlds. This redistribution of power can both empower the people who use the products and processes which are developed and help ensure that they are relevant to all the stakeholders who use or engage with them.

The concepts that underpin consumer and community involvement have been articulated by a range of authors from a broad range of disciplines. Within the areas of research and mental health, many in the field attribute the initial articulation to Arnstein (1969). Arnstein conceptualised involvement, which she referred to as participation, as a hierarchical ladder of processes with nine rungs that place significant value on the power of citizens to impact decisions that affect them (Arnstein, 1969). There are three areas, each made up of three rungs on the ladder, which describe a level of interaction between citizens, or people who use services; and policy makers, or creators of services. The three areas are non-participation, which describes situations where there is no interaction or exchange of power; degrees of tokenism, which are interactions where power is partly, but not completely exchanged; and degrees of citizen power, in which citizens have increasing control over the situation. This initial articulation has formed the basis of significant movements in areas as diverse as political science, development studies and health.

One particular movement which has developed from Arnstein's work is Hart's (1991) 'ladder of young people's participation.' The ladder is similar in style and content to Arnstein's, but focuses specifically on young people. The rungs on the ladder range from manipulation (level 1), to young people initiated and directed (level 7) and young people initiated, shared direction with adults (level 8). It was designed to assist people who understood that children and young people have a right to be active participants in their communities, and to put these values into action through articulating different ways that young people could participate or be involved.

The following section describes how the principles of involvement, which started with the above ladders, have been applied and developed in the areas of research and mental health. Following these overviews, the benefits that arise from using involvement methods are described.

2.3.2 Mental health

The academic discipline and clinical treatment of mental ill health has consistently involved stark differences in the levels of power afforded to people who experience mental illness and the professionals who care for them (Epstein, 2013; Gee, McGarty, & Banfield, 2015; Kaufman, 1999; Robson, 2008; Starkman, 2013). Consumer and community involvement in the mental health sector—one of the ways in which the power imbalance might be addressed—first arose in the form of the Consumer and Psychiatric Survivor Movement in the United Kingdom, United States,

Canada and Australia during the 1960s and 1970s (Epstein, 2013; Gee et al., 2015; Kaufman, 1999; Robson, 2008; Starkman, 2013). In Australia, the first clear articulation of involvement in mental health policy arose from the 1993 report of the National Inquiry into the Human Rights of People with a Mental Illness (the Burdekin report). The Burdekin report described the impact of societal stigma and disempowerment on the lives of Australians with mental illness (Burdekin, Guilfoyle, & Hall, 1993). It suggested that this impact could be reduced through actively involving people with a mental illness in mental health policy and practice.

In the quarter century following the Burdekin report, consumer and community involvement has become a high priority area both in Australia's national mental health policy framework (Browne & Hemsley, 2008) and internationally (OECD, 2014). International recognition is evidenced by the OECD's inclusion of 'mental health consumers' and 'mental health carers' as two of the four key stakeholder groups in the development of mental health policy and practice (OECD, 2014). Its importance in Australia is shown through policies such as the Australian National Mental Health Strategy, which includes the Statement of Rights and Responsibilities (P. Brown, 2012; Raphael, 1991); the First National Mental Health Policy (Australian Health Ministers, 1991); and the five National Mental Health Plans to date (Australian Health Ministers, 1993, 1998, 2003, 2009, 2017).

These policies aim to ensure that consumers and community members are involved from the micro level—for example in clinical service planning and treatment decisions; to the macro level—for example through providing input into how services operate, including helping plan and contributing to reform processes (Lloyd & King, 2003). Within the youth mental health field, an assumption which underpins the use of involvement practices is that young people will be more willing to use mental health services that have been designed in collaboration with young people (Swanton, Collin, Burns, & Sorensen, 2007). Given the high rates of mental ill health in this age group and the low rates of help seeking, as discussed above in Section 2.2.2, this function is particularly critical for this age group.

2.3.3 Research

Consumer and community involvement in research involves researchers recognising and valuing consumers and community members as active and equal partners in the research process, rather than as passive subjects of the research. The aim is to change research from being about, or for, consumers and community members to

being carried out with, or by, them. Where this aim is achieved, a range of benefits to the research, to consumers and to the researchers may result. A summary of some of these benefits is provided in the following section.

As discussed in Chapter 1, the terms used to describe the approach are not used consistently or clearly (Miller et al., 2017; Morley et al., 2016). One reason for this is that consumer involvement in research draws on, and has arisen from, two complementary, yet different, approaches and schools of thought—consumerist and democratic (Beresford, 2002). The former approach prioritises the improvement of the product through the involvement of consumers. By contrast, the democratic approach is concerned with the empowerment of consumers, and the exercising of their democratic right to be involved in decisions that affect their lives. For the purposes of this review, and project, no distinction is drawn between these two schools of thought. This is because the project focuses on the practice of involvement, and those who are involved, not the theoretical or ideological background. However, this distinction is noted because of the influence the two approaches have had on the development and execution of involvement practices.

In practice, consumer and community involvement in research is increasingly recognised in research direction and policy. In Australia, this is evidenced in the 2002 and 2016 joint statements between the National Health & Medical Research Council (NHMRC) and the Consumers Health Forum of Australia. The vision for these statements is: ‘consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.’ (page 2; National Health & Medical Research Council and the Consumers Health Forum of Australia, 2016).

Despite these high-level inclusions and mentions in policy, the extent to which involvement is practiced, and the quality of data which describes it, is not consistent or clearly established. This particularly pertains to the involvement of young people. For example, Brady and Preston (2017) conducted an evaluation of the extent and impact of young people’s involvement in studies funded by the United Kingdom’s largest research funder, the National Institute for Health Research. They concluded that most of the information collected by researchers regarding the involvement of young people noted only the stages of research in which the latter had been involved, with hardly any information on who was involved and how (Brady & Preston, 2017). They also note that most of the information collected on young people’s involvement is written by researchers (Brady & Preston, 2017). They suggest that there needs to be more

opportunities for young people to have a say on how they have been involved, and the difference that they think this has made to them and the research (Brady & Preston, 2017).

2.3.4 Benefits of consumer involvement in both mental health and research

A range of benefits—to the community, to researchers, to the research and service outputs, and to the consumers who are involved—arise from the involvement of consumers in research and service delivery. Broadly, these benefits can be related to the consumerist and democratic approaches described by Beresford (2002) and outlined above. The benefits to consumers specifically are described in detail below in Section 2.5.2 (motivations). The following section describes an overview of benefits that involvement brings to the research and research processes described to date. It demonstrates that these benefits have been predominately documented through primary research and researcher's reflections on the process.

Involvement of consumers and community members in both research and service development is widely recognised as helping research and services focus on issues that are relevant to patients and the public (e.g. Staniszewska et al., 2017). When young people specifically are involved, this is particularly important because of the differences in age and lifestyles which may occur between young people and researchers.

An essential feature of the involvement of consumers and community members, and young people in particular, is a substantial level of collaboration between all stakeholder groups (Ramey & Rose-Krasnor, 2015). Researchers reflecting on their previous involvement of young people have suggested that this can result in greater levels of mutual understanding or respect (Shaw, Brady, & Davey, 2011). Where young people are involved as researchers, it may also lead to research participants being more open and willing to discuss personal experiences (Kirby, 2004). Case et al.'s (2014) case study of a project which involve consumers in conducting focus groups to assess current perceptions of care, found this to be the case. In this study, the authors note that the involvement of consumers added validity, authenticity and legitimacy of the focus groups.

Where young people are involved in the research planning stage, their involvement may lead to data collection and outputs which are more appropriate. Researchers who have involved young people in mental health service delivery have described that they find it helpful in rethinking the issues they are presented with

(Ramey & Rose-Krasnor, 2015). Researchers who have involved young people in health and mental health research have suggested that the practice can lead to organisations and researchers working more closely with the end users and beneficiaries of their work (Blanchard, Hosie, & Burns, 2013; Fleming, 2010; Shaw et al., 2011). In some instances, this may even lead to the abandonment or revision of their previous ideas, as occurred in Owen et al.,’s (2010) study in which service users were involved in designing a text messaging intervention to reduce repetition of self-harm.

2.4 Consumer and community involvement: ways and processes employed, and contextual influences

2.4.1 Processes used

The active involvement, participation and engagement of consumers and community members is often achieved using a very broad range of processes and methods. The various methods used are often conceptualised as ladders, including those of Arnstein and Hart as discussed in Section 2.3 above (Arnstein, 1969; Hart, 1991), or more recently as spectrums of involvement, such as the IAP2 spectrum (International Association for Public Participation, 2014). Spectrums, such as IAP2, are a similar way to express the idea that participation, engagement and involvement can vary, and that the stages or rungs on a ladder are not necessarily discrete levels. As these conceptualisations convey, methods used range from those which are about informing, to those which involve collaboration with, and empowerment of, consumers. These methods can employ both formal and informal processes (McDonagh & Bateman, 2012). A review of the literature indicates that different groups have been taken part in involvement processes in different ways which have been described using a variety of names and terms (Domecq et al., 2014).

A summary of the most common processes used, and a critique of some of the benefits and limitations of them and where they sit on the IAP2 spectrum is shown in Table 2.2. A brief review of each of these processes, and examples of where they have been used, follows the Table.

Table 2.2 *Key features of common involvement processes*

Process	Key features	IAP2 level(s)	Benefits	Limitations
Participatory design	Iterative cycles between stakeholders, typically using workshops	Consult, involve, collaborate	Easily understood by researchers and young people; less resource intensive because of focus on workshops	Does not lend itself to the empower level of IAP2; can be limited in the type of involvement; more suited to some forms of research (e.g. design focused research) than other types
Participatory action research	Involvement throughout the research process, sometimes continuing after the research project has been completed	Collaborate, empower	Very in-depth form of involvement; emphasis on reflection phase, which allows stakeholder groups to learn from the experience	Resource intensive; requires researchers to have extensive links with community groups; may not be suited to non-community based research
Co-design processes	Creation of equal relationships between different stakeholder groups	All phases, depending on specific execution	Flexible, can be tailored to specific project needs or skills; may empower consumers through treating them as 'experts'	Can be used in such a variety of ways that the specific term can be meaningless; lack of perceptiveness can mean that involvement is tokenistic
Co-researchers	Consumers involved as researchers who have equal status with other researchers	Collaborate, empower	Genuine involvement as equals; consumers' expertise formally legitimatised	Requires training and availability of consumers; may result in some consumers not being able to be involved because of education and availability requirements; not

				necessarily suited to all ages or ability levels of consumers (e.g. young people and disabled people)
Researcher-led	Consumers are guided by researchers in specific ways or at specific stages	Inform, consult, involve	Less resource intensive than other methods; simpler because it is less of a departure from traditional practices	Consumers less actively involved; consumers may not feel as if their opinions have been as actively considered as with other methods
Consumer- or community-led	Consumers or community members lead the research, non-consumer researchers support	Collaborate, empower	Consumers lead the process; topics and processes are determined by consumers; empowers consumers to learn research skills	Requires consumers to have, or develop, research skills; has limited relevance to young people because of the high skill requirement

Participatory Design is a research method which is used in studies which aim to produce an intervention or product. It is underpinned by consumerist principles that emphasise the usability, effectiveness, and acceptability of the product that is being developed (Elf, Rystedt, Lundin, & Krevers, 2012; Orlowski et al., 2015). Interventions or products are developed by working in iterative cycles to build on each of the stakeholder's knowledge and understanding to develop and refine the product (Orlowski et al., 2015). The method has been used in a wide range of fields, such as mental health and human-computer interactions (Elf et al., 2012; Orlowski et al., 2015; Spinuzzi, 2005). As described in detail in Section 2.6, Wadley, Lederman, Gleeson and Alvarez-Jimenez (2013) used participatory design methods to develop an online therapy for young psychosis sufferers. One of the specific mechanisms they used was a workshop in which young people were presented with preliminary sketches of the intervention website and asked to comment on these.

Participatory Action Research (PAR), or Community-Based Participatory Research (S. Chen, Poland, & Skinner, 2007), is undertaken to empower consumer and community members by shifting authority and power away from the researchers who are conducting the research (Chambers, Pringle, & Juliano-Bult, 2012; S. Chen et al., 2007; Orlowski et al., 2015). It achieves this by involving stakeholders in a meaningful, in-depth, and sustained way throughout the research process. This involvement can take place at any stage of the process, from research design to implementation. This process is designed to ensure that the results of the research are suitable for use by consumers and community members, and that they are committed to using it (Dold & Chapman, 2011). As a result, projects which use it may be more likely to have their results or findings translated into community practices and policies (Chambers et al., 2012). Chen, Poland and Skinner (2007) used participatory action research to involve adolescents as co-evaluators of an applied research program called TeenNet. The following six-phase model was used: (1) involvement of a group of young people; (2) identification of issues by the young people; (3) planning of community action by the researchers and young people; (4) action; (5) research, reflection and reward in which communities took part in a participatory evaluation of their action projects and the overall process; and, (6) sustainability, which involved the ongoing efforts to continue identifying and addressing community concerns.

Co-design processes aim to create an equal relationship between a range of different stakeholder groups. Co-design processes have a strong focus on respecting the views of all stakeholders, and using their views to improve or create solutions that are fit for purpose and based on self-expressed needs (Szebeko & Tan, 2010). However, they are extremely broad, and comparisons between methods can be difficult because of the range of techniques referred to as co-design. An example of one model of co-design is described by Szebeko and Tan (2010). Their model involves six stages: diagnose; engage and discover; design; develop and test; influence, delivery and enterprise; and measure and sustain. This model enables designers to work throughout a project with clients and other stakeholders.

Co-design processes may involve young people designing parts of the research process, or facilitating data collection activities, such as running focus groups or conducting interviews (Hagen et al., 2012; Mawn, Welsh, Kirkpatrick, Webster, & Stain, 2015; Monshat, Vella-Brodrick, Burns, & Herrman, 2012; Smith et al., 2014; Wadley et al., 2013). Other terms used to describe this process, or parts thereof, include

co-design interviews (Monshat et al., 2012), co-design workshops (Robinson et al., 2014), and co-facilitating groups (Graham, Rose, Murray, Ashworth, & Tylee, 2014).

Where consumers are involved as researchers who have equal status to other researchers, they are referred to as *co-researchers* (McDonagh & Bateman, 2012). More commonly, young people are involved at isolated stages of the research process. Examples of this include project and research agenda development, such as for research on high-risk youth (Iwasaki, Springett, Dashora, McLaughlin, & McHugh, 2014; McDonagh & Bateman, 2012); and the dissemination and presentation of the research findings to a wide range of audiences (Fleming, 2010; McDonagh & Bateman, 2012), including at conferences (Crowe, 2007). Consumers have been involved in mental health service delivery in a broad range of ways: the design of mental health services, staff selection, and creating awareness of the problems and challenges of mental ill health (Ramey & Rose-Krasnor, 2015; Skinner & Fleming, 2007).

Researcher-led involvement processes are also utilised. These processes involve consumers being guided by researchers in specific ways, or at specific research stages. Examples of stages at which consumers have been involved include conducting data analysis (Sweeney, Greenwood, Williams, Wykes, & Rose, 2013), undertaking systematic reviews (Morley et al., 2016), and identifying research priorities (Banfield, Barney, Griffiths, & Christensen, 2014). Research which has created a new mental health treatment, or evaluated an existing one, has involved consumers in the testing process to ensure that the intervention is appropriate for the target audience (Hagen et al., 2012; Orlowski et al., 2015). Consumers have also assisted by recruiting research participants via their social networks in order to disseminate an awareness of the project to other young people (Smith et al., 2014).

Research can also be *consumer- or community-led* (Boote, Telford, & Cooper, 2002). Consumer-led research allows consumers to have greater control over the topic and design of the research than the above processes allow for. Examples of this include university departments led, or co-led, by consumers including the Service User Research Enterprise (SURE) at King's College London; and various consumer-led research networks (e.g., the Consumer Led Research Network in New South Wales, Australia). While this form of consumer research is growing in prominence, it has limited relevance to young people who do not usually have the skills and experience to take a leading role.

2.4.2 Governance structures

Advisory groups are one of the most frequently employed methods of involving consumers and community members in both research and service delivery (Gyamfi, Keens-Douglas, & Medin, 2007). For example, children and young people's involvement in publicly funded research in the UK has been largely facilitated through an advisory group, GenerationR, which is made up of local youth advisory groups from across the UK (Brady & Preston, 2017). Advisory groups enable researchers to consult young people throughout the research process, from the design stage through to evaluation and implementation (Howe, Batchelor, & Bochynska, 2011). The format and function employed varies depending on the nature of the research being conducted, the organisational structures that exist to support young people's participation, and the characteristics of the young people involved. For example, Mawn's use of the advisory group model involved meetings between the young people, clinicians and academics to discuss their differing ideas of what research should be prioritised (Mawn, Welsh, Stain, et al., 2015). Advisory groups provide a platform for group members to advise researchers about a topic of interest through a regular and formalised consultation process. These groups may be comprised solely of consumers and community members, or consumers and community members may provide advice alongside other experts (Monson & Thurley, 2011).

2.4.3 Contextual influences

In addition to the benefits outlined above, there are a broad range of contextual factors which impact on all stakeholder groups when involvement is used. The following section reviews the key influences on how involvement in research and health service development is practiced. As noted by Kirby (2004), many of the issues relevant to actively involving young people in research are similar to those for actively involving people in research in general.

One of the primary rationales given for consumer and community involvement is to address power imbalances in research and health service delivery. Through choosing to be involved, consumers can, reduce this power imbalance (Cargo & Mercer, 2008; Kirby, 2004; Lolacano Merves, Rodgerds, Johnson Silver, Sclafane, & Bauman, 2015; McDonagh & Bateman, 2012; Monson & Thurley, 2011; Shaw et al., 2011). A review of four youth involvement case studies suggested that researchers need to adapt their behaviours and structures to address this power imbalance and enable young people's voices to be heard (Powers and Tiffany, 2006).

Involvement requires structural and behavioural alterations to the research process including time, flexibility and resources. The time required to implement involvement processes often exceeds that accounted for during the planning stages of a research project (Coser et al., 2014). However, if a commitment to involvement is not maintained throughout the research process, this may lead to resentment, disappointment and a sense of failure among participants (Coser et al., 2014).

Involvement also requires organisations or researchers to be flexible in the allocation of resources and to be prepared to adapt to account for the changing needs of those they are involving (Monson & Thurley, 2011; Ramey & Rose-Krasnor, 2015). Where this flexibility can be achieved, it includes aspects such as providing space and time for young people to learn new processes (Powers & Tiffany, 2006); and contributes to the creation and maintenance of positive research environments, which are discussed further below (Fleming, 2010).

A number of organisational changes may be required to enable involvement to be effective. These include changes to how resourcing is conducted and allocated. Researchers and service providers have identified that involving young people in research and mental health service delivery is resource intensive (James, 2007; Ramey & Rose-Krasnor, 2015). The implications of not adequately resourcing the practice were discussed by James (2007) in his review of four case studies of consumer involvement in Australian mental health service delivery. These implications included the need to maximise consumer's contribution and avoid poor experiences. In addition, researchers have reported that the lack of adequate resources is a major barrier to involving both adults and young people (Chambers et al., 2012; Dold & Chapman, 2011; Hagen et al., 2012; Howe et al., 2011; Orłowski et al., 2015; Owens et al., 2010). This challenge has been identified in the broader adult involvement literature (Ocloo & Matthews, 2016), and by young people specifically as issue requiring consideration (National Children's Bureau, 2010). In allocating resources, such as additional researchers or administrative and support staff, care needs to be taken in planning how consumers interact with the team. Howe et. al., (2011) provide an example of a lack of clarity over who was the primary point of contact and support person for the youth involved by one research team. Such misunderstandings and disagreements within a research team can confound the pragmatic considerations, and lead to the perception of being ignored, which detracts from the effectiveness and experience of involvement (Hagen et al., 2012; Howe et al., 2011).

The challenge of structural and behavioural alterations is particularly pronounced in youth involvement in mental health research. Researchers have reported difficulty in recruiting and retaining young people with mental illnesses (Monshat et al., 2012; Orlowski et al., 2015). Owens et al., (2010) found that fluctuations in mental state and personal circumstances made retention of the same group of young people throughout the research process difficult. Both Monshat et al., (2012) and Orlowski et al., (2015) have raised the ethical challenges of working with young people with a mental illness. One way in which these challenges have been addressed is to involve consumers who are at a point in their recovery such that they can understand the project and effectively complete the tasks expected of them (Case et al., 2014).

Young people who are involved in research and service delivery have several expectations of the researchers and health professionals who involve them. They expect that their contributions will be heard with sincerity, will be acted upon in ways that are discernible to them and will be credited to them by the researcher (Hagen et al., 2012; National Children's Bureau, 2010). Researcher behaviour, and the processes they put in place, can influence how young people perceive these expectations to be met or not; failure to meet expectations can discourage young people from involvement. The most consistently perceived negative behaviour reported is researchers ignoring the contributions of young people (Dold & Chapman, 2011; Elf et al., 2012; Powers & Tiffany, 2006). Young people have also reported a lack of interest, insincerity and tokenism when interacting with some researchers (Collin, Rahilly, et al., 2011). In Collin, Rahilly et. al.,'s (2011) study of youth participation in the Australian online mental health service, Reachout.com, these negative experiences were documented with only some of the organisation's staff, yet resulted in decreased feelings of connectedness to the community and the organisation as a whole. Such undermined relationships reduce the perceived efficacy of young people's involvement, and can lead to frustration, disillusionment, disempowerment and a sense of isolation (Collin, Rahilly, et al., 2011).

Researchers' and health professionals' biases may be due to perceived underlying feelings of insincerity and a lack of interest. Consumers have identified researchers discounting their input as insufficiently academic in nature as a challenge to their involvement (Patterson, Trite, & Weaver, 2014). Similarly, researchers may underestimate the capabilities of young people, for example by failing to recognise their potential for leadership (S. Chen et al., 2007). This may be due to negative attitudes, and resistance to change among health professionals and managers (Ocloo & Matthews,

2016). In particular, researchers' negative attitudes toward young people with mental illnesses has been reported previously (Hickie et al., 2005; Orlowski et al., 2015)..

However, the perception of lack of interest may be due to the necessities of research and service delivery. There is a need to balance the perspectives of young people with those of other stakeholders, pragmatic allocation of resources and the technical and ethical requirements of research (Monshat et al., 2012; Orlowski et al., 2015). For example, Monshat et al., (2012) reported that the young people they involved in co-designing an online mindfulness program suggested recruitment material design elements that were not considered ethically sound, and hence these changes were not implemented.

Where young people have poor perceptions of researchers and health professionals, these may be alleviated by ensuring clear communication, clear expectations and maintaining positive relationships and environments. Miscommunication can be avoided, and perceived value increased, where researchers ensure young people are aware of the project and the expectations of their role are clearly defined (Hagen et al., 2012; National Children's Bureau, 2010). Kirby (2004) recommends that this communication include informing young people of how their contribution is to be used and how the research will be disseminated. Young people may be provided with summaries of the research in accessible forms and language, preferably including detail on how the outputs of the research have improved the lives of young people (Kirby, 2004).

Good relationships and research environments support involvement processes. Important relationships include not only those between researchers and young people, but also within groups of young people (Ramey & Rose-Krasnor, 2015). Appropriate resourcing (see above) to support consumers and community members can provide a positive environment (Monson & Thurley, 2011; Powers & Tiffany, 2006), and may involve having a dedicated support person (Kirby, 2004). A supportive environment can be assisted by researchers acknowledging the capabilities of young people they involve, and that these capabilities can vary between and within groups of young people (James, 2007; Lolacano Merves et al., 2015). Once these capabilities are understood, the setting of realistic expectations can contribute to a positive environment (James, 2007). Finally, by fostering relationships and an environment that makes research engaging and enjoyable ensures participants' experiences are positive, thus increasing their motivation and building cohesion (Kirby, 2004).

2.4.4 Diversity in involvement

Ensuring that the population of consumers who are involved in research and service delivery are diverse, and that the opportunities to be involved are inclusive, is a key issue with involvement. Within adult involvement in health research, the need to include the perspectives of a wide range of people and groups has been identified as being important by organisations including INVOLVE UK (Simons, 2012), and by consumer advocates in Crawford and Rutter's (2004) survey of service users involved in mental health trusts. The issue has also been identified in youth-specific work. For example, Hagen et al.'s (2012) guide to participatory design, written to shape the work of the CRC, argued that involving the specific groups of young people who will be the beneficiaries of the work is critical. A lack of diversity was identified by a group of young people who were involved in shaping an online youth mental health service and was linked to concerns around the development of services relevant to diverse groups of young people (Collin, Rahilly, et al., 2011). Similarly, youth mental health researchers have identified the narrow range of young people they are able to recruit for involvement processes as a limitation to their work output (Monshat et al., 2012). Within this discussion, specific types of characteristics which are present or not, have not been established. An important reason for this is that: '... it is not necessarily up to us to identify who finds it more difficult to have their voice heard – it will depend upon people's own perception of this which may vary across different areas and contexts' (page 4; Simons, 2012). Where authors, including Simons (2012), have listed groups who should be included to make the research more diverse, these have generally identified specific groups who are at risk of ill health or, in the case of mental health research and service delivery, groups who are less likely to seek help for mental health than others (Collin, Rahilly, et al., 2011).

Recruitment methodologies can result in a lack of diversity. Care is required to ensure that the chosen method or sampling strategy does not systematically exclude young people from particular sectors of society who may experience barriers to becoming involved. For example, a sampling strategy focused on schools may be a barrier to young people who are not in mainstream education (Shaw et al., 2011).

While diversity in involvement practice is desirable, researchers, adults and young people have all acknowledged that including diverse groups in a tokenistic way can be negative. James (2007) calls for researchers to both avoid tokenism and to consider diversity beyond the narrow definitions of Simons (2012) and Collin, Rahilly et al., (2011) discussed above. James (2007) acknowledges that young people are not

homogenous, but vary with age, developmental stage, experience, knowledge and skills, and should not be considered to be an homogeneous group based solely on their age. Among adults, it has been recognised that those who are currently involved are drawn from a narrow group of individuals with little consideration given to including people with different demographic characteristics (Ocloo & Matthews, 2016). Finally, young people believe tokenism to be an issue, and have advised researchers against this in their practise (National Children's Bureau, 2010).

2.5 Consumer and community involvement: the consumers who are involved

2.5.1 Their characteristics

Few details have been given of the characteristics of consumers who have been involved in research and mental health service delivery in published work to date. Where they have been described, it has predominately been due to researchers identifying the limitations they faced involving people with particular experiences and characteristics in their work (see Section 2.4.2 above). What these reports show is that, within the group of people who choose to be involved, there may be biases toward specific groups of people.

In the broader adult involvement literature, the characteristics of people involved have been described in three studies from the United Kingdom, in the areas of health and social care research, mental health research and mental health service delivery.

A key study in this area is Patterson, Trite and Weaver's survey of the activity and views of service users involved in mental health research (Patterson et al., 2014). It found that this group, termed a workforce, is: 'diverse, but characteristically mature and highly skilled, using a wealth of life experiences to inform research activity' (page 74; Patterson et al., 2014). The study found that the majority of people who participate are women (62.8%), have completed tertiary education (63.9%), and are ethnically white British (77.9%).

Tarpey's review of unpublished examples of involvement in health research suggested that most of the adult population of the UK does not get actively involved in health research or other activities (Tarpey, 2006). One example described in the report, in which consumers who had been affected by cancer were involved, found that the consumers who were involved were typically female, middle-aged, affluent and educated. Other people in the study who lived in rural or poorer urban areas tended to

express more concern with issues surrounding access to cancer services, than an interest in involvement in policy, planning or research.

An attempt to directly compare the views expressed by consumers who are members of mental health service user groups, and those who are not, was made by Crawford and Rutter (2004). Their survey-based study compared the research priorities of four different groups: members of a local mental health service user group, patients of mental health services, mental health service managers, and consultant psychiatrists. None of the characteristics of the service user groups were described. They concluded that the views of the members of the service user group and the random sample of patients were similar. However, the service user group members did note that they were not representative of local patients. For example, in terms of their cultural and linguistic backgrounds, they did not include the broad mix of minority communities present in the geographic area that the group covered (Tarpey, 2006).

Literature on young people's involvement in mental health service delivery is limited in a comparable way to that on adults. Where it does exist, it has found similar biases to those reported above. Two papers identified in this area are an evaluation of the online youth mental health service, Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011), and a description of the face-to-face youth mental health service program, Headspace (Coates & Howe, 2014). Both suggest that there is a bias among those who were involved toward women and people taking part in education. Three quarters of the young people who had been involved in the Reachout.com Youth Participation Program were female, and over half were currently studying (Collin, Rahilly, et al., 2011).

Between the two studies, the proportion of young people who self-identified as being from 'minority groups' varied. The majority of applicants to the advisory group described in Coates and Howe (2014) identified as being from minority groups which were not further specified. The only minority group to be identified in Collin, Rahilly et al., (2011) was Aboriginal or Torres Strait Islander young people (1.8%). However, the former group did prioritise the recruitment of people from minority groups, whereas Collin, Rahilly et al., (2011) did not state this as an aim.

Neither example of involvement attempted to recruit young people with particular experience of mental ill health. Despite this, all of the young people who took part in the Headspace youth advisory group either had current experience of mental ill health or had done so previously (Coates & Howe, 2014). While the proportion of young people who had any previous experience was not reported by Collin, Rahilly et

al., (2011), the mean level of psychological distress using the Kessler 10 was noted as being high using the thresholds recommended by the Australian Bureau of Statistics (Andrews & Slade, 2001).

The final domain of characteristics reported in the Collin, Rahilly et al., (2011) paper was young people's civic participation. It showed that the young people who were involved were also highly involved in their communities. Over 90% of respondents had taken part in either an online community group, a support group, a special interest organisation, or a local library within the last year.

2.5.2 Their motivations and barriers they perceive

Understanding what motivates consumers to be involved in research and mental health service delivery is an important step to involving them in ways that meet not only the desired organisational objectives, but also enrich their lives and meet their expectations. The following section reviews what has been found in a number of areas, with a focus on young people's motivations.

Consumers may be motivated to exercise their right to be involved in matters which affect them. This motivation has been described both by researchers reflecting on what they think adults' motivations for being involved in research are (McLaughlin, 2011), and also young people who have described their own motivations for being involved in health research (National Children's Bureau, 2010). Related to this, consumers may be motivated by a desire to have some influence on the processes that affect their, and other people's, lives (Tarpey, 2006). For example, consumers who have a lived experience of disability or long term illness may see involvement as challenging the social structures which make them feel less visible (Tarpey, 2006).

Young people and adult consumers are both motivated to learn more about the topic of the research, and influence the process and outcomes (Coates & Howe, 2014; National Children's Bureau, 2010; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Young people, in a guide for researchers about how to involve people, have stated that they believe that being involved in research is one way in which they may be able to make their voices heard (National Children's Bureau, 2010). Rather than just being participants and answering someone else's questions, this voice includes aspects such as being asked about what, and how, research is being done. By having their voices heard, they hope to challenge adult researchers' ideas about young people (National Children's Bureau, 2010), and potentially to change the system (Ramey & Rose-Krasnor, 2015).

Conversely, a lack of interest in the topic of the research or the research process can be a barrier to involvement.

One study discussed in the review conducted by Tarpey (2006) reported that some of the people they surveyed acknowledged that they generally lack the motivation to be involved in health or social care issues, including research. They said that they felt no immediate need to, either because they had no health or social care problems, were ill very rarely, or they had always received good treatment (Tarpey, 2006).

One motivation—documented only in the youth involvement in mental health service delivery field—is young people’s desire to develop professional relationships between themselves and researchers, or to make friends (Coates & Howe, 2014; Collin, Metcalf, et al., 2011; Ramey & Rose-Krasnor, 2015). For example, young people commenting on their reasons for deciding to be involved in an advisory group noted that they were motivated to build and maintain quality relationships between themselves and researchers (Coates & Howe, 2014).

Where incentives are offered in return for involvement, young people have identified that receiving these can be a motivating factor (National Children’s Bureau, 2010). Specific guidelines about this have been developed by INVOLVE, in consultation with young people, to guide researchers (National Institute for Health Research, 2016). The guide recommends that when young people are involved, they should receive appropriate reward and recognition for their contributions. What specifically these incentives should be, and what young people would like them to be is related to the particular activity or group of young people. For instance, the young people who contributed to the National Children’s Bureau (2010) guide suggested that a copy of the report they contributed to may be a suitable incentive.

The final, substantial area of motivations described in the youth involvement in research literature, is the development of new skills and knowledge. Based on researchers’ reflections and young people’s self-report, it has been argued that youth involvement in research affords young people opportunities to develop and acquire new skills (Coates & Howe, 2014; Coser et al., 2014; Fleming, 2010; Gyamfi et al., 2007; McDonagh & Bateman, 2012; National Children’s Bureau, 2010; Powers & Tiffany, 2006).

In addition to motivations for involvement, a related area which has been explored is the perceived barriers to getting involved. To date, explorations of barriers to involvement have predominately focused on those that are faced when consumers and young people choose to be involved. A consideration of these barriers is important

because, as explored above, there is a need to consider the breadth of consumers who are currently involved compared to those who are not. In addition, barriers may limit the motivations young people have for being involved.

The accessibility of an involvement activity can function as a major barrier to involvement in research for both young people and adults. As explored in the previous section, many of those who would be involved are also taking part in study or work. Because of this, activities which occur during business hours can be a barrier to involvement. This has been recognised by young people themselves (Coser et al., 2014; Kirby, 2004; National Children's Bureau, 2010), by researchers reflecting on their involvement of young people (Gyamfi et al., 2007) and adult consumers who have been involved (Patterson et al., 2014). Similarly, activities which take place in locations which are difficult to access have been recognised as a barrier to involvement in a survey of consumer researchers' experiences (Patterson et al., 2014). To date, this barrier has not been documented in the youth specific literature. However, a related barrier—that locations and research environments are perceived to be unwelcoming—has. This barrier has been identified through researcher and practitioner reflections on mental health service delivery (Gyamfi et al., 2007), and in health research (Cargo & Mercer, 2008). Finally, if researchers or health practitioners expect young people to bear the financial cost of involvement, even temporarily, this can be a barrier (Dold & Chapman, 2011; National Institute for Health Research, 2016).

Personal circumstances which are unrelated to the activity itself, but which impact on young people's lives, can be a barrier to involvement. These barriers are predominately isolated to young people's involvement. For example, if young people are transitioning between stages of life, such as between high school and university, this may impact on their ability to be involved. This barrier has been identified through both young people's self-report and researchers' reflections on their experience of involving young people (S. Chen et al., 2007; Lolacano Merves et al., 2015; Monson & Thurley, 2011; National Children's Bureau, 2010). The impact of these transitions can be that young people are either unable to commit to being involved in a whole research project, or that their attendance and availability fluctuates.

Consumers, and young people in particular, may lack self-confidence, or feel that they do not have enough knowledge to be involved (Kirby, 2004; Lolacano Merves et al., 2015; Monson & Thurley, 2011; National Children's Bureau, 2010). Additionally, in the case of mental health research, researchers have posited that mental

ill health itself may be a barrier to becoming involved for young people who have previously experienced a mental illness (Monson & Thurley, 2011).

2.5.3 Their experiences

Consumers' experiences of involvement in research and mental health service delivery have been discussed in a number of papers. As the following section describes, consumers who have been involved in these areas have reported a range of experiences and have also attributed some changes in their own lives to their involvement. These experiences include positive changes to their personal development, mental health and help seeking, skills, networks and relationships (Case et al., 2014; S. Chen et al., 2007; Collin, Rahilly, et al., 2011; Coser et al., 2014; Dold & Chapman, 2011; Gyamfi et al., 2007; Powers & Tiffany, 2006; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). As described in previous sections, the literature on young people's experiences is limited. For this reason, experiences described in the adult and youth mental health service delivery literature are also reviewed. The breadth of fields and processes may be considered a strength for informing our understanding of the experience of involvement. However, the often-qualitative methods used make it difficult to draw conclusive comparisons between reports, noting particularly that the aspects of involvement which led to the experiences are often undocumented.

One of the most common experiences identified by consumers in both youth and adult research and mental health service delivery is that involvement contributes to positive personal development. Specific aspects of this positive development include renewed self-worth, a sense of purpose, and self-confidence (Case et al., 2014; Collin, Rahilly, et al., 2011; Coser et al., 2014; Dold & Chapman, 2011; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Renewed self-worth and a sense of purpose were reported by the six young researchers who took part in the 'Youth Injection' participatory research project described by Coser et al., (2014). Through their roles as youth researchers, young people came to see their experiences as valued knowledge and believed that they had something positive to contribute to the community. Increased self-confidence was recognised as the major impact that involvement in Reachout.com's Youth Participation Program had on young people (Collin, Rahilly, et al., 2011). Specifically, over three quarters of the young people who responded to a survey about their involvement reported that it increased their confidence working with Reachout.com staff and external stakeholders.

Young people also derive a sense of enjoyment and belonging from being engaged in their communities, as documented through focus groups and interviews after their participation in involvement processes (Collin, Rahilly, et al., 2011; Coser et al., 2014; McDonagh & Bateman, 2012; Oliver, Collin, Burns, & Nicholas, 2006; Powers & Tiffany, 2006).

A number of studies which have examined adult and young people's involvement in mental health service delivery have suggested that it may lead to improvements in mental health and increase the likelihood that they will seek help (Case et al., 2014; Collin, Rahilly, et al., 2011; Ramey & Rose-Krasnor, 2015). Young people who had been involved in the Reachout.com Youth Participation Program associated their participation with increased understanding of when and how to seek help in regards to their mental health issues (Collin, Rahilly, et al., 2011). This program offered young people opportunities to be involved in activities—including the design of the service website and the development of the organisation—which are focused on youth mental health and wellbeing. Similarly, young people who were involved in the face-to-face youth mental health service reported, through interviews, focus groups and questionnaires following their involvement, that they gained positive mental health changes (Ramey & Rose-Krasnor, 2015).

Researchers have posited that involvement affords consumers opportunities to learn new skills, a theory which has been confirmed by consumers (Case et al., 2014; S. Chen et al., 2007; Collin, Rahilly, et al., 2011; Coser et al., 2014; McLaughlin, 2011; Powers & Tiffany, 2006; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Some studies have not specified the type of skills gained; (Case et al., 2014; S. Chen et al., 2007; Gyamfi et al., 2007; Tarpey, 2006) however, where specific skills have been nominated, these are related to the type of activity involved. For example, the four examples of youth involvement in health research reviewed by Powers and Tiffany (2006) showed that where young people were offered opportunities for leadership, this was an area in which they developed skills. Similarly, the young people who were involved as co-researchers in the Youth Voices project developed research skills (S. Chen et al., 2007).

Finally, experiences of involvement reported by adults and young people indicate that being involved can lead to improvements in their networks, their involvement with their communities, and their relationships (Collin, Rahilly, et al., 2011; Coser et al., 2014; Dold & Chapman, 2011; Powers & Tiffany, 2006). The most frequently described of these areas is that involvement leads to increased peer support (Collin, Rahilly, et al., 2011; Coser et al., 2014; Dold & Chapman, 2011; Powers &

Tiffany, 2006). This experience was acknowledged by all of the stakeholders surveyed by Dold and Chapman (2011). Social connectedness was the most significant benefit found in the cross-sectional survey of young people who had been part of Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011). Other related improvements reported by participants included unspecified networking opportunities and social skills (Collin, Rahilly, et al., 2011).

2.6 Youth involvement in mental health research

2.6.1 Overview

The active involvement of young people in mental health research draws on, and complements, the practices and research outlined in the preceding sections. The processes and practices used are similar, as are the benefits, challenges and barriers. Similarly, the academic literature on this topic is deficient in scope and depth. Despite increasing recognition of the importance of involvement in both the research and mental health fields, involvement of young people in mental health research is poorly documented at present, and significantly lacking in the published literature. This deficiency was illustrated by Orlowski et al.,'s (2015) systematic review of consumer involvement in the design of technology-based youth mental health and well-being interventions, which included 17 papers. The inclusion criteria for the review were broader than those considered in the YIMHR project, both with regards to the age range and the definition of involvement. The age range included children, whereas the present project includes only young adults. The review also included studies which, when examined for the present literature review, were not considered to have actively involved consumers. This incongruity demonstrates one of the challenges of research involvement—that the broad range of understandings of involvement leads to inconsistencies within the field.

The ways and processes through which consumers and young people have been involved in mental health research, and the barriers and challenges faced by researchers, are similar to those discussed in the broader involvement studies above. Consequently, the literature in both areas pertaining specifically to youth involvement in mental health research is not reviewed in this section.

In the course of identifying relevant papers for this review, eight papers were found which described the characteristics, motivations or experiences of young people who had been involved in youth mental health research (Elf et al., 2012; Graham et al., 2014; Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Mawn, Welsh, Stain,

et al., 2015; Monshat et al., 2012; Ross, Hart, Jorm, Kelly, & Kitchener, 2012; Wadley et al., 2013). The level of detail described in these papers varied. An overview of each of the papers follows.

Monshat, Vella-Broderick, Burns and Herrman (2012) involved young people in designing an online mindfulness training program. Young people were asked to comment on how useful, easy-to-use and enjoyable they found the proposed programme, and how the draft version and its planned evaluation strategy could be improved.

Youth mental health consumer advocates were involved using were involved using a Delphi consensus method to develop key messages for adolescents on how to provide basic mental health first aid to their peers (Ross et al., 2012).

A co-design workshop was used by Wadley, Lederman, Gleeson, and Alvarez-Jimenez (2013) to develop an online social therapy for young psychosis sufferers. The young people involved were six current and former mental health clients from the client advisory team of the research-focused clinic in which the project was situated.

Mawn, Welsh, Stain and Windebank (2015) describe the establishment of the ‘Youth Speak on Mental Health Research’ advisory group. The aim of the group was to focus on the long-term involvement and development of young people in all stages of the research process.

The second paper by the same team on this topic is directly concerned with young people’s perceptions of being involved. The paper, entitled ‘Getting it right! Enhancing youth involvement in mental health research,’ consisted of interviews with an opportunistic sample of eight young people about their experience of involvement, their motivations for doing so and their preferences about involvement (Mawn, Welsh, Kirkpatrick, et al., 2015).

A youth advisory group which guided the development of youth mental health services in New South Wales, Australia is described in Howe et. al.,’s (2011) paper. It describes the results of an evaluation of this group, which used a mixed methods approach including questionnaires, interviews and project records.

Young people aged between 16 and 25 who were carers of someone with a mental illness were involved, through a participatory design process, in developing a web-based support system in the study conducted by Elf, Rydstedt, Lundin & Krevers (2012).

The young people in Graham's (2014) study, which aimed to develop youth-generated quality standards for youth mental health in primary care, had sought help for mental ill health using primary care services.

2.6.2 The characteristics of young people who are involved

The papers described in the above section have each reported the characteristics of the young people involved in varying levels of detail. A synthesis of what is known in this area is provided in the following section.

In the four studies which reported the gender of the young people who were involved there was a bias toward women's participation (Elf et al., 2012; Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Monshat et al., 2012). The percentage of young women ranged from 50% (Elf et al., 2012) to 87.5% (Mawn, Welsh, Kirkpatrick, et al., 2015), with a mean of 71.6%.

Other than age, the most common selection criterion for participation in the projects was mental health status, or previous use of mental health services. Only three of the eight papers did not select young people based on their previous experiences. Two of these were studies which involved young people in ongoing advisory functions (Howe et al., 2011; Mawn, Welsh, Stain, et al., 2015), and one which developed an online mindfulness training program (Monshat et al., 2012).

In the cohort of youth consultants described by Howe et al., (2011), 37% of the young people were current or previous users of mental health services. Within the youth advisory group described by Mawn, Welsh, Stain and Windebank, (2015), the proportion of young people who had experienced mental ill health themselves, or been a carer or sibling of someone who had, was not recorded. The authors note that this was a strategic choice made with the aim of reducing stigma and ensuring that the work that the group contributed to focused on resilience and wellbeing. Monshat et. al., (2012) recruited young people through a mental health service website, Reachout.com, but did not purposively select young people who had an experience of mental ill health. Despite this lack of purposive selection, they found that 13 of the 20 young people who took part in designing the mindfulness program had a previous experience of mental ill health.

Only three of the papers reported on other characteristics of those who were involved. Two of these papers discussed the main activity that young people were taking part in. The living situation, and membership of a range of population subgroups were reported in each in one paper (Howe et al., 2011; Monshat et al., 2012; Wadley et

al., 2013). In the two papers which reported on the main activity that young people were engaged in outside of the project (Howe et al., 2011; Monshat et al., 2012), there was a high level of student representation among participants. Half of the participants in the Monshat et al., study (2012), and 56% of the young people involved in the Howe et al., (2011) study were students at the time of their involvement. These rates are similar to the proportion of students in this age group in the broader Australian population (Australian Institute of Health and Welfare, 2015). The young people who were involved in co-design workshops to develop an online social therapy are described as living in a variety of situations, including, alone, with a partner, with friends or with their parents (Wadley et al., 2013). However, the proportions of young people in each of these groups were not reported.

Only one of the eight papers, Howe et al., (2011), described any specific population sub-groups which the young people identified as being from. Of the 16 young people who were involved, two identified as Aboriginal or Torres Strait Islander, one identified as having a culturally and linguistically diverse background, one as having a disability, two as young carers and one as being homeless.

2.6.3 The motivations of young people who are involved

Qualitative research published to date on young people's involvement in youth mental health research suggests that their motivations may be similar to adults who are involved in research and mental health service delivery, as detailed in Section 2.5.2 above. However, this area was examined in only two of the eight papers that contained empirical data on the topic of youth involvement in mental health research (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015), which emphasises the need for a more detailed examination of the area. Howe et al., (2011) reported the motivations of the young people who were involved in the project, whereas the Mawn, Welsh, Kirkpatrick et al. (2015) paper explored the young people's perceptions of their involvement in mental health research. Specifically, they looked at ways that researchers could give back to the young people and how their involvement could be facilitated (Mawn, Welsh, Kirkpatrick, et al., 2015). As described above, some participants in each of these studies had previously experienced mental ill health, but not necessarily all the participants.

Young people in both studies reported that they were motivated to 'to make a difference,' suggesting that they perceived that being involved in research has the potential to make a wider societal impact (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015). This finding is similar to the more specific motivations

described in the broader involvement literature about wanting to achieve positive outcomes for other consumers or young people (Case et al., 2014; Coates & Howe, 2014; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). While there are minor differences in the motivations between the two areas, this commonality suggests that this is an area worthy of further investigation, and should be emphasised in recruitment activities and advertisements.

Another motivation which emerged in both studies was the idea of personal development. Young people in the Howe et al., study (2011) were motivated to help their career pursuits, and the young people in Mawn, Welsh, Kirkpatrick et al., (2015) expressed that, in order to facilitate meaningful involvement, researchers should provide personal development opportunities. One specific way this could be achieved would be to provide opportunities that could be added to a young person's curriculum vitae.

The final motivation reported by the young people in Howe et al., (2011), to contribute to the development of mental health interventions, did not explicitly emerge in the Mawn, Welsh, Kirkpatrick et al., (2015) study. This may be because of the latter study's focus on the mechanics of involvement, rather than explicit motivations.

2.6.4 The experiences that young people have when they are involved

Only three papers have discussed the experiences that young people have when they are involved in youth mental health research (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Mawn, Welsh, Stain, et al., 2015). Of those, only Howe et al., (2011) described these experiences in detail. The limited state of literature is reviewed in this section. It is important to note that there is no reason to suggest that young people who are involved in mental health research do not experience a similar breadth of experiences to young people involved in service delivery and other forms of research (see Section 2.5.3). Rather, it is probable that the absence of evidence for this is due to a lack of reporting on the subject, not an absence of experiences.

The type of experiences that young people report is related to the specific activity they were involved in. The young people involved in the two studies described by Mawn and colleagues describe experiences specifically related to research (Mawn, Welsh, Kirkpatrick, et al., 2015; Mawn, Welsh, Stain, et al., 2015). In contrast, the experiences reported in Howe et al.,'s study, which described involvement in service development, include those related to young people's broader lives, such as their wellbeing (Howe et al., 2011). As described in the conclusion to this chapter (Section 2.7) and the empirical work of this thesis, one of the aims of the YIMHR project was to

fill this gap - to document the range of experiences that young people gain from being involved in mental health research specifically.

The young people who were involved in the Youth Speak advisory group described by Mawn were offered mentoring and training in research skills, and reported gaining these skills (Mawn, Welsh, Stain, et al., 2015). The subjective experience of gaining these skills was investigated in the related Mawn, Welsh, Kirkpatrick et al., (2015) paper. This investigation identified challenges in the experience of involvement, with some young people describing involvement in the data analysis stage as being boring, while others expressed interest in this particular stage.

A relationship between being involved and positive mental health outcomes was suggested by both Howe et al., (2011) and Mawn, Welsh, Kirkpatrick et al. (2015). In the Howe et al., (2011) description this was due to some young people, who had previously experienced mental ill health, reporting that the exposure to other young people who had also experienced mental ill health helped them to realise that others had been through similar experiences. In Mawn, Welsh, Kirkpatrick et al., (2015) involving young people in the dissemination stage of research was identified as an opportunity to challenge mental health stigma.

In addition to these experiences, Howe et al., (2011) reported a number of additional effects. They found that involvement led to improvements in participants' wellbeing, increased involvement in their broader communities, and an enhanced relationship with adults. These findings were reported through group interviews with the young people involved.

2.7 Conclusion

Consumer and community involvement in health research and mental health service delivery has arisen from a range of disciplines, and the rationales cited for the use of it are broad. Both within Australia and internationally, mentions of involvement in high level policies and practices are frequent. Examples of this include the work of INVOLVE UK, and the joint statements by the National Health and Medical Research Council and the Consumers Health Forum of Australia. When young people are actively involved in mental health research, it has been suggested that this may lead to higher rates of uptake of the services designed using involvement.

Despite these high-level recommendations and policy statements, the translation of these broad directions into documented action remains limited. Where involvement has been conducted and described, this has predominately been done from the

perspective of researchers and health practitioners. With some exceptions, these descriptions have neglected to clarify who was involved in the work. When these exceptions are considered, however, some trends are evident. Consumers, and young people in particular, are typically female, and either educated, or involved in study. Their motivations for being involved include making improvements to the research process, and to their own lives. They have positive experiences when they are involved, and report increased skills, mental health and expansion of their networks. A key issue which has been raised, but not adequately addressed or solved, is that involvement should be more inclusive and the groups who are involved should be more diverse than they are at present.

When the involvement of young people in mental health research specifically is examined, these broad trends are replicated but the absence of literature is even more pronounced. The research described in this thesis, the YIMHR project, was developed to address this gap. As will be described in Chapter 3, this project is a more direct examination of the young people who are involved. This is made possible by examining the young people who were involved in the Young and Well CRC, a large research organisation which involved young people in their program of work on young people's mental health and wellbeing. The work attempts to understand the characteristics of the young people who are involved in mental health research, exploring their diversity, and document their motivations and experiences.

3 Design and background

3.1 Overview

The present chapter describes the design of the Youth Involvement in Mental Health Research (YIMHR) project, and the organisation which the project uses as a case study, the Young and Well CRC (the CRC). Section 3.2 describes the project aims, and Section 3.3 provides a detailed account of the CRC. Following this, an overview of the studies that make up the project (Section 3.4), the participant groups involved in the studies (Section 3.5), and the methods used (Section 3.6) is provided. The final two sections in the chapter, Section 3.7 and 3.8, describe why the age range of the young people in the project was restricted to 18 to 25 years, and how the researcher's lived experience informed the project.

3.2 Project aims

The goal of the YIMHR project was to improve the practice of youth involvement in mental health research by systematically exploring their involvement from their own point of view. This goal reflects the absence of focused, direct reporting and examination of the characteristics, motivations and experiences of these young people in the literature to date. The project had three aims, which are described in Figure 3.1.

Aim 1: Characteristics

To identify the characteristics of young people who are involved in youth mental health research, to compare these with other young peoples' characteristics, and to examine researchers' beliefs about these characteristics

Aim 2: Motivations

To compare the self-reported motivations of young people involved in mental health research to both researchers' perceptions of these motivations and the motivations that other groups of young people report for similar activities

Aim 3: Experiences

To compare young people's actual and desired experiences of involvement in mental health research, and to compare this with how researchers involve young people

Figure 3.1 *YIMHR project aims*

The project involved investigating an organisation that had conducted research into young people's mental health, and which had mandated the use of youth

involvement throughout the projects it funded. This organisation, the CRC, is described in the following section.

3.3 The Young and Well Cooperative Research Centre

3.3.1 Vision, outcomes and pillars of success

The CRC was Australia's largest youth mental health and technology research collaboration at the time it was created. It was established under the Australian Government Department of Industry and Sciences' Cooperative Research Centres program and existed for the five-year period from 1 July 2011 to 30 June 2016.

The vision of the CRC was: 'a digitally connected world where technologies are used to support young people to feel safe, healthy and resilient' (page 1; Young and Well Cooperative Research Centre, 2016b)

The seven long-term planned outcomes of the organisation were:

- A reduction in youth suicide, suicide attempts and self-harm in young people;
- A reduction in youth mental health problems including depression, anxiety, problematic drug and alcohol use, and eating disorders;
- Increased rates of help seeking by young people;
- A reduction in lost productivity of young people due to days absent from education or work;
- A reduction in social isolation experienced by young people and their families;
- Improved mental health resulting in a reduction in medical, care and welfare costs; and
- An improvement in quality of life of young people, their families and their communities (Young and Well Cooperative Research Centre, 2016b).

To achieve these long-term outcomes four pillars of success were articulated. These were:

- Scientific rigor,
- Innovative use of technologies,
- Youth participation, and
- End user engagement (Young and Well Cooperative Research Centre, 2016b).

The last two of these pillars of success are central to this project. As noted in Section 1.2, what was meant by the CRC's use of 'youth participation' and 'end user engagement' was synonymous with the more commonly used term 'involvement,' as defined by INVOLVE UK.

The end product of the CRC's directive to research projects to use youth participation and end user engagement techniques was largely left to the discretion of individual researchers and project leads. When the CRC head office was reviewing and approving the project plans they ensured that each project plan included the active involvement of young people. However, because of the breadth of academic disciplines across the CRC and the range of topics being investigated, no particular process or stages of involvement were mandated.

3.3.2 The Cooperative Research Centres model

A Cooperative Research Centre (a CRC) is a company formed through a collaboration of businesses and researchers, and funded in part by the Australian Government. CRCs assemble multidisciplinary teams from across research providers to address end-user driven research. The overall activities of a CRC are managed by a head office which funds research projects. This form of governance allows the head office of a CRC to mandate topics and other requirements while working in collaboration with experts in the field, including representatives from industry and academic sectors.

An important feature of the CRC model is that the degree to which individual research projects interact with, or are supported by, the head office of the CRC can vary. The head office signs off on all project plans, and attempts to support the projects throughout their existence, but the degree to which this is welcomed by the projects varies.

3.3.3 Structure and partners in the CRC

The CRC was comprised of Reachout.com, as the lead organisation, together with both essential and supporting partner organisations. These organisations were from universities and the broader mental health and wellbeing industry, including service providers and government. The organisations were primarily Australian; however, a number of international organisations were also members. Thirteen of these organisations, the 'essential partners,' were more heavily involved than the others. These organisations made significant cash and in-kind contributions and participated in

organisational governance, program leadership and project management. This meant that the essential partners provided significant input into the work of the CRC, and that staff from these organisations contributed across projects and research streams.

The 13 essential partners were:

- Beyondblue
- Black Dog Institute
- The University of Sydney
- Butterfly Foundation
- Headspace
- Murdoch University
- Orygen, The National Centre of Excellence in Youth Mental Health
- Queensland University of Technology
- The Australian National University
- The University of Melbourne
- The University of South Australia
- The University of Western Sydney
- VicHealth

The remaining 60 ‘supporting partners’ made cash or in-kind contributions and were participants in the research programs conducted by the CRC. The list of supporting partners can be seen in Appendix 3.1.

The CRC was led by a board of seven independent directors who met every two months. The board and the head office of the CRC were supported by four advisory groups—the Scientific Leadership Council, the Members’ Advisory Committee, the Technology and Innovations Collective, and the Youth Brains Trust (the YBT).

The last of these, the YBT, was a youth advisory group which guided the strategic direction and research of the CRC. Each yearly cohort of the YBT was comprised of 20 young people aged 12 to 25 years. The sub-set of this group of 20, which was aged between 18 and 25 years, varied between each cohort and was not recorded. Young people applied to the YBT by submitting a six question, open-ended application to the CRC head office. Applications to join the YBT were solicited by the CRC head office through social media and partner organisations. The questions were designed to allow applicants to tell their own story, and to describe the skills and other experience that they would bring to the group. To ensure the YBT group comprised a plurality of voices, a key principle in the CRC’s selection process was to identify people

with life experiences that were not yet represented, or which were underrepresented, in the existing YBT group. The six questions in the applications were:

1. In no more than 150 words, tell us about yourself.
2. If you were to initiate some research relating to young people, technology and wellbeing, what would it be?
3. What skills do you have that you can bring to the team?
4. Why do you want to be involved with the Youth Brains Trust of the Young and Well CRC?
5. Is there anything we can do to support your participation in the Youth Brains Trust?
6. Is there anything else you would like to add?

The activities that young people took part in as part of the YBT varied considerably, and depended on their interests, the activities of the CRC head office and CRC researchers. The one activity which was consistent across participants and cohorts was a weekend at the CRC head office during which they learned about the CRC, youth mental health research, and got to know each other as a group. This weekend occurred within the first six months of each cohort of the YBT. Young people's involvement formally ended 12 months after they were selected into the YBT.

3.3.4 The research of the CRC

The CRC's research agenda was organised into three streams, with a total of 31 research projects. These streams each promoted the core outcomes of the CRC using a range of different methods and were aimed at different target populations. The streams were titled 'Safe and Supportive,' 'Connected and Creative' and 'User Driven and Empowered.' Each of these research streams focused on a different aspect of the vision of the CRC.

The Safe and Supportive stream was made up of six research projects which focused on four key challenges: digital citizenship and safety, respectful relationships, participation, and help-seeking.

The Connected and Creative stream focused on young people who may be at greater risk of developing a mental health difficulty due to a number of risk factors, including experience of social isolation, discrimination, violence and/or a lack of resources. The four projects and eight sub-projects in this stream aimed to generate baseline data about how vulnerable young people integrated existing technologies into

their everyday lives, tracked how this use changed, and carried out predictive mapping of target groups' technological needs.

The final stream, User Driven and Empowered, focused on developing innovative services for young people who were experiencing mental health difficulties. It aimed to ensure the services were easily accessible and available in an environment that worked well for young people. It comprised 10 projects and involved 19 partners. The approach taken involved work in three main areas: supported self-help, creating new digital settings for mental health service provision and revolutionising professional practise.

YIMHR was formally based in the User Driven and Empowered stream. However, it informally sat outside of the three-stream structure due to its use of data from all of the streams and the CRC head office.

3.4 Studies

The YIMHR project was comprised of a 5 study multi method program of research. The five studies were designed by the researcher (RR) specifically for this research project, and were not part of the original structure or design of the CRC. The five studies of the YIMHR project were university student focus groups (Study 1), researcher interviews (Study 2), analysis of advisory group applications (Study 3), survey of advisory group applicants (Study 4), and survey of community members (Study 5). The relationship between each of these studies and the three project aims are shown in Figure 3.2. Studies 1, 2 and 3 employed a qualitative approach. Studies 4 and 5 employed quantitative methods. The approaches used are described in Section 3.6 below.

Study 1 (focus groups with university students) was a scoping study which was designed following an initial review of the literature. This initial review ascertained that there was limited research in the specific area. The findings of this study were used alongside existing work to narrow the scope of the key concepts being examined, and to refine the project aims.

The subsequent four studies were designed as a set to capture various aspects and stakeholder groups.

They were conducted concurrently, however the analysis of the results was conducted sequentially in order to allow the results of each study to inform the subsequent study. This was because the timing of the data collection was largely dependent on the actions of the CRC. For example, the data for Study 5 was collected

when the CRC was halfway through the 5 years of its funding and Study 4 was designed to survey one cohort of the YBT across their involvement.

	Aim 1: Characteristics	Aim 2: Motivations	Aim 3: Experiences
Study 1: University student focus groups (Chapter 4)	✓	✓	✓
Study 2: Researcher interviews (Chapter 5)	✓	✓	✓
Study 3: Analysis of advisory group applications (Chapter 6)	✓	✓	✓
Study 4: Survey of advisory group applicants (Chapter 7)	✓		✓
Study 5: Survey of community members (Chapter 8)	✓	✓	✓

Figure 3.2 *YIMHR project aims and studies*

Study 1: University student focus groups (Chapter 4)

Study 1 was a series of semi-structured focus groups that examined university students' perspectives on participation, engagement and involvement in mental health research. The study was undertaken to inform the design and execution of the project due to the limited existing work in the area. It examined participants' previous experiences of participation in research, their motivations for involvement and engagement, and their ideas around how researchers should involve young people in mental health research.

Study 2: Researcher interviews (Chapter 5)

The perspectives and experiences of researchers who were part of the CRC were explored in the second study using semi-structured interviews. This study examined researchers' beliefs about the characteristics of the young people who they had involved, their perceptions of the latter's motivations and how they had involved young people in their work.

Study 3: Analysis of advisory groups applications (Chapter 6)

The characteristics and motivations of young people who apply for, and are members of, a mental health research advisory group were examined in Study 3. This was done through an analysis of applications to the YBT, the CRC's youth advisory group.

Study 4: Survey of advisory group applicants (Chapter 7)

The results from Study 3 were elaborated in Study 4 through a longitudinal survey. The study examined the characteristics and experiences of the young people who applied to be members of the YBT in 2013 over a period of 12 months. The characteristics reported by this group were compared to the Australian population, and the group who were accepted into the YBT were compared to those who were not. The study aimed to ascertain if participants changed as a result of their participation in the YBT on a range of relevant measures.

Study 5: Survey of community members (Chapter 8)

Study 5 used an online cross-sectional survey to compare the young people who had been involved in the CRC with their peers who had either been involved in or participated in other forms of research, who had taken part in civic participation activities, or who had not been actively involved in their communities. The areas examined were participant characteristics, experience of mental ill health and help seeking, involvement with the CRC, involvement with groups other than the CRC, and technology use.

Relationship of individual studies to the overall project

As described in the preceding sections, the majority of studies considered similar, but slightly different, stakeholder groups and used different research methods. Study 1 was an overarching scoping study involving young people and the findings contributed to the design of the other studies and to the overall project's findings. Study 2 provided a point of contrast to the other studies by including the perspective of CRC

researchers in the project. This inclusion was important to ensure that the structure and work of the CRC could be easily compared to existing work, and also to further understand how researchers relate to young people. Studies 3 and 4 took a similarly in depth look at the CRC, but examined the work of the central youth involvement mechanism of the CRC- the Youth Brains Trust. Finally, Study 5 was similar to Study 1 in that it examined involvement in the CRC through a broader lens than Studies 2-4. This was achieved by comparing young people's experiences in the CRC to those who were involved in other contexts. How each of these studies contributed to the project aims is shown above in Figure 3.2.

3.5 Participant groups

YIMHR involved four participant groups: young people who were aged between 18 and 25 who were involved in the CRC, young people involved in the YBT of the CRC, other young Australians and researchers who were part of the CRC.

3.5.1 Young people involved in the CRC research projects

An estimated 1000 young people were involved in the CRC across 31 research projects. These young people were involved in a broad range of ways across the CRC's research projects. The experiences of these young people are described in Study 5 (Chapter 8).

3.5.2 Young people involved in the Youth Brains Trust

The Youth Brains Trust (YBT) was investigated specifically because of its central place in the CRC's governance structure, and to enable comparisons with, and extension of, the previous literature focusing on youth advisory groups with similar structures.

3.5.3 Young people in Australia

The final group of young people comprised young Australians aged between 18 and 25 years. This was the largest and least specific of the four groups of young people. It was included in order to compare the demographic profiles of young people involved in the CRC with the broader cohort of young Australians in Studies 4 and 5.

3.5.4 Researchers who had involved young people in mental health research

Researchers who involved young people in the CRC were included to provide insights into the work of the CRC from the point of view of researchers, and to understand how they viewed the young people who were involved in the CRC.

3.6 Methods

A multi-method approach was used in the project. An overview of the methodological approaches used in the project is provided below. As reviewed in Section 2.6, no previous studies in this area have used a multi method approach, most likely because of their small scale and limited sample sizes.

Specific details of how these methods were used in each study are described in the chapters which describe each study (Chapters 4 – 8).

3.6.1 Qualitative methods

Qualitative research encompasses a wide range of data collection and analysis methods (Willig, 2013). Because qualitative methods can be used to create research designs that do not pre-suppose answers or frameworks, they are useful in studies which aim to describe or explore a phenomenon which is not well understood (Willig, 2013). They also have the advantage of allowing the identity and perspective of the researcher to be incorporated (Braun & Clarke, 2006). This latter feature was important in this project because of the influence of the researcher's lived experience on the design and execution of the project, as described below (Section 3.8).

As discussed above, the project aimed to comprehensively describe the young people who are involved in an extensive program of youth mental health research. In light of the limited existing work in the area, an approach to qualitative research which focused on description, rather than interpretive interplay with existing theories, was chosen. One approach which does this is Qualitative Description (QD). As outlined by Sandelowski (2000, 2010) and Neergaard, Olesen, Andersen and Sondergaard (2009), QD should be the method of choice when a description of a phenomena is the aim of the study. The approach involves low inference interpretation of participants' experiences, which given the limited literature to date, made it an appropriate method to investigate the aims of the project.

QD can involve a range of data collection methods (Neergaard et al., 2009; Sandelowski, 2000, 2010), including those which were employed throughout the project: semi-structured focus groups (Study 1), semi-structured interviews (Study 2),

and an analysis of existing data (Study 3). The rationale for choosing each of these methods is described in the relevant chapters.

The reporting of results of a QD study involves staying close to the data and describing participants' experiences in a language similar to the informants' own language. In the YIMHR project this style of reporting allowed the young people's voices and experiences to emerge with minimal additional interference from the researcher.

A criticism of the QD approach is that it can lack rigour. Because of this, it is important to use strategies to enhance the rigour of the method (often referred to as validity criteria) and to reflect on what benefits these strategies have achieved. The strategies employed in this project for this purpose are those proposed by Milne and Oberle (2005): authenticity, credibility, criticality and integrity. Authenticity involves ensuring that the informants are free to speak, that their voices are heard and that their perceptions are accurately represented. Credibility involves capturing and portraying a truly insider perspective. Criticality involves reflection on the critical appraisal applied to every research decision and integrity involves reflecting on researcher bias, informants' validations and member checking and researcher triangulation. Reflection on the use of these strategies in the project can be found in Chapter 9, Section 9.5 (Strengths and Limitations).

All qualitative data were managed using NVivo for Mac 10.1.13, and were analysed using the analytical method proscribed by Sandelowski (2000, 2010), qualitative content analysis. Specifically, the form of analysis used was that referred to as 'conventional content analysis' by Hsieh and Shannon (2005), with specific terminology borrowed from Braun and Clarke's (2006, 2013) guides to successful qualitative research. As defined by Hsieh and Shannon (2005), the goal of qualitative content analysis is to provide knowledge and understanding of the phenomenon under study'.

Common to many forms of qualitative analysis, this is a constructivist approach which acknowledges the existence of a range of meanings that could have arisen from the data, and that pre-existing knowledge cannot be eliminated from the analysis (Braun & Clarke, 2006). For all of the qualitative studies in this project, the following approach was followed.

The data collected- either transcripts (Studies 1 and 2) or the pre-existing applications (Study 3) - were read repeatedly by the researcher (RR) to achieve a deep immersion in the data and the information. In all studies, this immersion phase occurred

over a number of months to ensure that this immersion was sufficiently deep. During these periods, data for other studies and research for the broader project was also being conducted. These co-occurrences resulted in the immersion phases being complemented by broader thinking about the topic, which informed the analysis.

The data were then read word-for-word and labels, called ‘codes,’ were assigned to the most basic segments or elements of the text (designated ‘text extracts’) that can be derived from the data. The number of codes applied to each text extract vary depending on the possible multiple or complex meanings of the extract. As many codes as required to capture this meaning are applied to the section of text. Where the data being analysed was collected using a protocol (e.g. a focus group or interview), then codes are applied without direct reference to this.

Following the completion of the initial coding, the codes are reviewed. Where the codes are found to be very similar, for example ‘CALD’ and ‘culturally and linguistically diverse,’ they are merged into one code prior to step 2.

After the codes have been reviewed, and collated as necessary, themes and features are identified. Braun & Clarke describe a theme as: ‘patterned meaning across a dataset that captures something important about the data in relation to the research question, organised around a central organising concept’ (page 337, Braun & Clarke, 2013).

A feature is similar to a theme but does not have a central organising concept. It simply clusters together many different ways that an idea is evident in the data. Features are used to inform the interpretation of the themes.

Themes are generated from the codes by reviewing the codes and the related text excerpts, and grouping these into related areas. This is an iterative process, which took place over a substantial period of time (between 2 weeks and 2 months). The time between stages allowed RR to reflect on each section of the text. Where no clear theme emerged, or where there was substantial apparent overlap, the broader research team was involved to assist with overcoming these challenges.

These ‘initial’ themes are reviewed using Braun & Clarke’s (2013) levels of thematic reviewing as a guide. Level one involves reviewing the text extract attached to each of the codes and assessing whether the codes which had been assigned to a theme formed a coherent pattern. Where they do not, the theme was reworked by moving some of the codes to other themes or renaming the theme. Level two, which is conducted after Level one, involves considering the validity of each of the themes in relation to each other.

3.6.2 Quantitative methods

Quantitative methods, specifically online cross-sectional surveys and longitudinal studies have a range of different advantages to qualitative methods. These include the ability to use pre-existing measures; sampling of large populations, including through online dissemination; the ability for participants to be less readily identifiable; and the ability to ascertain if participants change over time (deVaus, 2002). The importance of these attributes for the project are outlined below.

Surveys facilitate the use of standardised measures, enabling the comparison of participant groups within studies, and with other studies of comparable populations (deVaus, 2002). Where possible, concepts were measured using pre-existing scales which were selected on the basis of their psychometric properties and appropriate length (deVaus, 2002). The CRC developed a list of Standard Measures which the organisation expected all researchers to use throughout their projects (Young and Well Cooperative Research Centre, 2013). Where possible, the specific measures used were drawn from this list. Researcher-devised questions were only used where suitable scales were not available.

Large-scale survey methods, and online delivery in particular, facilitate de-identification. Ensuring participants were not readily identifiable was an important factor for the YIMHR project because of the potential pre-existing relationship between the researcher and young people who had been part of the CRC.

The administration of surveys online, thus allowing for sampling of larger populations than was possible using alternative methods, was important in Study 5. The target population for this study was all young people who were involved in the CRC (estimated to be 1000) and all young Australians aged 18 to 25. Attempting to access a cross-sectional sample of these populations using either paper-based surveys, or more in-depth qualitative methods, would not have been practical.

Finally, longitudinal surveys facilitate comparisons within the same population sampled at multiple time points (Haslam & McGarty, 2003). This feature was used in Study 4 to compare the young people who were accepted into the YBT with those who were not.

3.7 Choice of age range

The age range examined in this thesis, 18 to 25 years, is a subset of the broader group researched by the CRC. The decision to limit the age range was made for two reasons. Firstly, young people aged 12 to 17 and 18 to 25 have some similarities, but

differ in many ways, for example: the level of education that they have had an opportunity to complete, the degree of independence with which they are able to access health services, and the type of activities that they take part in on a daily basis.

Secondly, within standard Australian ethical frameworks (National Health & Medical Research Council & Australian Research Council Australian Vice Chancellors Committee, 2007), people under the age of 18 years are not considered to be able to give informed consent to participate in research without permission from a parent or guardian. Obtaining parental consent would have required participant identification and matching data to participants. Given the pre-existing relationship between the researcher and the CRC, and the consequent possibility of identification, research methods which did not identify potential participants were preferred. Thus, the participant groups were limited to people over the age of 18, who could give their own consent.

3.8 Reflexivity

Reflexivity, which involves the researcher acknowledging their role in the production of the work (McLeod, 2001), was used in this project to acknowledge my prior experience, and to allow this to inform the work in a productive way. The suitability of the use of reflexivity in the PhD process has been described by Etherington (2004), who highlights that this process in particular lends itself to the investigation of a topic that has a pre-existing, or personal, meaning to the candidate due to the length and duration of the thesis.

My background as a young mental health consumer who has been involved in mental health research, and specifically in the work of the CRC, was an important influence on this work. The initial inspiration for the topic came from my own experiences as a member of the YBT, and prior to this as a member of Reachout.com's Youth Participation programs. These experiences provided a more extensive insight into the lived experience of being a young person who has been involved in research than can be surmised from the presently limited literature on the topic.

In addition to the insights I was able to bring to the work, the relationships I had developed afforded easier access to, and awareness of, sources of information about involvement compared to a researcher who did not have such relationships. For example, a researcher who did not have a personal experience of applying for an advisory group may have been aware that written applications are used. However, they may be less likely to know about the questions in the application, and their relevance to

a research project. Similarly, the CRC head office may not have allowed an external researcher to contact other researchers and young people multiple times.

In order to balance the influence of these experiences and relationships, retain a level of impartiality and ensure that my experiences did not unduly influence the results of the project, I employed a number of techniques. Firstly, I discussed the progress of the analysis and the findings of the studies with the members of my supervisory team who were not closely aligned with the CRC. These discussions helped me understand when my own experiences were clouding the results of the analysis. Secondly, I distanced myself from the personal and professional relationships I had with members of the CRC head office and executive during the time of my candidature. This distancing allowed me to develop a critical distance and a greater degree of impartiality than I initially had. Further reflections on this, in light of the results of the project, are described in the discussion and conclusion chapter in Section 9.5.

3.9 Involvement of young people in project design

While young people other than the researcher were not formally involved in the YIMHR project design, in one respect the project entails involvement at the highest level of involvement – consumer led-research as noted in Section 3.8 above. In another respect, it is acknowledged that young people other than the researcher were not involved. While further involvement would have been ideal (see Section 9.5, Strengths and limitations, for a discussion of this), it was beyond what was possible for a PhD and the requirements of the degree.

4 Study 1: University student focus groups

4.1 Introduction

4.1.1 Overview

The first study of the Youth Involvement in Mental Health Research (YIMHR) Project was a series of focus groups which examined university students' experiences of taking part in research across the breadth of engagement, participation and involvement. The study was designed following an initial review of the literature and consultation with the Young and Well Cooperative Research Centre (the CRC) head office, both of which identified a paucity of extant work from the perspective of young people. This warranted an exploratory study which examined four broad areas: young people's previous participation in research, their motivations for doing so, their thoughts on how researchers should recruit young people to participate and be involved in research, and how they thought young people could be better involved in mental health research. Previous work which informed the design of this study can be found in Chapter 2. The specific areas relevant to this study are: the benefits of consumer involvement (Section 2.3.4), contextual influences (Section 2.4.2), and consumers' and young people's motivations (Sections 2.5.2 and 2.6.3) and experiences (Sections 2.5.3 and 2.6.4).

4.1.2 Study rationale

Young people were asked directly about their experiences of being engaged, involved and participating in research, and their ideas and views about changes researchers could make to how they involve young people. Broad, open-ended style questions were employed to allow young people's ideas to emerge with minimal constraints. The findings from this study were key to informing the aims and design of the YIMHR project, including narrowing the focus from engagement, participation and involvement, to concentrate on involvement.

4.2 Design

4.2.1 Choice of method

The study used a qualitative descriptive approach, as described in Section 3.6.1. The data were collected using semi-structured focus groups. This method was chosen because focus groups can elicit a wide range of views, perspectives and understandings of an issue. They can therefore be a useful exploratory tool for looking at under-researched areas (Beyea & Nicoll, 2000; Braun & Clarke, 2013).

4.2.2 Human Research Ethics approval and consent

The Australian National University's Science and Medical Delegated Ethics Review Committee approved the ethical aspects of this study (Approval number 2013/224; see Appendix 4.1). Participants provided consent to participate by signing a consent form before the focus group began (see Appendix 4.2).

4.2.3 Participants

The participant group was a convenience sample of current university students aged 18 to 25 from the Australian National University (the ANU). Participants were recruited through the researcher's existing networks and the Centre for Mental Health Research (CMHR) at the ANU. The former were accessed through an event page on Facebook, which provided details of the focus groups, their location and the participant information sheet (see Appendix 4.3). The event page was a landing page on Facebook, to which the researcher's Facebook friends and broader networks who met the inclusion criteria were invited. The event could be shared by anyone invited to the group and resulted in the focus groups being disseminated through broader ANU student networks.

A CMHR network of potential participants for CRC-funded projects, based at the ANU, was established in the year prior to this study during a series of university events about mental health. This network consisted of a list of names and emails of students who were interested in ongoing involvement in research. The students were sent one email inviting them to participate in the focus groups, and providing them with the researcher's contact details and the participant information sheet. Participants were offered a movie voucher in return for their participation.

4.2.4 Procedure

The focus groups were conducted between 8 and 17 May 2013. All the groups were held at the CMHR and were facilitated by the researcher and a research assistant. An audio recording of each group was made using a Marantz Professional Solid-State Recorder. These recordings were transcribed verbatim, by the primary investigator, within 48 hours of being conducted. Following the initial transcription, transcripts were checked against the recording twice for accuracy. To allow for ease of reading and for clarity, instances of paralinguistic ('umm', 'ah') were removed from the transcripts (Willig, 2013). Each participant was assigned an identifying code in the order they signed up to the focus groups (e.g. the final participant to attend the focus groups was Participant 28).

4.2.5 Focus group questions

Participants were asked a series of open-ended questions examining their experiences of participating in research, their motivations for taking part, their experiences of, and ideas about, recruitment, and their views about how young people could be more actively involved in research. Where the researcher and the assistant perceived it to be helpful for the group, a white board was used to document lists of ideas generated during discussions. These lists were used only to help participants interact with each other and were not retained following the end of the group. Indicative examples of the questions asked within each area can be seen below, with the full protocol available in Appendix 4.4. The question areas were:

- Previous research participation
- Motivations
- Experiences of, and ideas around, recruitment to research studies
- Methods of involving young people in research

Area 1: Previous research participation

The purpose of the previous research participation questions was to gain an understanding of if, and how often, participants had previously participated in research. The answers to these questions would provide an indication of how familiar they may be with research methods.

- Have you participated in research before? (Show of hands)
- What sort of research have you participated in?
- Would you participate in other research? (Show of hands)

Area 2: Motivations

Participants' motivations for attending the focus group, the barriers and facilitators they had experienced, and thought that others may experience, were examined in Area 2.

- Were (or would) your motivations for participating in research, other than research like this, be similar to participating in this sort of research?
- Why are you here participating in research today?
- How did you find out about the focus groups?
- What motivated you to click on the advertisement and information sheet?

- Was there anything about the wording of the advertisement, or how you found out about it, that made you particularly interested?
- Do you think the fact that it was advertised as a mental health focus group affects your participation, or who might participate?
- What might impede you from participating?
- What barriers can you see that might stop people from participating?

Area 3: Experience of, and ideas around, recruitment to research studies

Participants' personal experiences of being contacted by, and recruited to, research studies, and their opinions regarding how researchers could improve their practise of doing this, were examined in Area 3.

- If we want to attract a group of students to participate in research, what are the best ways we could do that?
- How would you prefer to hear from researchers?
- Should we identify ourselves as being from the University; does who is conducting the focus groups make a difference to you?
- What forms of media would you prefer to hear from researchers through?

Area 4: Methods of involving young people in research

The methods of involving young people in research question aimed to elicit young people's ideas of how they could be involved in research, and the phases at which they could be involved. The answers to these questions were designed to be compared to the methods via which young people have been involved in research to date. The final question aimed to elicit participants' views regarding whether they thought that people would be interested in being involved or participating in different ways. For example, people who are shy might be less interested in ways that involve interacting with other people.

- What ways do you think that young people can be involved in the research process?
- Which ones of these have you participated in?
- Do you think certain people or groups might be more attracted to active or passive participation?

4.3 Analysis

The data were analysed using qualitative descriptive analysis, as described in Section 3.6.1. During the analysis it became apparent that, despite the codes being applied without reference to the question framework, the major themes which had emerged from the study were closely related to the four overarching question areas. The theme tables which were not linked to the question areas can be seen in Appendix 4.5. The table describing the major themes which have been linked to the question areas accompanies the results below (Table 4.1).

4.4 Findings

4.4.1 Participant characteristics

Six focus groups were conducted, with a total of 28 currently enrolled ANU students, aged 18 to 25. The number of people in each focus group ranged from two to six.

Demographic characteristics were obtained via a brief demographic survey administered at the start of each of the groups. Participants were predominately female (60.7%, n=17) and studying at an undergraduate level (92.8%, n=26). A large minority of the sample (28.5%, n=8) self-identified as having been diagnosed with a mental illness.

4.4.2 Themes

Nine major themes, and several minor themes pertaining to each of the major themes, resulted from the data analysis. As noted above, these are presented and discussed in relation to the four question areas. The relationship is shown in Table 4.1. The minor themes are presented in italics throughout the following section.

Table 4.1 University student focus groups: major themes

Question area	Themes
1. Previous research participation	Participant's prior research participation
2. Motivations	Barriers Concerns that arise due to the topic of mental health Facilitators
3. Experience of, and ideas around, recruitment to research studies	Incentives Recruitment Relationship to the person or organisation conducting the research
4. Methods of involving young people in research	Phases of the research process that young people could be involved in Ways that young people could be involved in research

4.4.3 Area 1: Previous research participation

Participant's prior research participation

Participants were asked about their prior experience of participating in research, and how they had found out about the present study. The majority of participants *had participated before*. This participation, which also encompassed examples of engagement and involvement, was predominately in psychology studies in exchange for course credit as part of their first-year psychology course. The methods through which they had been involved were diverse, from online surveys to conducting their own research. Participants *would participate in other research* following this instance of participation, particularly if they were interested in the topic being investigated.

I've done some psychology research, like participated in it as an undergrad, especially first year psych where you're required to do some as part that, but also you see like on the back of bathroom doors requests for participants –

Participant 1 (Group 1)

Participants varied in the way they found out about the focus groups. Avenues through which they had heard about the groups indicated that people other than the researcher had promoted the study, in addition to the direct avenues of advertisement.

I saw your post on Facebook via a friend so I was like 'yeah, why not.' –

Participant 26 (Group 6)

In response to questions examining how they had interacted with the recruitment materials, participants displayed a high level of trust in the researcher and the study itself. Some participants disclosed that they *were happy to sign up without reading all the material about the study that was provided to them*, having based their decision to

participate on factors such as knowing the overall concept behind the study, and being attracted by the incentive on offer.

To be honest I didn't read through all of the details, I was in a bit of a rush, but because I already knew the gist of what it was about I was happy to sign up for it without knowing all of the details. – Participant 9 (Group 2)

This lack of attention to detail was further reflected in participants' reactions and responses to the information sheet. While some participants had engaged with the information sheet, others responded that *minimal attention was paid to the information sheet*.

I sort of skimmed it [the information sheet] – Participant 7 (Group 2)

4.4.4 Area 2: Motivations

Barriers

Participants raised a range of areas that they perceived may pose barriers to either their own, or others' participation, engagement, and involvement in research. These areas included logistic, attitudinal, and technical research barriers.

The logistic barriers nominated by participants included situations where they perceived that taking part in research was *too hard to organise*, where the activity was in an *unfamiliar location*, or where they or others may *not be aware that it was happening*.

Sometimes it's easier if you just kind of have to put your email in a box and then someone else initiates contact. You'd probably get a higher response rate that way because the person isn't having to do the work, its others. – Participant 22 (Group 5)

A specific logistic barrier discussed was the *time costs*. Participants' identity as university students was apparent in the discussion of this barrier, as the time costs discussed were specific to the time of year, or university semester, in which the research was being conducted.

It's just a really busy time of semester as well, and people don't want to commit to something that they're not quite sure about, or don't feel completely comfortable with. – Participant 27 (Group 6)

Attitudinal barriers discussed by participants were those barriers which related to their own, or others' attitudes toward the topic of the research. Examples of these

barriers included that other young people may *not be interested* in being involved in research, *not feeling as if their personal contribution matters*, and *research going against their values*.

There's a small or significant number of people, I don't know, who don't care about mental health and aren't interested – Participant 7 (Group 2)

That it's not going towards a politically motivated, or something that's got like commercial funding, interest groups that are trying to push for a certain outcome or something? – Participant 27 (Group 6)

The *technical* barriers that participants discussed were related to the interaction between participants' characteristics and face-to-face research methods. For specific groups of young people there may be *cultural and linguistic barriers* to participation, engagement or involvement, as may be experienced by international students in a university setting.

They [international students] might also feel more comfortable being in a focus group with other internationals, because what I've noticed in tutes [tutorials] where it's been mostly domestic students is that, I've had this happen in like philosophy classes, politics classes, where it's a lot of domestic students in those sorts of areas, and you know there'd be one or two international students and they might feel uncomfortable speaking up, because of the language barrier and also 'cause domestic students, I guess, feel a lot more comfortable speaking up and they're used to it. – Participant 8 (Group 2)

For other groups of young people, such as those who experience mental ill health, participants discussed that they *might find group or unfamiliar situations challenging*.

People who may have issues with their mental health, that may be less likely to come to something like this, because they are inherently less engaged with the community? – Participant 5 (Group 1)

Concerns that arise due to the topic of mental health

Participants were asked directly if their choice to take part had been influenced by the focus groups being advertised as 'mental health focus groups,' or if they thought that other people may be influenced. This question elicited a wide range of responses from participants. For some participants, the use of the *mental health* term *didn't influence their participation* as their interest in the research project was not related to

their mental health aspect of the group. For these participants, their interest related either to their relationship with the researcher, or a more general altruistic motive.

To be honest it didn't really influence me doing it that much. Even though I have relatives that have mental health issues, all research is valid research, it doesn't add any particular weight in my mind although it is important. – Participant 24 (Group 6)

Other participants noted that the use of the term 'mental health' *may make other young people less likely to take part* because of stigma about mental health, or a discomfort with the thought of having to discuss their experiences in a group setting.

A small number of people might be uncomfortable with being in a focus group which is kinda [sic] a social setting, or they might feel uncomfortable talking about mental health. – Participant 8 (Group 2)

A third group of participants expressed that the use of 'mental health' *made them more likely to participate*. This was related to their perception that mental health is a topic worthy of further exploration, or a desire to share their own experiences with researchers.

I thought it was something I thought was worthwhile, and like a good use of my time. – Participant 27 (Group 6)

Discussions within some groups developed into a more general discussion of how the use of the words 'mental health' in research study advertising may influence other young people's choice to take part in a research project. Participants' understandings of the wide variety of concepts that make up mental health were displayed in these responses, including the idea that *specific mental health terms used may influence participation rates*. Mental health was perceived to be a more general term that is inclusive of positive mental health, whereas specific diagnostic labels such as depression, or anxiety were perceived to be related to research with a more clinical or negative focus.

I think mental health is less strong than, say, depression, or if you said something like anxiety in university students. I think that would be harder, would turn people away more than mental health. Because mental health can be a positive thing as well. Whereas depression is seen as a negative thing. – Participant 14 (Group 3)

Irrespective of the specific term used, however, was a perception that the use of any mental health term *will attract a particular sample*. Participants discussed that people in these samples may have actual or self-perceived specific knowledge or expertise in the area.

I think that the heading of mental health focus group indicates that you might need to have some sort of specialised knowledge or expertise in that area. –

Participant 3 (Group 1)

The impact of mental health stigma, and participants' awareness of this stigma, was apparent in their perceptions that the term 'mental health' *could be polarising*. Related to this polarising nature was a recommendation from participants that when researchers are working with young people in mental health research they *need to involve people in private ways*.

For something like mental health research I think a lot of people don't want to expose to their friends what they think about some matters –

Participant 16
(Group 3)

Facilitators

There were three different areas which participants perceived might facilitate their own, or others' likelihood to participate in research, or research involvement activities. These facilitators included *ease of initiating* the opportunity, such as having the researcher initiating contact with them, and research methods which they could take part in from home; the research activity being *perceived to be easy or have little cost to the participant*, either financial or temporal; and social incentives such as *friends being invited or were attending*.

I saw on the event that you'd replied directly to each person who was attending. So it was not like you just pressed attending and then nothing happens for a while. It seemed like it was really soon too. I don't really know what I'm doing in a couple of weeks on Friday at 2pm, but knowing it was like the next day I was like 'yeah, I can make that', and it looked like you got back to people really quickly and replied to my email within like 5 minutes. I was just like 'oh.' It made it really easy I guess, that you wouldn't be waiting on people and signing up to some vague things at an undefined time.' –

Making it super easy to participate, so not necessarily having to go places and that. I think people are much more likely to do things if they are procrastinating,

and it's just something short and sweet they can do like from their bed. –

Participant 19 (Group 4)

My girlfriend is doing this as well and she was like 'you should do this' so I said 'okay.' – Participant 6 (Group 1)

Participants also perceived the specific research process which was used could be either a facilitator to their participation, or a barrier. One particular facilitator that they described was interest in the experience of being part of research. They discussed that some young people *like doing research projects*.

I've done a bunch of surveys and monthly emails from people, but a focus group to me sounded really interesting at the time because I'd never been a part of a focus group before, and it was a discussion rather than a fill in the blanks. – Participant 25 (Group 6)

A major facilitator to participation, engagement or involvement in research was the topic being investigated. Where they were *interested in, or related to, the topic*, they were more likely to take part in the activity.

Yeah, I think anything similar, especially if it included tests or something like that, like you know looking at photos, anything that was a bit more fun I suppose. But just an interesting topic, it doesn't have to be anything relevant to me I suppose, just interesting. – Participant 18 (Group 4)

The importance of the topic and the degree to which it influences young people's decision to participate was further discussed in their view that if researchers are able to *make the topic of the research personal*, then other young people are more likely to want to take part.

I do think that those who have had an affiliation with mental illness are more likely to go to a website and participate in research. – Participant 15 (Group 3)

Participants' likelihood to participate in an activity, either research itself or an involvement or engagement process, was also influenced by their perception of the impact of the research project. They discussed that they were more likely to participate if they could *see the impact of their participation*.

I think if I was given information about the project so I could see 'oh, this is something that's being really developed, and that's interesting,' then I could see

the reason I should be involved is this and this and they're doing something that needs help to do this and this. – Participant 9 (Group 2)

The final factor which participants perceived would impact on the likelihood of participating, being engaged or being involved was their desire to be *comfortable with ethical aspects of the research* prior to choosing to take part in an opportunity. This discussion revealed a level of awareness around the sensitivity with which mental health research should be conducted, and the potential risks to participants if this is not done.

Where you're addressing mental illness the ethics of it can be quite important in terms of making sure identification and all that kinds of stuff, it can sometimes be a thing for people. – Participant 22 (Group 5)

4.4.5 Area 3: Experience of, and ideas around, recruitment to research studies

Incentives

Participants' views regarding researchers' use of incentives varied and were discussed in considerable detail in several the groups. Each participant was presented with a movie ticket as a thank you for their participation in the present study, to which their reactions varied. Some participants felt that *money and movie tickets were not an incentive* for several reasons including their motivations for taking part were altruistic, or that the monetary value of the incentive was not equivalent to what they could earn for the same amount of time in paid work.

Money especially I can actually make more by working. Money's never that much for your time anyway. And movie tickets, I don't really find that sort of stuff an incentive. – Participant 26 (Group 6)

A number of possible alternative *types of incentives* were generated, with the relative merits of each discussed. Participants were largely in favour of food and drink being offered as incentives, either during their involvement, or in the form of vouchers. Those who had studied first year psychology courses felt that *research credit* was a suitable incentive.

Research credit for psychology students, or something academic, or you know monetary or whatever. Either way would probably work quite well depending on what the people want – Participant 17 (Group 3)

Those participants who were not motivated by material incentives nominated ideas for less material incentives, such as *updates about the project*.

Updates I think would be interesting, particularly if it is an area of research like this one where you're keen to have people's continued involvement. –

Participant 9 (Group 2)

Where participants did express a desire for material incentives, they valued the idea of *having a choice of incentives*. They felt that the *instant gratification* of being given something directly following their contact with the research team was important, and that what they were given *needs to be something convenient to redeem*.

I guess if it's like a long enough project you could almost work the incentive structure across the whole project? I guess? Like obviously it's silly to pay people a dollar to do a 2-minute online survey, but I guess like you could almost have a points system, like if it's over a few years have a points system and then sort of 'come to this focus group' and it's like ten points or whatever or something like that. – Participant 11 (Group 2)

Although it is a significant incentive of instant gratification of movie tickets after doing something like this. – Participant 7 (Group 2)

Recruitment

Following the discussion of possible incentives, a further dialogue took place about how researchers could more effectively recruit young people to both participate and be involved in research studies. Participants expressed a wide range of ideas about *things that the researchers can do to better facilitate recruitment* of other young people to research studies. These ideas included highlighting any incentives that are offered and generating awareness of the project prior to specifically asking people to participate.

Exposure in lectures as well, just to know the opportunities are there at the university. Like if the lecturers and the researchers are promoting stuff, and are enthusiastic about it, so our teachers, I think then that would probably motivate me to do stuff. – Participant 14 (Group 3)

Participants nominated a range of ways that researchers could broaden the set of *tools or techniques that can be used for recruitment*. They suggested that researchers use *social media to recruit young people* as it is a setting that young people frequent and are familiar with.

Posting on pages that are specific to particular groups where you know it's a group of people who are obviously interested in this area of study, I think that would be extremely effective. – Participant 8 (Group 2)

Some participants were in favour of researchers approaching them face-to-face, specifically on their university campus. However, other participants thought that this would be intrusive or unwelcome.

I'd personally prefer to hear it in person, so if it was a student I guess if you were looking like at student research, to have someone come up in front of a lecture and say, 'this is what I'm studying, are you interested in getting involved, then you can do this x,y,z,' but again that's going to the same problem that I criticized before, of you know having a very narrow group. But if someone personally says to me this is something that's happening I'm much more likely to listen and to actually consider it than if I'd, you know, seen it on some social media forum or via an email or something like that. – Participant 9 (Group 2)

The final substantive idea generated was the creation of a university-wide database of research opportunities. This idea was independently generated in the majority of focus groups, with the precise form that it should take varying between groups.

Maybe if the actual official ANU website had a place... I don't know, maybe one of those flashy boxes – you know, the boxes that move. – Participant 14 (Group 3)

Regarding how often young people should be approached, participants generally favoured the idea *regular invites to participate in small activities*, particularly in the case of a long-term research project.

A little email once a month saying, 'how are you feeling?' This is how we're going; do you feel like answering these questions? If not that's fine. – Participant 16 (Group 3)

The final dimension of recruitment discussed was *methods through which they didn't want to be contacted*. Participants felt that some methods of contact would be too intrusive and would impact on their sense of privacy. These methods included targeting the clients of mental health services directly or being sent text messages.

I find it really creepy when like organisations and stuff text me. – Participant 7 (Group 2)

Relationship to the person or organisation conducting the research

Due to the way participants were recruited to this study, many participants *knew the researcher personally* and cited this as a reason they chosen to take part in the present research project.

I think I still would have come because I'd say my girlfriend said [researcher's name] is doing this research which isn't really altruistic because I already know you. – Participant 6 (Group 1)

Where participants didn't know the researcher personally, but had a shared group membership with the researcher, or empathised with the researcher, these aspects were discussed as reasons that heavily influenced the likelihood that they would participate.

I think I'd almost be more inclined to help out a PhD student than a researcher... because I feel like, PhD student - not too far from me. I know what it's like to struggle to get people to be part of a group... so it's that I identify with your struggle. – Participant 27 (Group 6)

The positive impact of shared group membership was also reflected in participants' views that *not knowing the researcher* may be a disincentive to participate in research.

Where participants did not know the researcher, the *type or status of the organisation conducting the research* impacted on their choice to take part. Participants reported that they were unlikely to participate or be involved in research being conducted by organisations or researchers with which they had no prior relationship. However, an exception to this was if researchers were from universities, as this was perceived to make them, and by extension their research, more trustworthy and worthwhile.

I do think being associated with the ANU does add legitimacy to the research. It's not just someone mucking around with stupid stuff it's going to be serious, important, and go somewhere useful. – Participant 12 (Group 2)

4.4.6 Area 4: Methods of involving young people in research

Phases of the research process that young people could be involved in

Participants expressed a diverse range of ideas about the phases of the research process in which young people could be more actively involved. They considered that young people being involved *at every point* was optimal.

Every point might be useful I suppose. Maybe not like what colours to put on the website, but the important substantial things I suppose. Feedback would be relevant at every point I think. – Participant 18 (Group 4)

However, they also acknowledged that in some cases this would be impractical. When asked about specific phases of the research, participants were of the view that it was particularly important that young people are involved *at the design phase*.

You could tailor things to students at the ANU just by asking them what they think the problems are. – Participant 13 (Group 3)

Irrespective of the phase at which they were involved, young people felt that there should be *a range of intensity levels* to accommodate their varied abilities and levels of interest.

I think passive information would be good as well as active things for people who might be interested. – Participant 15 (Group 3)

Ways that young people could be involved in research

Participants generated and discussed a wide range of ways that young people could be involved in research. The most frequently mentioned of these methods were traditional forms of research participation, such as *surveys*, *online consultative methods* and *face-to-face methods*. These methods were favoured because of their familiarity, and the ease with which participants felt they could take part in them.

Surveys are always a good idea, particularly if you can just grab people when they walk past sometimes. Like the union court trivia thing that happened? That got a lot of people involved in that mainly because there was a BBQ also. – Participant 1 (Group 1)

Online consultative methods, while familiar and of interest to participants, were considered to be more open to failure as they require a critical mass of young people before they were considered worthy of young people's time.

I think forums can go either way; if lots of people use them they're really good, but if they're clearly not being used they're really unappealing. And like if no one is using it, why bother, it just looks bad so if people don't use it then I guess people won't use it, it's kinda [sic] circular. – Participant 12 (Group 2)

In addition to the traditional and familiar, novel methods of involvement and some examples of research participation were suggested by young people. In the context of research into youth mental health, *journals for people to reflect on their experience of mental ill health* were suggested as a research participation process, as these could help young people in their recovery as well as providing research data.

So if you think about something during the day about mental health, or you come across some personal experience, you should write it down you know in a journal form; just little ones maybe because the thing with mental health is that it's really personal... what did you think of today, or what is the mental health thing that's affecting you today. It might be easier for a lot of people. – Participant 14 (Group 3)

Young people were also interested in being involved in research by conducting *data analysis*, as they felt that this would help them develop their own skills in looking after their mental health in addition to assisting researchers.

That would actually probably be good for you, in terms of your own mental health, if you could analyse what's going on with them. Like look at their problems, and what they're doing right and sort of learn from that in that way too. – Participant 13 (Group 3)

Participants also suggested that researchers could use games to involve young people in research. This was thought to be a simple way that participants, particularly those who may not be as likely to take part, could be involved.

As someone who's a bit of a hermit, and doesn't leave the university much, doesn't look at social media much, and is a complete hermit sorry but maybe you could have, I don't know, a cool game. – Participant 6 (Group 1)

They were also eager to have young people involved in creating project websites directly; however, this suggestion generated discussion around whether or not students would have the level of skill required to efficiently help out.

Web design. So getting people to help with the actual creation. So I know a lot of undergrads who really like web design. They don't have a lot of time to do it, but

if it was, if they could be involved in that, there would be a lot more interest in the outcomes. – Participant 16 (Group 3)

The final area of discussion in this theme was around having opportunities to take part and be involved in research built into university courses. Some participants were in favour of this, as they believed that it would be an easy way to get students involved in research. Others felt that the university curriculum is already overcrowded, and if involvement were to be made compulsory young people may resent this, and subsequently provide lower quality contributions to research.

Having undergrad courses that are compulsory for everybody in the university where you do participate in some form of research and doing that would possibly foster a research culture.... – Participant 5 (Group 1)

That would be such a bad idea; I just think it would be such a bad idea to make anything compulsory. – Participant 1 (Group 1)

4.5 Discussion

The findings from this study suggest that the young people who choose to participate, and be involved in, research have high rates of previous research participation and may not be from culturally and linguistically diverse backgrounds. While the influence of mental health on their motivations is varied, they are strongly motivated by positive relationships with the organisation or researcher. The amount of time and effort that they are willing to go to to take part in research is low; and high levels of effort being required of them may be a barrier, as may not being interested in the topic of the research. The varied views around the incentives young people would like to be offered, and the phases of research in which they would like to be actively involved, show the importance of ensuring young people are consulted in the design of any methods or processes of involvement and participation.

Participants in this sample had a high level of previous participation in research. This finding, while potentially influenced by the research focused nature of the university attended by the students in this sample, has not been previously described in the literature. This trend may suggest that the young people who choose to be actively involved, or participate in, youth mental health research are likely to have previously taken part in similar opportunities or work. Where this does occur, it may mean that they are more familiar with research practices and topics than other young people. However, several elements specific to this study may have been the cause of this

finding, as opposed to it being a broader trend within youth mental health research. These elements include the specific sample for this study—university students at a research-intensive university, who may be more likely to have been exposed to research than other young people; and the snowball sampling recruitment method used. Because of these potential causes, further work with broader samples is required to establish if this is a trend within the groups of young people who choose to be actively involved in youth mental health research. If established, it is a bias that researchers should measure and take account of when they are involving young people. Higher levels of research literacy and existing knowledge from previous involvement may impact on the responses young people give, and how they approach research. Conversely, such a bias may present a barrier to young people, with no prior experience of involvement, to becoming involved. Minimising the impact of this bias, if it exists, may be achieved by either acknowledging it as a limitation, or prioritising recruitment of young people who have not previously been involved or participated in research.

Participants expressed a range of views regarding if, and how, the term ‘mental health’ had acted as a motivation or disincentive for taking part in research. They discussed that different mental health terms may influence young people’s decision to participate or choose to be involved in research, in different ways. Differing perspectives on whether specific mental health terms are a motivation, or otherwise, is reflective of the heterogeneity of young people who are involved as acknowledged by James (2007). These differences may reflect a variety of understandings about what ‘mental health’ and related terms mean. Recognition of this has been previously noted by Jorm and Reavley (2012), who showed that within the Australian population there are a range of understandings of the terms used to describe mental ill health. This finding highlights the need for researchers to understand how the terms they are using are understood by the populations they are working with, not just how they understand the terms themselves. When applied to youth mental health research involvement, this could be achieved through pilot testing of terms with young people prior to the use of these terms in research, or by offering definitions of the terms being used to ensure that both participants and researchers understand terms in the same way.

Cultural and linguistic diversity (CALD) was discussed by participants as a potential barrier to other young people taking part in research, either through participating or being involved. While, similarly to the finding about the high level of previous participation, this may be attributable to the sample, previous work has not explicitly identified this, or similar, as either a barrier or motivator to involvement.

However, where the characteristics of young people and consumers who have been involved have been reported, the proportions of people from culturally and linguistically diverse backgrounds are low (Howe et al., 2011; Patterson et al., 2014). In Howe et al.,'s (2011) list of the characteristics of young people who were involved in mental health research, only one person of 16 identified as being from a CALD background. Considering these findings, the suggestion by participants in this study that being from a CALD background may be a barrier appears likely. In addition to identifying this as a barrier, participants provided suggestions about ways practice could change, such as having targeted opportunities for specific groups of young people who may not feel comfortable participating in a group with others. These suggestions provide pathways through which the previous acknowledgement, that there are a lack of sufficiently diverse groups of young people in research, could start to be overcome may be overcome (Collin, Rahilly, et al., 2011; James, 2007; Orlowski et al., 2015; Simons, 2012; Wadley et al., 2013). That diversity is acknowledged by young people as a barrier to involvement shows the need for more detailed work in this area. This work is required to both identify the extent of the problem and create strategies through which it can be overcome. This endeavour is furthered in the rest of the studies in the project, and recommendations are made in each study's chapter and the conclusion.

The importance of young people having a positive relationship with the researcher or organisation conducting the study was shown in the theme 'relationship to the person or organisation conducting the research.' The importance placed by young people on these relationships shows that researchers and research organisations should invest in, and work with, communities of young people. This concept has not been previously identified in the youth involvement in mental health research field specifically, but has been identified in the youth mental health service delivery field (Coates & Howe, 2014; Ramey & Rose-Krasnor, 2015). For example, young people commenting on their reasons for deciding to be involved in an advisory group remarked that they were motivated to build and maintain quality relationships between themselves and researchers (Coates & Howe, 2014). These findings warrant attention as building these relationships may be one way in which more young people can be accessed, and then motivated, to be involved or to participate. If adopted, the practice may also enrich the wider communities through strengthening the networks of both the researchers and communities. The cooperative research centre model, through which the CRC was funded, is one potential way in which this might be achieved at an organisational level. The cooperative research centre model involves partnerships between researchers,

university and industry, or community groups being built into the fundamental funding structure and operation of the organisation. This model provides an incentive for all involved parties to work together, such as recruiting young people through community-based networks and promoting each other's work where appropriate. Partnering with young people and organisations who work directly with them in this way may lead to greater levels of recruitment of all young people, and recruitment of groups who are otherwise challenging to reach. The impact of biased samples could be avoided by purposive selection of lead organisations, and by having relatable young people as partners in involvement in research.

The theoretical underpinning of the need to demonstrate shared group memberships can be found in social identity theory, which suggests that reinforcement of positive, shared group identities can be used to show members of a group that similarities exist (Haslam, Jetten, Postmes, & Haslam, 2009). Highlighting the group memberships that researchers and potential participants share will allow researchers to demonstrate to participants that they share similarities and have had similar experiences. Specific ways that this could be enacted in recruitment include involving additional young people as co-researchers, or research ambassadors, to help create these links between potential participants and the research. Where the researcher themselves is a young person, as in the current study, this is particularly simple to achieve.

Young people's reflections, that the time that research requires can be a barrier to participation and involvement, suggest that researchers should consider this to a greater degree than they do so at present, and consider making attempts to reduce it. While similar barriers, such as the need to ensure that activities are available at times and spaces that are accessible to young people, have been identified previously (Kirby, 2004; National Children's Bureau, 2010), this specific barrier has not. Young people in this study suggested that researchers could minimise young people's experience of the barrier by changing how they go about youth involvement. For example, researchers should consider and explicitly acknowledge not only the time that the research activity itself takes (e.g. interviews take one hour), but other time costs such as travel to and from a location, or the time required to arrange a time for participation. Additionally, researchers should take into consideration what may be going on in the lives of the people that they are attempting to work with. For example, researchers may be able to avoid conducting research activities at times of high stress, such as exams, and making a variety of opportunities available to account for the range of hours when young people may be taking part in work and study.

Another area where researchers should consider taking into account young people's circumstances is the incentives that are offered in return for time or views. The specific incentives that participants valued varied considerably, as did their preferred timing of receiving the incentive. This shows that there is no 'one size fits all' approach to incentivising involvement and participation in youth mental health research, and consequently that this is an area in which researchers should consult specific participant groups before offering incentives. Some participants value the instant gratification that comes from being given an incentive at the time of the activity, and others feel that less immediate incentives are of more value to them. One example suggested by participants—researchers giving young people updates about an ongoing project—is a current example of best practice which should be utilised. Young people, in the guide to youth involvement practice written for researchers by young people and published by the National Children's Bureau (2010), have specifically commented on updates to research they are involved in as something they would value. These findings contribute a further reason for undertaking this practice, as young people may perceive receiving these to be an incentive to participate or to continue participating.

The idea that young people may not take part in research participation or involvement activities because they are not interested in what is being examined was mentioned by participants. This finding is similar to those from an unpublished study discussed in Tarpey's (2006) review. In that study, young men acknowledged that they felt no immediate need to get involved in research, either because they had no health or social care problems, were ill very rarely, or they had always received good treatment. One way in which this lack of interest could be overcome is, as suggested by participants, researchers making their studies as relevant as possible to the lives of the young people they are attempting to involve and have participate. By showing a relationship between the issue being studied and young people's lives, their interest, and willingness to take part in research activities on the topic may increase. Given the high prevalence of mental ill health in young people (Patel, Flisher, et al., 2007) this may be a relatively simple endeavour to implement.

Participants discussed that they, and other young people, are not willing to go to much effort to participate or be involved in research opportunities. This finding, which is similar to a lack of interest being a barrier to involvement, is of interest. However, again, it's emergence may be related to the sample in this study. It suggests that even when young people are interested in the topic of the research, and want to take part, they feel that the burden of recruiting them or making them aware of opportunities

should remain on researchers, not themselves. One action that could be implemented is that researchers consider reducing, as far as ethically and feasibly possible, what participants need to do in the lead up to involvement. Preferential use of research methods that require minimal effort from young people may assist in overcoming this barrier. Examples may include online or phone-based methods which can be undertaken at a place of the young person's choosing, such as on social media or at schools and universities. However, a key consideration for researchers attempting to reduce the effort required of young people in this way is that the processes used should be appropriate for the specific project and the people involved. For example, what constitutes minimal effort would be different for young people in rural areas and those who attend the same university as the study investigator.

Young people would value the opportunity to be involved at all phases of a research project, yet in this study were unable to name specific research phases without being prompted. This broad finding was also mentioned by young people in a similar study by Mawn, Welsh, Kirkpatrick, Webster and Stain (2015). In Mawn's study, the young people interviewed stated the belief that they can and should be involved in all stages of research. As in the present study, they were unable to name specific research stages. This may be due to a lack of understanding about the phases that research projects entail or may be indicative of a wider deficit in knowledge about research. Young people's involvement in some of these phases have been previously identified, such as consultative methods (Orlowski et al., 2015), creating the study website (Orlowski et al., 2015) and through face-to-face methods (Orlowski et al., 2015). These findings may suggest that there is a greater range of processes that researchers could use to involve young people in their research than they do at present. However, these finding may also be indicative of both the breadth of terms that are used to describe how young people are involved and participate in different research traditions, and a variance in terms used among young people.

The final two areas described by participants were their experiences of, and ideas about, recruitment to research studies and the media that they would prefer researchers to use. Within both of these areas divergent views were expressed. This breadth of views highlights the importance of involving young people from the commencement of the project, or prior to this at the grant writing and planning stages, to allow their insights into how young people should be recruited to be captured. The function of the Youth Brains Trust in the CRC, as described in Section 3.3.3, is an example of a measure intended to involve young people from these early stages. The

YBT is explored in two of the latter studies of the project which involved young people (Study 3, analysis of advisory group applications, and Study 4, survey of advisory group applicants). Through involving young people in the research planning and project plan review process, recruitment and media choices can be tailored not only to researcher needs, but also to the needs of specific groups of young people.

4.5.1 Limitations

Two limitations related to the recruitment strategy and participants occurred. Firstly, restricting participant recruitment to students currently enrolled at the researcher's university is likely to have biased the findings as university students are known to have higher rates of volunteering than the general youth population (Australian Bureau of Statistics, 2012a; McCabe et al., 2007). This suggests that students in this study may have responded differently to the questions about their motivations compared to a less restricted sample.

Secondly, one of the six focus groups had only two participants. This low number may have limited the discussion and idea generation in that group, and may have increased the reliance on the researcher to provide ideas and inputs. This limitation was considered in the analysis phase, and it was noted that the differences between the discussions in that group relative to the other groups were minor.

One of the methods used in the recruitment strategy, an online snowball strategy from the researcher's networks, impacted on respondents' experiences of finding out about the study, and their reasons for participating. This bias was evident in the theme 'relationship to the person or organisation conducting the research.' The relationship between the researcher and participants is unlikely to be as close in other research studies, which may mean that the findings from this theme in particular may not be generalisable to other research.

4.6 Summary

The first study in the YIMHR project has explored young people's experiences of being involved and participating in research, and their ideas and views about changes researchers could make to how they involve young people. The findings from this study suggest that being from a culturally and linguistically diverse background may be a barrier to involvement and participation in research. Young people's motivations may be impacted by the specific term used to describe mental health, and their relationships with organisations and researchers. Finally, they are only willing to go to a low level of

effort to take part in research, and to stay involved, but are interested in being involved throughout the research process.

The findings from this study, and concurrent discussions with the CRC head office, were used to refine the aims of the YIMHR project. The most significant changes made were to narrow the scope of the project from the entire spectrum of involvement to only active involvement, and to focus specifically on the experience of involvement instead of preferences for participation.

The open-ended focus groups used in this work have allowed young people's ideas about how researchers can change and improve their practice to emerge. These suggestions include working with community and youth organisations to build positive relationships, and consultations around desired incentives for involvement.

5 Study 2: Researcher interviews

5.1 Introduction

5.1.1 Overview

The second of the five studies in the Youth Involvement in Mental Health Research (YIMHR) project explored the perspectives of the researchers who involved young people in the research of the Young and Well CRC (the CRC). The study was a qualitative description study, using semi-structured interviews as the data collection method. This study contributes to all three of the project aims by providing insights into researchers' perspectives on the characteristics and motivations of young people (Aims 1 and 2) and describing how they involved young people in their work (Aim 3). The study contributes to the project, and the youth involvement in mental health research literature in two ways. Firstly, it compares the experiences of CRC researchers to the reflections of other researchers in the existing literature. Secondly, it also provides a point of contrast to the other studies in the project which were focused on the views of young people.

Five areas were examined in this study: researchers' experiences of involving young people in mental health research, their experiences with the CRC, their approach to involving young people in their work, their perceptions of and ideas about involving young people, and their understandings of why young people choose to be involved.

This study has drawn on several specific areas of previous work. These areas include the rationale and benefits of the use of involvement as described in Section 2.3; the processes used (Section 2.4.1); the contextual influences (Section 2.4.2); and the characteristics, motivations and experiences of the young people who are involved in mental health research (Section 2.6).

5.1.2 Study rationale

Very few studies have involved the reporting of researchers' perspectives on involvement other than reflections on their own use of an involvement process. Further, to date there has been no explicit consideration of the extent to which the backgrounds or workplaces of researchers affect how they involve young people and their reasons for doing so. As some of the challenges faced in involving young people may be situation specific (such as limited funding), the context in which the researcher conducts their research is important. This context may impact on the manner in which they approach their work, and their perceptions of the process of involving young people in research.

The present study aimed to address these limitations by collecting primary data from researchers who were part of the CRC about their perspectives and experiences of involving young people in their research. As described in Chapter 3, the CRC was comprised of researchers from both universities and industry using youth involvement techniques to develop mental health interventions for young people. Given the paucity of primary data on the topic and the lack of a clear understanding as to how young people are involved in research, the CRC's researchers were ideal for investigating these areas.

A purposive sampling technique allowed for the perspectives of researchers from three types of workplaces (CRC head office, universities and industry) to be compared. A qualitative description method approach was employed to allow exploration of the area in the absence of clear previous data.

5.2 Design

5.2.1 Choice of method

This study used a qualitative description approach, as described in Section 3.6.1.

Data were collected using semi-structured interviews, which combine elements of a formal interview and features of an informal conversation (Willig, 2013). Interviews were chosen as they afforded the ability to compare the perspectives of participants in the analysis, while also providing sufficient flexibility to allow participants to elaborate on their specific experiences. When compared to other qualitative methods, they have the advantage of not enabling participants to identify one another. This was crucial as the study examined researchers' perceptions and experiences of the work they were undertaking with their funding body or workplace, and therefore potentially involved sharing negative perceptions about these.

5.2.2 Human Research Ethics approval

The Australian National University's Science and Medical Delegated Ethics Review Committee approved the ethical aspects of this study (Approval number 2014/634; see Appendix 5.1). Participants provided consent to participate by signing a consent form before the interview began (see Appendix 5.2).

5.2.3 Participants

The participant group was purposively selected from members of the CRC's head office and partner organisations as listed on the CRC website in November 2014

(Young and Well Cooperative Research Centre, 2016a). This website listed the names, organisational affiliations, positions, CRC research stream(s), and affiliated projects of the 300 members of the CRC collective, including those staff who were responsible for the administration and management of the CRC (the CRC head office). Members of the researcher's university (The Australian National University) were excluded from the study because supervisory and close collegial relationships existed between the researcher and these individuals, which may have influenced responses and analysis.

The remaining members of the CRC collective were categorised into three groups based on theorised differences in how they may have involved young people. These three groups were: the CRC head office, university-based researchers, and industry-based researchers. To capture a diversity of views across the CRC, two participants from the CRC head office were selected alongside two research participants (one university and one industry partner) from each of the CRC's three research streams (Safe and Well Online, Connected and Creative, and User Driven and Empowered).

Eight key informants from across the CRC were selected as potential participants from the three groups to include a range of levels of seniority and topic areas. The number of participants was limited because of time and resourcing constraints. However, this limitation was somewhat mitigated through the purposive sampling strategy. The three groups were used to maximise the heterogeneity of experience across the sample.

These potential participants were invited to participate in the study via email on 25 November 2014. The text of the emails and information sheet used in this study are available in Appendix 5.3. Six potential participants responded to the initial email within three days and agreed to participate. A follow up email was sent after one month to the two remaining potential participants who had not yet responded to the initial email. Of these, one responded agreeing to participate and the other did not reply. The latter individual was not followed up further and another person from the same participant group and experience level (low seniority from the CRC head office), was selected. This person was sent the same initial email as above and responded positively to this invitation.

5.2.4 Procedure

Telephone interviews were conducted between 29 November 2014 and 18 February 2015. Telephone interviews were used, rather than face to face interviews, because all participants were located in different states to the researcher.

Seven interviews were conducted by the researcher calling the participant from a landline and recorded using a Marantz Professional Solid-State Recorder with the phone on speaker mode. For practical reasons, one interview was conducted by the researcher calling the participant from their mobile phone instead of a landline. This interview was recorded directly onto the researcher's encrypted Mac laptop computer using QuickTime Player Version 10.3 (727.4). The interviews varied in length from 20 to 40 minutes, with an average length of 25 minutes.

The researcher transcribed all interviews verbatim within 48 hours of them being conducted. Following the initial transcription, transcripts were checked against the recording twice for accuracy. To allow for ease of reading and clarity, instances of paralinguistic (e.g., 'um') were removed (Willig, 2013). Participants were emailed a copy of the transcript of their interview, with a request that they review it for accuracy and respond within two weeks of the email being sent.

Seven of the eight participants responded to this email, six saying they were happy with the transcript as it was, and one participant responding with minor changes to their transcript that clarified the expression of their answers. The requested changes were noted, and the amended transcript was analysed. No attempt was made to follow up the participant who did not respond.

5.2.5 Interview questions

Participants were asked a series of open-ended questions examining their experience, approach, and perceptions about involving young people in research in five broad question areas as presented below.

1. Previous experience involving young people in mental health research (participant experience).
2. Experience with the CRC.
3. Approach to involving young people.
4. Perceptions of, and ideas about, youth involvement.
5. Perceptions of why young people choose to become involved.

The interview protocol took the form of key questions and prompting questions. If the researcher judged that the response to the key question provided sufficient detail, prompting questions were not used. The key questions are described in the following section; the full protocol, including prompting questions, is detailed in Appendix 5.3.

Area 1: Previous experience involving young people in mental health research

The purpose of the participant experience questions was to gain an understanding of how long participants had been involving young people in their work, and their familiarity with the practise. The key questions are below.

- For how long have you been involved in the mental health sector or mental health research?
- For how long have you been involved in the youth mental health sector or youth mental health research?
- For how long have you been involving end users in your research or work?
- For how long have you been involving young people in your research and/or work?

Area 2: Experience with the CRC

Participants were asked a series of questions about their work with the CRC to determine their motivations for involving young people, and to elicit specific details of how they did this within their CRC project or work. The key questions were:

- Why have you chosen to involve young people in your CRC work?
- How do you involve young people in your CRC work?
- What media do you use to involve young people in your work?
- Thinking about the ways you involve young people, what do they do when they are involved?

Area 3: Approach to involving young people

The theoretical model or background, or lack of one, from which participants approached involving young people may have influenced the way in which they involved them in their research. The questions in Area 3 were designed to elicit an understanding of this.

- Do you approach your work with Young and Well, particularly the work involving young people, from a theoretical model or background?
- How do you feel this affects your practice?

Area 4: Perceptions of, and ideas about, youth involvement

The next series of questions focused on identifying the perceived challenges and benefits of involving young people in youth mental health research. They also explored how researchers planned to use their experience with the CRC to modify and develop their future practice. The questions are described below.

- What challenges do you see arising from involving young people in your research and/or work?
- What benefits do you see arising from involving young people in your research and/or work?
- Do you think involving young people in research involves different challenges, benefits or issues, compared to involving those over 25 years?
- In future projects or work, what would you do differently with respect to involving young people as a result of your CRC experience?
- How do you think involving young people changes a project?

Area 5: Perceptions of why young people choose to become involved

The final question aimed to elicit participants' perceptions of the motivations of the young people who had been involved with their work. This question was designed to complement the findings from the other three studies in this thesis that investigated young people's self-reported motivations for taking part in involvement processes and activities.

- Why do you think young people choose to participate in the work we do?

5.3 Analysis

The study was analysed during the period from May to December 2015. Participants were assigned a one-digit participant code in the order the interviews were conducted. Data were analysed using a qualitative content analysis approach. The process is described in detail in Chapter 3 and is summarised below.

As occurred in the analysis in the preceding study (Chapter 4), the major themes which arose from the analysis were closely related to the areas used in the interviews. This relationship is illustrated in Table 5.1, which describes the final major themes. The initial theme tables are available in Appendix 5.4.

5.4 Findings

Table 5.1 shows the major themes that were identified and how these relate to the question areas. As noted above, participants' responses to Question Area 1 constituted a feature, not a theme.

Table 5.1 *Researcher interviews: major themes*

Question area	Themes
2. Experience with the CRC	How participants involved young people in their work with the CRC <u>Why participants involved young people</u>
3. Approach to involving young people	<u>Participant's approaches to involving young people</u>
4. Perceptions of and ideas about involving young people	Challenges that arise when involving young people Changes to future work as a result of the CRC experience Importance of working in group <u>appropriate ways</u>
5. Perceptions of why young people choose to become involved	<u>Why participants think that young people choose to get involved</u> <u>Views regarding the diversity of young people who get involved in research</u>

Aim 1 of the YIMHR project was to identify the characteristics of young people who are involved in youth mental health research, to compare this with other young peoples' characteristics and to examine researchers' beliefs about these characteristics. This aim was progressed through one theme from Area 5, 'views regarding the diversity of young people who are involved in research.'

Two themes from Areas 2 and 5 contribute to understanding Aim 2: to compare the self-reported motivations of young people involved in mental health research to both researchers' perceptions of these motivations, and the motivations that other groups of young people report for similar activities. These were 'why participants involved young people' and 'why participants think that young people choose to get involved.'

The remaining themes progressed understanding of Aim 3: to compare young people's actual and desired experience of involvement in mental health research, and to compare this with how researchers involve young people.

5.4.1 Area 2: Experience with the CRC

How participants involved young people in their work with the CRC

Participants' approach to involving young people varied depending on their workplace, the nature of their research, and, in particular, the needs and main activities

of the group with whom they were working. Responses to this question area also encompassed participation processes, as well as involvement processes.

For example, *young people's involvement with the CRC head office* was, for the most part, focused on young people working with research teams and the CRC head office to communicate the activities of these groups to other young people, including those in the broader community. Involvement in the Youth Brains Trust (the YBT), the CRC's youth advisory group, included an additional focus on the branding and central vision of the CRC.

They support our media and communications activities, and then we also involve young people directly in projects. – Participant 3 (CRC head office)

...we had a youth brains trust before we'd even launched the organisation –
Participant 5 (CRC head office)

Several participants mentioned *details of their specific projects* including the topic, or title, of their work. To protect the privacy of participants, this sub- theme cannot be explored in detail. However, the eight participants had collectively involved young people in all *stages of the research process*, which are described below. By doing this, participants felt they had ensured that young people's voices had been heard throughout the process.

My project was conceived with the involvement of young people from the very beginning. – Participant 2 (University)

Participants actively recruited young people to be involved in their projects. They reported doing this primarily through existing stakeholder networks.

We recruited young people, I can't remember how. I think it was just from emails through the Youth Ambassadors at Reachout.com. – Participant 1 (University)

Where participants' projects had involved the development of new products, such as mobile applications, they had involved young people in the product development stage. Young people contributed by *giving feedback on the design* and experience of using the products.

We use them to test the kind of development of the concept along the way so we'll quite often, as we're developing prototypes and things like that, bring young people back to kind of test the, what do you call them, the kind of visual design, the things like that. – Participant 6 (Industry)

Following the development of their projects, participants involved young people in *user testing* evaluating the effectiveness of the products or interventions.

Once we've done that we'll probably finalise the build and then go into more of a kind of larger scale trial, where we look at overall acceptability and effectiveness. – Participant 7 (University)

The final stage at which young people were involved was in disseminating the results of the research to relevant stakeholder groups, including in the media. Participants commented that involving young people in this research stage helped give their findings or interventions the relevance and legitimacy that they wouldn't have otherwise had.

It's amazing the difference that you know having young people co-present those presentations, or helping to launch your report, or talking with media outlets. You know people, they are able to give the project more legitimacy but also show people that this isn't abstract research, this is research that is contributing to the benefit of real people's lives. – Participant 5 (CRC head office)

The *methods by which young people were involved in these processes: online, offline, or a combination of these two*, varied depending on the stakeholder group to which the participants belonged. Participants from all three types of workplaces had involved young people using both offline and online methods. The offline methods used varied from group workshops to phone interviews. The online methods, which were more frequently used by participants from industry and the CRC head office than universities, included online focus groups and surveys.

So our study, I'm mostly involved in the study component of it, like the randomised controlled trial, it's all online. So we recruit via Facebook. What else are we using? Google ads, and we used gumtree for a while, and we're using direct email mail. – Participant 1 (University)

We used online because it was about using technology so the groups that were interviewed, the kids that were interviewed, were interviewed on focus groups using our livewire.org platform... So that was how we involved young people and so they gave their permission and consent. What's interesting about that research of course is no one is actually verbally speaking, it's all done by typing into the platform, so that makes it quite unusual in that you are actually

capturing what people are saying through typing rather than words so that was interesting. I think it made it unique for us. – Participant 4 (Industry)

Why participants involved young people

The belief that young people should be involved because *it leads to improvements in research outcomes* in general, and specifically that *it leads to increased levels of interaction with the research outputs* were strongly held by many participants.

I genuinely believe you get a better outcome. – Participant 6 (Industry)

If it's a product that they've designed, and they are happy with it, they are more likely to use it. – Participant 1 (University)

Participants also felt that involving young people *leads to improvements in research processes* and that *it leads to improvements in the use of project resources*, ensuring that they are focused on the project and are the ultimate beneficiaries of the research.

I think it gives a focus to it. I think that it makes it real for the researchers and others involved in a project what it's about. It keeps us all honest. – Participant 8 (Industry)

The key benefits for us really are around us making better decisions about how we use our resources, what we invest our time and money in. – Participant 3 (CRC head office)

In contrast, three participants mentioned that they had involved young people *because it was a condition of their CRC funding*.

I was under the impression it was mandatory actually. Okay. I mean, yeah if I'm working with the Young and Well, I assume I need to work with young people. – Participant 2 (University)

Involving young people was considered by participants to be of value to the young people who are involved. All but one of the participants mentioned that *young people have a right to be involved*, demonstrating that the reasons researchers involved young people were not confined to a desire to improve the research, but also reflected the deeper value system of the participants.

It's a bedrock thing for me in my own values system. I mean, it's the right of children and young people to participate in activities that impact on their lives.

– Participant 8 (Industry)

Similarly, some participants supported the use of involvement practices because it can be *beneficial to the young people*.

They would sort of be the key ones but then there's also benefits to the individual young people of being involved around things like self-esteem, self-efficacy, skill development, and the ability to give back. – Participant 3 (CRC head office)

These motivations for involving young people in the research process were underpinned by participants' *previous positive experiences of involving young people* and the belief that it is *beneficial in a general way*.

I used to always say I'm a teacher at heart, rather than a researcher, so I actually like working with young people most of the time. – Participant 2 (University)

You just get so much, so much benefit, out of taking the time and resourcing youth participation¹ effectively that, yeah, I think it's ridiculous not to do it. – Participant 5 (CRC head office)

5.4.2 Area 3: Approach to involving young people

Participants' approaches to involving young people

Some participants were able to identify the model or framework that underpinned their approach; others could not clearly identify such a model. These differences were associated with the participant's workplace affiliation. Those from industry were more likely to identify as having *no particular model or background*, whereas participants from university backgrounds were more likely to have an *identifiable model or framework* for their youth involvement practice.

It makes me feel like I should have this massive theoretical underpinning that involves everything we do. I guess you know I've come from more of a community organising kind of space, but even that wasn't really done with a lot

¹ As described in Section 1.2.1, the CRC described involvement as 'youth participation' and 'end user engagement.'

of theory behind it either. It was more practical, just trying something, seeing what works, seeing what people, what resonated with people, and doing more of that. – Participant 5 (CRC head office)

...in terms of our involving young people in the actual research we're kind of, we use a user experience testing and participatory design. – Participant 1 (University)

This diversity of approaches to involving young people across the CRC is indicative of both the diversity of the background of the partners in the CRC, and the wide variety of topics studied within it.

Specifically, in relation to Young and Well, I think one of our big challenges is that each of our organisations that we work with approach youth participation in a slightly different way. – Participant 3 (CRC head office)

5.4.3 Area 4: Perceptions of and ideas about youth involvement

Challenges that arise when involving young people

A number of challenges that researchers had faced when involving young people in either involvement activities or research participation were identified in the data. These challenges included those around working collaboratively with both fellow researchers and young people, such as the difficulty of balancing their voices with those of other stakeholders. Other challenges included researchers' previous negative experiences when involving young people, and several concrete barriers to involving young people. These challenges were more often raised by participants from industry than from universities or the CRC head office.

The challenge of working collaboratively was associated with the experience that *different groups involve young people differently*. Participants expressed this by identifying a range of misunderstandings, and instances of miscommunication, that had occurred between other researchers and the young people involved in their projects. These miscommunications had at times impeded, or changed, their work.

I think related to that is kind of the skills, particularly of sort of some of our researchers working in universities who are less familiar with working with young people in a participatory way... We've had to do a lot of work to kind of get them on board with how to work in that sort of way. You know, so things like you know how to write information sheets in a way that appeals to young people, or at the very least doesn't put them off, and you know how do you

structure interview questions so that they are easily understood and engaging for young people. And you know how do you ensure that the language you're using to recruit young people to a study looks, or is, accessible, that sort of stuff is pretty important. – Participant 3 (CRC head office)

In other cases, the concerns had arisen because of previous negative experiences when collaborating with others from different types of workplaces and were associated with a belief that *some researchers do not value involving young people.*

Because most people, you know, and I do know from my, you know, 30 odd years' experience, is that young people are not people that everyone wants to work with. – Participant 4 (Industry)

Another challenge of involving young people in research related to situations in which *the voices of young people and researchers were in opposition to each other.* Participants expressed uncertainty about how to find a compromise between the ideas and opinions of young people, and the researcher's previous experience and knowledge based on the scientific literature.

I think one of the challenges for us as an organisation is, and it's a challenge generally, is whose voice do you privilege in any research projects. –

Participant 4 (Industry)

The remaining challenges identified in this theme reflected practical barriers to involving young people. Some participants expressed frustration with the *use of small samples* in youth involvement, as they felt concerned that this may limit the generalisability of the input provided by young people.

So one of the biggest challenges is I guess, particularly when you're doing like face-to-face and participatory design work, the number of people that you can involve is so minimal. So, if we're designing products which we want to be effective for, you know, hundreds of thousands if not millions of young people, yet we're probably restricted to like 30-40 young people being involved in the participatory design process. That's how, I mean, how representative that is I guess? So which is why we also do the iterative process of going back and testing with groups of young people, as well to make sure that the ideas and concepts are kind of validated across different groups. So that would be, that would be a big one. – Participant 6 (Industry)

Another practical challenge of involving young people in research related to the difficulty of *keeping young people involved*.

Well, in a broad sense they can be difficult to involve, so you know we'll always you know sort of arrange for about 12 young people to come to a workshop, but expect maybe 5 to turn up. – Participant 7 (University)

The final practical challenge mentioned by participants, and one that emerged across the interview questions, was that of *insufficient resources*, both fiscal and human.

Some of the negative things about involving young people is that it can be quite resource intensive, certainly in terms of the cost as well as time. – Participant 6 (Industry)

Participants also identified that the participation of young people lead to *particular ethical challenges*. These included the greater complexity of obtaining ethical clearance to conduct research with people under the age of 18 years and needing to seek consent from the parents and guardians of these young people for them to take part.

I think though that the fundamental difference between those two demographic groups [people over 25 and under 25] is that again, it goes back to the human right, rights of the child... you need to make sure that you seek consent in an informed way, and your actions do no harm. I think adults have more power, and more ability, to both protect themselves and to tell you if you're getting it wrong than young people do who, because of often, because of the power imbalance between young people and adults, it might be more open to, um to, to manipulation, or to more open to risk. So, I think that's the fundamental difference between the two. – Participant 8 (Industry)

Changes to future work as a result of the CRC experience

Most participants indicated that the work they had conducted as part of the CRC had changed their intended approach to their future research, either with respect to youth involvement, the processes they would use to involve people, or project factors. Of the participants who had not previously involved young people in their work, the majority of these indicated that they *would continue to use youth involvement* in their work after the CRC or would modify their current methods to *involve young people more*.

Well we've got a few other projects that that we've got now that are outside the CRC, and we're pretty much essentially doing it the same way. – Participant 7 (University)

For the next round of research we really want to change [the extent to which the CRC educated the collective about youth participation methods], so we want young people to be far more engaged² in the whole process of developing the research projects and refining them. – Participant 5 (CRC head office)

Some participants, including those from the CRC head office, *would be more prescriptive with procedures* in their future work. This would enable them to work better with stakeholders, such as other researchers, by creating a shared understanding of expectations and outcomes.

I think in some ways we would be more prescriptive with our researchers around what we expect from youth participation practice. – Participant 3 (CRC head office)

Importance of working in group-appropriate ways

Participants emphasised the importance of using involvement processes and mechanisms which are appropriate to the attributes of the group the research is focused on. Researchers recognised that *young people have particular needs*, which included the challenges associated with life-stage transition or their use of technology in ways that differ from other groups. Participants believed that these attributes necessitated *working in age appropriate ways*, and that this was important regardless of the stakeholder group involved in the research.

...depending on what you are developing you want to make sure it's appropriate for that age group, and I think younger people have different needs to a lot of older people. – Participant 1 (University)

Partially I think that's because they are also in a state of transition, in a state of flux between one life to another life, or between different countries, and they are not very sure of themselves as well. Of their own character, their own likes, dislikes, personalities. – Participant 2 (University)

² As described in Section 1.2.1, the CRC described involvement as 'youth participation' and 'end user engagement'

5.4.4 Area 5: Perceptions of why young people choose to be involved

Why participants think that young people choose to get involved

Most participants believed that young people enjoyed being involved in research *because it enables them to contribute to something bigger*. Participants' responses suggested that they recognised the importance of their work to the young people who choose to take part in involvement activities.

It attracts a group of young people that really want to make a difference, either because of their own lived experience, and you know wanting to participate because they feel like others benefit from the experience they had and finding some solutions to that. – Participant 6 (Industry)

In addition to this view was the idea expressed by one participant that young people were involved *because it benefits the young people involved*, as stated by Participant 3 relating to *why participants involved young people* above.

Finally, participants posited that young people might choose to become involved *because of previous personal experiences* such as an experience of mental ill health.

I think a lot of the young people who are involved with the Young and Well CRC have experience of mental health difficulties, or they've seen peers experience mental health difficulties, or family members. – Participant 3 (CRC head office)

Participants also raised the possibility that young people want to be part of research involvement activities *because it is interesting to them* or *because the experience is meaningful to them*.

I think they are genuinely interested in their mental health and wellbeing. – Participant 7 (University)

Researchers also believed that young people become involved in research *because it enables them to connect with others* or *for networking and career development purposes*. They commented that one way this was achieved in the CRC was through group activities, such as the YBT, because these activities allowed young people to meet each other and to build networks in that way.

I think some young people also see it as an opportunity to get more involved in their communities, to get experiences, and to kind of have access to networks that might support them in their career or their development, and I think that that's actually a really positive thing as well. – Participant 3 (CRC head office)

The other really important thing in health care is that research projects allow people to come together who have similar issues and to talk to one another. – Participant 4 (Industry)

Young people were paid for their involvement in some projects. In such cases researchers believed that this *payment* might have served as a motivation for being involved, although the strength of this motivation relative to other factors was questioned by some participants.

They might be interested because of the reimbursement we offer them, although it's not very much, so that might not be a huge interest. – Participant 1 (University)

Views regarding the diversity of young people who are involved in research

One theme that emerged was the extent to which those young people involved in the CRC research reflected the diversity of the wider population of young people in Australia. Participants differed in their opinions as to how adequately diversity was reflected in their research. For example, one participant praised the *current diversity in youth involvement* and, in particular, how this had improved in the time they themselves had been involved in the youth mental health sector.

I think the one thing that I would highlight is the increasing diversity of young people that are part of the Young and Well CRC.... But I think as the group of young people who have access to the internet has diversified, as the young people who are using services have diversified, so too have the young people who have gotten involved in activities like the CRC. – Participant 3 (CRC head office)

Participants expressed the view that *involving sufficiently diverse groups is a major challenge to involving young people*. Some participants focused on identifying these specific diverse groups, with their focus being predominately on the groups with which they had worked or currently work.

I think more of the challenges come from ensuring that we don't treat young people as a homogenous group. So not all young people are the same, they don't have the same experiences, and they don't speak with one voice. – Participant 3 (CRC head office)

Participants mentioned that *young people from culturally diverse backgrounds are underrepresented in youth involvement in research*. This group, which was believed

by participants to be of higher risk of mental ill health than other groups of young people, was also thought be particularly difficult to involve.

I don't think we're very good at reaching young people from different backgrounds, you know like non-English speaking backgrounds. I think we probably need to do more work in that area. – Participant 4 (Industry)

The other group of young people thought by participants to be underrepresented in research was *young people who are not seeking help for mental ill health*. This group was of particular concern to the participants as they believed that underrepresentation in research of those who do not seek help might result in interventions and products less suited to this important group.

One of the things that worries me about involving young people is that the group of young people you get is obviously a really interested sample, and they really want to be involved so it's a very different population to the population that we're trying to get. – Participant 1 (University)

5.5 Discussion

5.5.1 Overview

The following section considers the findings in the context of the aims of the YIMHR project and the extant literature. The main findings of the study are that there may be some groups of young people who experience barriers to being involved or who may not choose to be involved, that young people are motivated to be involved to benefit both themselves and the research, and that workplace setting has an impact on how involvement is practiced. The majority of findings are consistent with those which have previously been described in the literature. This congruence is important for the YIMHR project as it shows similarities between the experience of the CRC and other studies of youth involvement in mental health research.

5.5.2 Researchers' beliefs about young people's characteristics (Aim 1)

This study examined researchers' beliefs about the characteristics of young people who choose to be involved in their research (Aim 1). The findings suggest that there is a concern that young people from culturally and linguistically diverse (CALD) backgrounds specifically may be challenging to recruit and less likely to take part, but that this is improving over time. It shows that there is a need to increase awareness of this.

These findings are similar to previous work, which has shown that researchers and health practitioners in the youth space have identified recruiting a broad group of young people as an issue which needs to be considered further in involvement (Collin, Rahilly, et al., 2011; James, 2007). The suggestion that there may be low numbers of young people from CALD backgrounds also emerged in Study 1 (university student focus groups), and CALD young people have been identified as a group underrepresented in volunteering in Australia (Muir et al., 2009). In addition, this congruence indicates that CALD young people may experience specific barriers to taking part in research (both participating and being involved).

These findings raise the significant possibility that there are some groups who may not currently be taking part in youth involvement in mental health research. They suggest that there is a need to systematically investigate the demographic profiles of participants. This was undertaken in the subsequent studies in the project, and the results are presented in the following chapters.

5.5.3 Researcher's perceptions about young people's motivations (Aim 2)

Participants nominated three key reasons why they thought that young people choose to be involved in research: because it enables them to contribute to something bigger, because of personal experiences and because it benefits their own lives. In some areas these findings are congruent with previous work, while in others they build on this previous work by providing a greater level of detail than has previously been reported.

Researchers in this study indicated that they believe that young people choose to be involved because it is beneficial to the young people themselves. This finding is similar to a range of more specific ideas which have been expressed by young people as motivations in the youth involvement in mental health literature previously. For example, young people in the Howe, Batchelor and Bochynska study (2011) were motivated to help their career pursuits, and those in the Mawn, Welsh, Kirkpatrick et al., (2015) study expressed that, in order to facilitate meaningful involvement, researchers should provide personal development opportunities. One specific way in which this could be achieved would be to provide opportunities that could be added to a young person's curriculum vitae. This finding is interesting when considered in conjunction with the comments made by young people in Study 1, that activities which take too much time or effort may be a barrier to being involved. It is possible that researchers do not prioritise reducing the burden of involvement due to their belief that young people will make an effort to gain the potential benefits. If this is not effectively communicated

to the young people they are seeking to involve, it results in the effort becoming a barrier to involvement. Alongside this, as with the young people in Study 1, not all young people will perceive or value the development benefits from involvement, and hence the effort required becomes a barrier to the involvement of a portion of the youth population. One way in which the relationship between researchers' and young people's perspectives could be more conclusively ascertained would be to interview both the researchers and young people who had been involved in a particular study which used youth involvement. By asking both groups about their motivations and experiences of involvement and comparing the two groups, causal links between the beliefs that researchers hold about involvement, their choice of processes and young people's experiences of these could be explored.

Participants also suggested that they believe that young people get involved because it allows them to contribute to something larger than themselves. This suggests that researchers believe that young people are altruistically motivated to be involved, and is an idea which is supported by studies from the broader involvement literature. Specifically, a key motivation which has been identified by both adults and young people is the desire to achieve positive outcomes for other consumers or young people (Case et al., 2014; Coates & Howe, 2014; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Within the youth involvement in mental health research literature specifically, young people in two studies have reported that they are motivated to be involved because they believe that it allows them to make a difference (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015). A way in which these findings could be operationalised in future work is for researchers to describe and emphasise the impact that they believe their work will have. If young people can see what their contribution and time will do, they may be more willing to take part and devote time and effort to the task.

Some of the participants who had involved young people who had experienced mental ill health suggested that young people may want to take part because of this experience. This finding has previously been identified as a factor which motivates consumers to be involved in research by Tarpey (2006) in her review of unpublished studies of involvement. However, it has not been previously identified as a factor which motivates young people. This may be because previous work in the broader involvement literature has largely focused on service users specifically, who may be more likely to attribute their motivations to a previous experience of mental ill health. In contrast to this previous focus, this was not the exclusive focus of the CRC.

Consequently, further work is required to establish the extent to which this motivation is present in young people who are involved in mental health research. This further work was initiated in the subsequent studies in the project.

5.5.4 How researchers involve young people (Aim 3)

The majority of results in this study contribute to Aim 3 of the project—to compare young people’s actual and desired experiences of involvement in mental health research, and to compare this with how researchers involve young people. The findings suggest that, even when involvement is planned into the work of a project or organisation, challenges remain. While across the CRC, researchers had involved young people at all stages of research, at an individual project level the practise of involvement varied. The similarities between these findings from within the CRC, and previous reports from the broader youth involvement area, suggest that the findings from the YIMHR project may be able to be generalised to broader youth involvement in mental health research.

Most of challenges have been previously reported in the literature, with the exception of the concern that arose from researchers’ previous negative experiences with other researchers. These occurred when collaborating with researchers from different types of workplaces, and when there were different perspectives on involving young people. This finding raises the possibility that a researcher’s context may affect how they perceive the involvement of young people, and consequently may influence their execution of it. It shows the need for clear communication within and between organisations who plan to involve young people. One way in which this may be achieved is through clearer, or more intensive training of researchers in involvement techniques. An attempt to do this was made by the CRC in the guide to the use of participatory design techniques written by Hagen et al., (2012), which was provided to all CRC researchers. More intensive examples include the ‘Involving People in Research’ initiative (Consumer and Community Health Research Network, 2018).

It is noteworthy that researchers nominated as a challenge the failure of funding bodies to cover the expenses required to involve young people in research, despite the CRC mandating that youth involvement activities be included in the project plans it approved and funded. This challenge has been previously mentioned by both researchers and service providers, who have identified that the practice is resource intensive (James, 2007; Ramey & Rose-Krasnor, 2015). Researchers have reported that the lack of adequate resources is a major barrier to involving both adults and young

people (Chambers et al., 2012; Dold & Chapman, 2011; Hagen et al., 2012; Howe et al., 2011; Orłowski et al., 2015; Owens et al., 2010). This finding shows that further work is required to address this issue, both in terms of how researchers plan for and also how it is funded.

The above findings show the need for funding bodies who prescribe the use of consumer and community involvement, and for involvement advocates, to do more to support researchers' uptake of involvement practices. Such measures may assist researchers in overcoming these challenges and encourage the development of communities of practice. These will provide researchers with avenues to discuss specific challenges and find ways to overcome them as they arise. To date, no Australian guidelines for researchers or funding bodies have been developed to assist in planning for resourcing and funding, although guidelines have been developed in the UK by INVOLVE (National Institute for Health Research, 2018b). These guidelines should consider the extra resources that may be required for research which actively involves young people. For example, young people in Study 1 suggested that they may be more likely to take part in involvement activities if they had a connection to the researcher. This is one change to regular practice which may take extra time or resources, and would need to be factored into project or research plans.

Three of the other challenges mentioned by participants also show that there is a need to continue to educate researchers about the practice of involvement, and what will be required when involving young people. The specific challenges were working collaboratively, both with fellow researchers and with young people; the need for more time and greater flexibility when involving young people, compared to traditional research methods; and, the difficulty of balancing the voices of young people and other stakeholders. All these issues have been previously acknowledged in the involvement literature. Specific challenges related to the first of these, working collaboratively, have been identified by both researchers and consumers. For example, researchers discounting their input as insufficiently academic has been identified by consumers as a challenge to their involvement (Patterson et al., 2014). Similarly, researchers may underestimate the capabilities of young people, for example by failing to recognise their potential for leadership (S. Chen et al., 2007).

The second of these challenges, the need for more time and greater flexibility when involving young people, has previously been mentioned by researchers in the youth field specifically, including Monson & Thurley (2011) and Ramey & Rose Krasnor (2015). The difficulty of balancing the voices of young people and other

stakeholders is one of the challenges which has been more regularly discussed in the literature to date. For example, Monshat et al., (2012) reported that the young people they involved in co-designing an online mindfulness program suggested recruitment material design elements that were not considered ethically sound, and hence these changes were not implemented.

The final finding raised by participants, which pertains to Aim 3, is that they had a positive experience of involving young people through their work as part of the CRC. This was illustrated by their responses outlining their future intentions as to how they would involve young people. This suggests that CRC researchers valued both the impact and benefits of youth involvement. This is a novel finding, as previous work has not directly commented on a researcher's likelihood of continuing to use youth involvement methods following an initial instance of use. It raises the possibility that consortia, such as the CRC and INVOLVE UK, provide a valuable vehicle for encouraging researchers to actively involve young people in mental health research, and are avenues by which researchers are able to learn and explore the use of the technique.

5.5.5 Limitations

The CRC collective comprised 300 members, of whom only eight were interviewed for this study. Consistent with usual practise for qualitative studies, the purposive sampling strategy used was designed to sample a breadth of experiences across that group. However, the resulting views and perspectives of this sample were not necessarily representative of the CRC collective as a whole. The deliberate exclusion of the researcher's own research group may have exacerbated this potential lack of representativeness. Future work should consider sampling a greater number of participants.

Related to this, the shorter than anticipated length of the interviews was also a limitation. Prior to data collection, it was anticipated that the interviews would take up to 90 minutes. In practice, they were considerably shorter (average of 25 minutes). Potential reasons for this include: participants had not considered the aspects of their work that the interviews discussed in as much detail as the interview required or, participants had not included young people to the extent anticipated. Alternatively however, this discrepancy may simply have been an error on the part of the researcher in anticipating how long the interviews would take.

As discussed in Chapter 1, involvement and engagement processes exist along a spectrum, and the terms used to describe specific processes can vary considerably. This

diversity was not explicitly discussed with participants prior to, or during, the interviews. Consequently, there may have been differences between participants' intentions, and how the researcher understood the terms they had used. This may have occurred either at the interview stage or during the thematic analysis.

Finally, the relationship between the CRC, the interviewees and the researcher may have influenced participants' responses to be more favourable about the extent they had used youth involvement, and to minimise the challenges they faced. While this relationship afforded access to participants which may not have otherwise been feasible, the influence it may have had on responses cannot be discounted.

5.6 Summary

The present study has confirmed and extended the current state of knowledge about how researchers involve young people. This knowledge is based on primary data derived from interviews with researchers from differing workplace backgrounds. In general, the primary data collection method confirmed observations reported in the literature. Specific areas in which this was apparent were the challenges faced in using youth involvement, researchers' views about young people's motivations for being involved, and the ways in which researchers had involved young people. This congruence is important, as it suggests that the CRC as a case study may be indicative of broader youth involvement practice, thus providing a level of confidence for the generalisation of the YIMHR project findings.

Finally, the study highlighted some areas of disagreement among researchers, for example the question of whether the young people who choose to take part in involvement activities are sufficiently diverse. This disagreement shows the need for further work in this area. Specifically, it demonstrates that there is a lack of consistency between current researchers within the CRC and previous studies, in this regard. Subsequent studies in the YIMHR project address this area.

6 Study 3: Analysis of advisory group applications

6.1 Introduction

6.1.1 Overview

Understanding who applies to be a member of a youth involvement advisory group for mental health research, and why they apply, may help researchers target recruitment and help inform involvement processes and practices. To date, their characteristics and motivations have only been examined in a small number of papers, in varying amounts of detail. When these papers do go into more detail they have largely focused on those who have been involved not those who are interested in being involved.

The present study, Study 3 of the Youth Involvement in Mental Health Research (YIMHR) project, supplements these previous findings through the use of the same qualitative research method (qualitative description), with a different a different data collection method—archival data analysis. An analysis of applications submitted to the YBT of the CRC allows young people’s opinions and descriptions of themselves to be examined without influence from the researcher. The study contributed to the project by providing insights into who the young people perceive themselves to be (Aim 1), and their motivations for applying to be members of this advisory group (Aim 2).

The project draws and builds on two areas of literature as reviewed in Chapter 2. Firstly, what is known about the characteristics and motivations of consumers and young people who are involved in research and mental health service delivery (Sections 2.5.1 and 2.5.2). Secondly, the characteristics and motivations of young people who are involved in youth mental health research specifically (Sections 2.6.2 and 2.6.3).

6.1.2 Study rationale

Because of the exclusive focus on consumers and young people who have been involved in the field, the characteristics and motivations of the people who are interested in being involved have not been considered to date. The present study aimed to address this gap by examining applications to a group, rather than a retrospective form of data collection with people who had been involved,

This method has not previously been used in the youth involvement or youth mental health literature. This may be because of the difficulty in accessing pre-existing data sources due to privacy concerns. The project’s relationship to the CRC (see Chapter 3) assisted in accessing the required data for the present study.

6.2 Design

6.2.1 Choice of method

The construction of a profile of young people based on self-description, rather than on a pre-formulated closed-item questionnaire constructed according to researcher-formulated categories, helped address Aim 1 of the YIMHR project. This profile provided insight into the factors that motivate young people to be involved in a research advisory group, and how they present themselves to gain an appointment to the role. Additionally, the use of pre-existing data limited the effort required by participants (Braun & Clarke, 2006). This was important because some of the members of the population of interest (the 2013 YBT cohort) had already participated in Study 4 (survey of advisory group applicants) and were eligible to participate in Study 5 (survey of community members).

The YBT was an advisory group that shaped the direction of the CRC, advising the board of directors and working in partnership with the CRC's broader community to further the organisation's strategic objectives (see Section 3.3.2). Questions 1 and 4 were selected for analysis on the basis of their relevance to YIMHR's aims. Question 1, 'in no more than 150 words, tell us about yourself' provided information about the characteristics of young people who are involved in youth mental health research (Aim 1). Question 4, 'why do you want to be involved with the Youth Brains Trust of the Young and Well CRC' informed Aim 2, to understand the self-reported motivations of young people involved in mental health research.

6.2.2 Human Research Ethics approval

The Australian National University's Science and Medical Delegated Ethics Review Committee approved the ethical aspects of this study (Approval number 2013/576, see Appendix 6.1).

6.2.3 Participants

All young people aged between 18 and 25 years, who applied in writing to be members of the YBT between 2011 to 2013, were identified as potential participants. Of the 208 potential participants, 47 (23%) agreed to provide their applications for the study. Potential explanations for this low participation rate are discussed in Section 6.5.4.

6.2.4 Procedure

Potential participants were contacted via email by the CRC's Youth Participation Officer (Appendix 6.2). The email included an information sheet about the study and invited participants to authorise the release of a de-identified copy of their YBT application. Potential participants were not offered the opportunity to review their application prior to releasing it, a decision which was made to limit the amount of effort and time required by the CRC Youth Participation Officer.

The information sheet informed potential participants that the researcher had been a member of the 2012 YBT, and consequently that she may be able to identify participants from their applications despite the de-identification process. The email and information sheet also stated that the decision on whether to take part in the study would have no impact on their relationship with the CRC.

Participants consented to taking part by replying to the email authorising that their application be released to the researcher. The Youth Participation Officer collated these responses and sent a file containing the applications to the researcher via an encrypted email. The records of consent to the study were archived with the CRC's head office.

6.3 Analysis

The study was analysed in the period beginning April 2015 to January 2016. The study used a qualitative descriptive approach as described by Sandelowski (2000, 2010), and the data were analysed using the type of analysis of choice- conventional content analysis as described by Hsieh and Shannon (2005), as detailed in Section 3.6.1.

Participants were assigned an identifying label comprising the order in which the applications were sent to the researcher and the year in which they applied. The initial theme tables can be found in Appendix 6.3.

6.4 Findings

6.4.1 Participants' descriptions of themselves

Eight themes emerged from the analysis of the responses to the first application question, 'in no more than 150 words, tell us about yourself.' The themes are listed in alphabetical order in Table 6.1 and are described in detail below.

Table 6.1 *Analysis of advisory group applications—characteristics, major themes*
Themes

Interact with a range of academic topics and ideas

Interested in and are already helping others
Interested in other people
Introversion and comfort with solitude
Have a diverse range of life experiences and have found self-confidence through this
Have a wide range of attitudes and approaches to life
Have a wide range of hobbies and interests
Have engaged with mental ill health, either through their own experience or being conceptually interested

Interact with a range of academic topics and ideas

Young people who applied to the YBT interact with a wide range of academic topics and ideas through both work and study. They characterise themselves as having *an interest in a wide variety of academic fields*, encompassing arts, science, and business.

I'm interested in everything, I honestly am. At the moment I have a growing interest in storytelling and personal histories, and deliberation and participatory practice. These are on top of ongoing thought around psychology, social systems, health and education, and social change. All of this becomes part of big-picture thought around the evolution of human society. – Participant 3 (2011)

This diverse range of interests was also reflected in their experiences of *having studied in a wide variety of fields*.

After completing a Bachelor of Social Science at the University of Newcastle last year, I am now enrolled in the associated Honours program and exploring rural young people's perception of place and space... Prior to University I attained a Certificate IV in Alcohol and Other Drug Work and worked for a brief period in a local youth centre. – Participant 2 (2011)

Of the specific areas mentioned by participants, two were directly related to the CRC. Applicants mentioned that *they are interested in and use technology*, and *they are interested in research*. The mentions of these areas of interest show that the young people applying were aware of, and engaged with, two of the key areas of interest to the CRC.

A person who's incredibly passionate about innovation in the technology sector and has this can be utilised by various communities/demographics (combined).
– Participant 2 (2011)

I am currently writing my first academic journal article and am very interested in the idea of research and statistics. – Participant 31 (2013)

Young people support these areas of interest through studying and working in these fields. They have a *wide variety of work experiences*, ranging from the not-for-profit sector to government work.

I am 25 years old, working full time at not-for-profit organisation Melbourne City Mission and studying part time to attain my Bachelor of Applied Social Science. – Participant 44 (2013)

When I'm not studying, I work with NSW Communities as a Group Leader in outdoor recreation for children and young people with behavioural and emotional difficulties. – Participant 39 (2013)

This variety of work experiences supports their *specific career aspirations*, which include being members of helping professions, consulting, and a range of professional careers. Finally, these work and academic interests are supported by their *enjoyment of studying and applying themselves*.

I'm passionate about learning, something I discovered when I was very young and the adults could not give me adequate answers to why things work. – Participant 1 (2011)

Interested in and already helping others

Applicants to the YBT are both interested in, and often are already, helping others. Participants desire to *create positive change* in a broad, non-specific way. Further to this, they are interested in *generating social change* in a wide range of fields such as bullying, equality and social justice.

I love talking about feminism, poverty alleviation, the power of young people, mental health. – Participant 32 (2013)

They achieve this change through their current activities, which include *helping other people* by working and speaking with them; *involving young people through participatory methods* and *volunteering*.

I'm passionate about issues facing young people, especially those who cannot yet vote. I'm interested in improving their lives, in collaboration with them. I know what it's like to be too young to 'have a say' and too old to leave the responsibility to the 'oldies.' – Participant 1 (2011)

They also expressed these ideas through their aspiration *to work with young people* and the idea that underlies all the other sub themes, that this group of young people *are altruistic*.

I like accountability and once I finish my degree, I want to get into policy within child safety, focusing on transitioning from care. – Participant 34 (2013)

Interested in other people

The importance of other people in the lives of applicants was evident in their comments about *having relationships with other people*, which range from close familial ties to living in the community with others. Young people not only enjoy their relationships with other people, they *enjoy communicating with other people in a variety of ways*. Through this, they display an understanding of different modes of communication and how they can use these modes of communication to further these relationships.

Conversation is the intellectual food of my life, and people are why I get up in the morning. – Participant 3 (2011)

The specific groups of people in whom they are interested were not identified, with the exception of other young people. Participants displayed an interest in young people in particular, specifically in helping them improve their lives.

I am a young person passionate about making the world a better place for other young people – I believe that we have the power to make change now. We don't need to wait until we're older. – Participant 12 (2012)

Introversion and comfort with solitude

Young people expressed that they enjoy being alone in two ways: *they enjoy leisure activities undertaken alone* and *they describe themselves as introverted*. This theme is in contrast to many of the other areas and themes arising from this question, which reflect a perceived level of extraversion, and further contributes to the idea that these young people are a diverse group.

I am a fire twirler, I am mindful, and I meditate, I am a dog person, I cook and make music, I am solar-powered, I am handy with paper and fabric, I journal daily. – Participant 3 (2011)

I spend a lot of time analysing emotions and experiences, and am very introverted as a result. – Participant 11 (2012)

Have a diverse range of life experiences and have found self-confidence through this

Applicants felt that their life events and experiences may be uncommon. Their responses to this question show that they take pride in the ways in which they perceive themselves to be different. *They identify as being different in specific ways* including their ages, which encompassed the whole range included in this study, 18 to 25 years. Furthermore, *they have lived in a range of places and situations*, from overseas to a university's residential hall.

I'm a 23-year-old woman... at the moment I'm living in Melbourne for university, but my family is in Sydney and I'm intending on returning to there in a couple of months. – Participant 39 (2013)

The ways through which *they appreciate their own diversity* was shown in applicants' self-confidence and sense of self-identity.

Hey! I'm also known as the 'Glitter Queen' because I wear a lot of glitter and like to sparkle up people's lives). – Participant 42 (2013)

Have a wide range of attitudes and approaches to life

Applicants have a wide range of attitudes and approaches to life. They expressed that *they are eager to learn more about and explore the world*, and *they enjoy doing new and different activities* while doing so.

I have always been driven by two main aims: to help other people be happy, and to learn something new as much as possible. – Participant 24 (2012)

I am an energetic person with a passion for travel and new experiences. – Participant 4 (2011)

Related to these desires and activities were the approaches that young people take to achieve them, such as that *they feel positive about their future*, and that *they are hardworking*, and *creative*. Related to this, *they are also open-minded* in how they relate to other people.

I consider myself an extremely driven, passionate and positive person. – Participant 5 (2011)

I am an open minded, optimistic, artsy fartsy Fine Arts student and a dork. – Participant 22 (2012)

Other attributes included that *they are easy going and they have a positive attitude to life*, which results in applicants expressing high levels of passion about what they do.

I love what I am studying, and my two jobs are so different and yet both fulfil my desire to learn and engage with quality individuals. I am an enthusiastic, motivated and organised person. I love to run and spend time with friends. –

Participant 46 (2013)

Have a wide range of hobbies and interests

Participants described having a wide range of hobbies and interests that were not directly related to the CRC's key conceptual areas. These included that *they enjoy doing exercise*, such as various types of sport, and *are interested in being outdoors* which in some cases extended to *travelling the world*.

In my spare time, I run long distance and often participate in small charity runs. I have, to date, completed two half marathons, the Melbourne Marathon and the Great Ocean Road Ultra Marathon (45k). – Participant 14 (2012)

I'm also quite passionate about the outdoors and have been involved in Scouting (both as a member and as an assistant leader) from a young age. – Participant 41 (2013)

Two other areas of interest were mentioned, *they enjoy public speaking* and *they are interested in health and nutrition*.

I have a strong interest in helping others out and getting involved with support groups, doing talks or presentations. – Participant 8 (2012)

I'm an absolute gym-junkie and passionate about the role of exercise in daily wellness. This is balanced out nicely with a love for all things food and nutrition. – Participant 15 (2012)

Have engaged with mental ill health, either through their own experience or being conceptually interested

A large number of applicants *have experienced mental ill health or adverse life events*. These experiences encompassed a wide range of behaviours and events—from struggling themselves, to losing someone they knew to suicide.

Yet when I was in Year 10, due to peer pressure and bullying, I developed anorexia nervosa and clinical depression. I struggled through this during high

school, and managed to turn my life around through giving back to the community. – Participant 24 (2012)

The group of young people who mentioned that *they are conceptually interested in mental ill health* was in some, but not all, cases the same group who had experienced tough times. Conceptual interests covered a diverse range of mental health areas; however, half of the group expressed interest in the general concept of mental health without specifying further.

I'm an active young man with a passion for mental health advocacy. – Participant 27 (2013)

6.4.2 Why participants want to be involved in the Youth Brains Trust

Young people who applied to be members of the YBT did so for a wide range of reasons. The six major themes which emerged from the analysis of this question are shown in Table 6.2 and are described in detail below.

Table 6.2 *Analysis of advisory group applications – motivations, major themes*
Themes

Aspects of their identities have relevance to the CRC
They value the CRC and what the organisation does
They see potential in the CRC and want to be part of that potential
They have a capacity and desire to help people
Through the YBT they will gain access to opportunities they wouldn't have otherwise
Young people are interested in the CRC and its key conceptual areas

Aspects of their identities have relevance to the CRC

Participants expressed the idea that certain aspects of their identities have relevance to the CRC, and that these aspects will allow them to make particularly relevant contributions to the YBT. The major aspect of their identity mentioned in this regard is that they have a lived experience of mental ill health.

It's so important to me to help young people avoid the suffering I went through, especially with the overwhelming presence of cyber-bullying today. – Participant 17 (2012)

Participants also mentioned that they have *experience in helping friends and family through experiences of mental ill health.*

I have lived with mental health issues for many years and have supported my friends and family through these situations. – Participant 36 (2013)

A variety of other aspects of participants' identities were also mentioned as ways that they *feel they represent young people or other related identities*. These include their sexual identity, being from somewhere other than Australia and feeling as though they are a voice for young people in Australia.

More specifically I feel that I'm very in tune with the ideas and sentiments of a broad cross-section of young people due to the work I do with Big Help Mob. – Participant 25 (2012)

They value the CRC and what the organisation does

A small group of young people mentioned that they already *feel that they are part of the CRC* prior to their acceptance into the group.

I want to be a part of the Youth Brains Trust because I feel like I have a stake in the CRC in so many ways – as a young person, as an Inspire YA, and as someone involved in the development of the bid - and I want to contribute to make sure it goes right. – Participant 3 (2011)

Young people who had applied to the YBT in 2012 and 2013, after the CRC had been established, perceived that the *CRC does a wide range of positive things*.

I would feel so proud to be part of the Youth Brains Trust and know that I'm part of something that is changing and improving the way young people are treated and provide more understanding to adults to the complexities we face living in a technology savvy society. – Participant 42 (2013)

They see potential in the CRC and want to be part of that potential

Applicants in the formative years of the CRC, the first two cohorts of the YBT (2011 and 2012), expressed the belief or hope that they *think that the CRC will do a wide range of positive things*. These beliefs include broad and significant changes to the mental health and research landscapes, such as changing research practises and improving access to services.

YAW-CRC [the CRC] has the potential to make such a difference in the way that health providers and professionals engage with young people, and I think that to be a part of that would be a huge honour, and truly does have the potential to make a difference in the lives of so many young people. – Participant 16 (2012)

The value that participants placed on the CRC was further shown in the way that *they want to help the CRC*.

There is a definite gap when it comes to mental health services for young people in Australia, and I would like the opportunity to be able to help fill these holes, and I hope that through the Youth Brains Trust, I will have the opportunity to do so. – Participant 7 (2011)

Participants expressed desire to be part of the potential that they felt the CRC represented, *they feel the YBT will be a positive experience.*

Being involved in an organisation such as the Young and Well CRC is what I want to do with my life, and I believe that being involved in the Youth Brains Trust would be an indescribably incredible opportunity to meet and be inspired by new people, enhance myself as an individual for the future, and be part of a truly amazing movement. – Participant 15 (2012)

They have a capacity and desire to help people

Applicants wanted to be part of the YBT because they feel that they have a capacity and desire to help people. This was expressed in two specific ways—that *they want to help other people*, and *they feel they have an ability to make change*. These altruistic desires were not specifically targeted at one group of people or location and ranged from wanting to help young people to the more general sentiment of wanting to make a difference. These desires are supported by applicants' sense of self-efficacy which was expressed in how they feel they have the ability to make change.

I want to learn about the process of doing this on a large collaborative scale such as in the CRC, with multiple organisations and sectors, so I can continue to use these skills and remarkable perspective in my life and in further action. – Participant 3 (2011)

I am passionate to participate in the national dialogue and to participate in developing this dialogue where it otherwise wouldn't exist. – Participant 24 (2012)

Through the YBT they will gain access to opportunities they wouldn't have otherwise

Participants wanted to be part of the YBT because they felt that by being members they would gain access to opportunities they wouldn't otherwise have had. Participants anticipated that the YBT would allow them to improve on a personal level, *improving their personal development by improving their skills* and also *having an outlet for their passion.*

...involvement with YBT also presents me with an excellent opportunity to continue my personal development so I can continue to help young people in the future. – Participant 5 (2011)

I want to be involved in the Youth Brains Trust and the Young and Well CRC because I know I have a skill-set and a passion to make change and to help develop positive programs for young people. - Participant 12 (2012)

Applicants to the YBT were a driven group who were interested in, and eager to help, others. This was evidenced by the *career aspirations that they felt the YBT would help them further.*

The way that young people use technology is constantly changing, and for me this area is where I want to focus my life. I can't think of a better place to start than with the CRC. – Participant 14 (2013)

Participants also felt that the YBT would provide them access to other people, both in their wider communities and the mental health sector. They expressed a strong desire to *get involved in their wider communities* and felt that the YBT would facilitate this.

While I am happy to try, and already am, doing this on my own, I am well aware that combining our efforts will create a louder voice and bigger movement. – Participant 12 (2012)

Related to this participation in their wider communities is that they feel that being members of the YBT will allow them to engage in *collaborating with others in the sector*, primarily their peers, but also professionals.

I also feel that this is a fantastic opportunity for me to meet with my peers and professionals in the mental wellbeing sector and better understand what else is happening within our community. – Participant 14 (2011)

This belief that the YBT would allow them access to wider communities demonstrates that young people had engaged with the role of the CRC prior to applying and were informed about its place both in the mental health sector and in the broader community.

Young people are interested in the CRC and its key conceptual areas

Participants expressed a desire to be members of the YBT because they were interested in the CRC as an organisation and its key conceptual areas. Applicants were *interested in the CRC itself* and held positive views about it as an organisation.

From what I have seen the Young and Well Cooperative Research Centre addresses issues and concerns which I believe are incredibly important, and I would love the opportunity to get involved and assist in any way I can. –

Participant 16 (2013)

The key conceptual areas of the CRC in which participants were interested included being *interested in mental ill health and young people*.

I saw that the Young and Well CRC released a report just recently on young men's mental health and wellbeing. This is caught my attention. I found it very encouraging from an advocacy perspective and I would like to be involved in helping to do more, especially to help the design of interventions which are targeted towards young men. – Participant 27 (2013)

Participants also *have positive views about technology* and see the CRC as playing a role in dispelling negative ideas around it. This shows an awareness of how technology is viewed by the wider youth population, and opinions about what to do about it. Similar feelings were mentioned regarding mental ill health – participants are interested in helping people who experience mental ill health and would like to see the CRC help address some of the perceived gaps in services.

Moreover, technology and social media are the primary avenues that young people engage in today and thus the cross-roads of young people, technology and wellbeing is a profoundly relevant and indeed critically important to study and help affect positive change. – Participant 17 (2012)

Participants also expressed positive views about how the CRC involves young people in their work; in particular *they feel that involving young people is important*. Applicants perceive that there is a dearth of youth voices in research and they feel that the CRC may have a role to play in changing that.

I strongly believe that youth engagement and input is crucial in, at least, all organisations working with and for young people. – Participant 7 (2013)

I feel that often the problem is that young people aren't given the chance to decide what will improve their well-being. The Youth Brains Trust and the

Young and Well CRC seems like an opportunity for young people to be heard and make choices for themselves. – Participant 3 (2011)

The final CRC conceptual area mentioned by the applicants shows that *young people display an interest in, and have positive views of, research itself*. Research was viewed by participants as a key first step in developing better mental health care. Young people also *have positive views about research*, which showed a deeper understanding of what the CRC does rather than merely engaging with the issues on which the CRC works.

Most importantly, it involves preventative research which is so important, because young people shouldn't have to wait until they have hit rock bottom before they can access support in their community—support of wellbeing should be a life-long thing. – Participant 18 (2012)

6.5 Discussion

6.5.1 Overview

This study analysed the lived experiences of applicants to a youth mental health involvement advisory group, the YBT, as expressed in their own words. It found that the young people who apply are a broad group, with varied interests and experiences. They have few uniting features, with two exceptions. The majority have knowledge of mental health, either through their own experience or because they are interested in it, and they are interested in their relationships with other people. Their motivations for applying include that they feel they will be able to explore parts of their identities and interests; they are interested in the work of this organisation, because they want to help other people; and because they believe that they will gain access to other opportunities through being involved with this group. Comparisons with extant literature are made where possible; however, noting the distinctive nature of the study, the discussion below focuses predominately on what can be learned from the findings of this study.

An important consideration for the interpretation of these findings is that young people wrote the applications to gain membership of the YBT, not to provide a true and accurate representation of their characteristics and motivations. This may have resulted in young people emphasising experiences and motivations that they felt showed an understanding of the focus of one or more of the CRC's key areas. An example of this bias may be seen in the emphasis placed on experiences of mental ill health, and their altruistic motivations.

6.5.2 Young people's characteristics (Aim 1)

Young people who apply to be part of a youth mental health advisory group show two clear common characteristics: a familiarity with mental health, and a preference for positive relationships with others. On most other dimensions, there appears to be considerable variance among applicants. This variance is greater than has previously been described; however, that is likely to be because of a lack of previous investigation into the area, not an absence of variance in other groups.

Young people who applied to the YBT have experience with mental ill health, either their own or others, and have experiences that demonstrate that they are proactive in protecting their own mental health. This area is important in the context of youth involvement in mental health research, and yet has only been explored to a limited extent to date. One reason for this is that prior work describing the characteristics of adult consumers involved in research has involved only service users. In contrast, work in the youth specific area has more frequently involved young people who do not necessarily have a previous experience. For example, one study of an advisory group which had a similar form and function to the YBT, Howe et al., (2011), reported that only 37% of the young people who were involved had an experience of mental ill health.

Young people's self-descriptions in this study indicate that there may be a similar prevalence of mental ill health among this group. However, as noted above, this may be due to young people choosing to emphasise parts of their identities that they think are relevant to the CRC. This issue is explored further through quantitative methods in the following two YIMHR studies. As discussed in Chapters 8 and 9, if a trend toward higher rates of mental ill health and related experiences is established, this trend should be monitored in future work. This is necessary as it is probable that young people with prior experience of mental ill health will bring different insights to the work than those who do not. Based on the current work, it cannot be established if people who are not comfortable disclosing experiences of mental ill health may be under-represented. Further work is required to establish if there is a trend toward involvement of groups who are not representative of the Australian youth population. If there is, it may be an unrecognised limitation of the work and services developed using their input. It may indicate that further effort is required if services are to be developed to address other sectors of Australian society who may also be at risk of mental ill health.

Applicants display a high level of interest in their relationships with other people. This finding is informative with regards to the specific involvement processes

that researchers use with young people, and the importance of designing the initial stages of these in consultation with them. In this way, researchers will be able to prioritise processes which are responsive to young people's needs. In an advisory group setting for example, these processes could include having expectations and experiences as an agenda item at the first meeting of the group.

Other than these two clear characteristics, the results suggest there may be greater variance between young people who are interested in taking part in youth involvement opportunities than has previously been documented. For example, applicants described being interested in a wide range of academic topics and ideas and having varied attitudes and approaches to life. An important, potentially confounding, factor is that applicants' descriptions of themselves may have been influenced by a desire to appeal to the areas they believed the CRC was interested in. Despite this, the findings are interesting in light of the need to ensure that there are a diverse group of consumers and young people involved in research, as suggested by various authors (Crawford & Rutter, 2004; Hagen et al., 2012; Simons, 2012). The issue was also identified as a concern by university students when discussing their previous experiences of being involved in research (Study 1); and by the researchers in Study 2 who expressed concerns about the lack of diversity of young people interested in being actively involved in their research. The results indicate that young people come from a wide range of backgrounds and have a broad range of interests, attitudes and approaches to life. To investigate this further, quantitative measures of population diversity are included in the subsequent two studies—the project survey of advisory group applicants (Study 4) and survey of community members (Study 5).

6.5.3 Young people's motivations (Aim 2)

Young people apply to youth involvement advisory groups for a broad range of reasons. These include to explore their interests and identities; because they hold the organisation to which they are applying in high regard and are interested in areas related to it; and because they are altruistic people. These findings inform Aim 2 of the project, which sought to understand the self-reported motivations of young people who are involved in mental health research.

Young people also apply because they believe that, if they are accepted to be part of an advisory group, they will have an opportunity to explore aspects of their identities and areas of interest. In particular, where young people have an experience of mental ill health or interest in the area, they may wish to explore this. This motivation

is similar to that described by young people in Howe et. al.,’s (2011) study, in which young people reported that they were motivated to contribute to the development of mental health interventions. These motivations may mean that they want to share these experiences for the benefit of other people and organisations, they feel they have learned things from their experiences or believe that they can prevent other people from suffering in the way that they have. They inform the practice of youth involvement by reinforcing the idea that organisations need to be prepared to create spaces which are conducive, not only to their research outcomes, but to the health and wellbeing of the young people with whom they work. One way in which this might be achieved would be protocols to ensure that young people were adequately cared for, which might include self-care guidance materials, mutual care strategies, or providing practitioner-led care where appropriate for the research topic and setting.

Applicants displayed an understanding of, and appreciation for, the CRC as an organisation when they applied, and it is clear that they were motivated to contribute to it. As noted above, an important limitation of the method used, particularly in regard to this finding, is that young people’s desire to be part of the YBT may have strongly influenced these results. Acknowledging this, Coates and Howe (2014) noted comparable findings in their study which described young people’s self-reported motivations for being involved in similar mental health youth advisory groups in Australia. The strong reputation of the CRC within networks of young people who were already active participants in their communities, and the way it involved them in informal ways through its partner organisations meant that the CRC was readily able to recruit young people. This finding shows the importance of researchers and organisations investing in their reputation and links with young people, both within and across sectors. It offers support for research funding models, such as the Cooperative Research Centre model, which gain leverage from the already established reputations of partner organisations. Future research and organisations should be aware that they need to be attractive and interesting to the young people who apply. One way to achieve this would be to make these areas clearly apparent in recruitment or advertising materials.

A desire to help other people, and a self-perceived capacity to do so, is one of the most common reasons for wanting to be involved reported by consumers and young people (Case et al., 2014; Coates & Howe, 2014; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Thus, it is perhaps unsurprising that young people who applied to be part of the YBT also commented on it. A previous example of this comes from Tarpey’s (2006) working paper about why people get involved in health and social care research

in which she identifies altruism as a motive. Within the youth involvement in mental health research literature it has not been specifically identified. However, this is likely to be due to the limited amount of work which has focused directly on this specific area. Future work should examine altruism in more depth to develop a greater understanding of why these young people think that they have a capacity to help, and if the specific reasons for this could be used to create involvement processes which utilise their particular capabilities. In conjunction, researchers could capitalise on this motivation by emphasising how instances of involvement will lead contribute to helping other people in recruitment materials and involvement activities.

Young people applied because they felt that by being part of the YBT they may be able to gain access to opportunities they would not otherwise have had access to. These findings are related to previous results from both the youth involvement in mental health research literature (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015), and the broader involvement literature (Coates & Howe, 2014; National Children's Bureau, 2010; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). In this previous work, young people and consumers have reported that they are motivated to take part in involvement to develop themselves, and to gain skills. Unlike previous work, however, the present study has examined the motives of a group of young people who wanted to be involved, not only those who were involved. This difference may have influenced the key novel addition from the present findings—the participant's belief that they would not have had the opportunity to gain these experiences other than from the YBT. This factor may, as with other findings, be attributable to participants' desire to be selected to the YBT. However, it shows that the opportunity to gain experience is a key motivating factor to young people, and that young people recognise youth involvement in mental health research as a way to gain experience relevant to them. Future studies may examine this further, comparing young people's expressed beliefs and understanding about the different forms of research involvement. Such studies may, for example, identify that youth advisory groups are perceived to be a particularly valuable way to gain skills which allow them to further their careers, or to get involved in their wider communities.

6.5.4 Limitations

As noted above, the findings which have emerged from this study are likely to be more favourable toward the applicants than other forms of data collection. This bias, which is characteristic of this form of data collection, is due to the possibility of young

people presenting an ideal version of themselves when they sought to be selected as members of the group (Haslam & McGarty, 2003). Future work which seeks to compare the findings of this study to other data collection methods should take note of this potential bias.

The number of applicants who participated in this study was proportionally low, with less than one quarter of the requested applicants consenting to share their applications. This may have resulted in a bias towards those who were accepted, or the young people who, regardless of their acceptance or not, had a stronger or ongoing relationship with the CRC.

No data were collected about the reasons that young people chose not to participate. Potential reasons for this may include: the length of time between writing the application and being asked to release it (up to 3 years for some participants), that no opportunity was given to participants to review the text of their application before releasing it and that the majority of participants may have known the researcher. Not allowing participants the opportunity to review their applications may have resulted in potential participants who were unsure about whether or not they wanted to participate deciding not to participate because they were not able to review it. Future work could overcome this latter limitation by including this additional step in the process.

The likelihood that the majority of participants may have known the researcher is likely to have had both a positive and negative influence on the number of applicants. Some participants may have chosen to contribute to a friends' work more so than they would have contributed to a strangers. Others may have not wanted to be vulnerable to a friend, and thus may have not provided their applications.

6.6 Summary

This chapter has detailed the third study in the YIMHR project, and the second of the four studies which show how young people's voices can contribute to the understanding of how they are involved in youth mental health research. It has contributed to Aims 1 and 2 of the project by providing the first case study of how young people represent themselves, their skills and their motivations when they apply to a high-level mental health governance group. The findings of the study demonstrate a breadth of experience and interests in these young people, with a few common features. The latter include a significant proportion who have been previously involved in the mental health sector or have experience with mental ill health. Their reasons for applying are similarly diverse, ranging from being altruistically motivated, to believing

that they will gain access to opportunities and networks that they would not have had otherwise. The findings of this study build on existing work by expanding previously limited insights which have focused only those who have been involved, not those who wanted to be. The correlations between previous and current work suggest that previous findings, while limited, are valid. The following chapter builds on and complements this study by providing a profile of one of the annual cohorts of the YBT using quantitative measures.

7 Study 4: Survey of advisory group applicants

7.1 Introduction

7.1.1 Overview

The fourth study of the Youth Involvement in Mental Health Research (YIMHR) project explores the characteristics of applicants to a mental health research advisory group. The study is an analysis of the young people who applied to be members of the Youth Brains Trust (the YBT) of the Young and Well CRC (the CRC). This study complements the qualitative analysis in the previous chapter by examining the characteristics of one cohort of the YBT using quantitative measures. It contributes to Aims 1 and 3 of YIMHR.

The study has three objectives. Objectives 1 and 2 contribute to Aim 1 of YIMHR and Objective 3 contributes to Aim 3. The objectives are:

1. To describe the characteristics of young people who apply to mental health research advisory groups, and to compare the characteristics of young people who are accepted, to those who are not.
2. To compare the characteristics of young people who apply to mental health research advisory groups to their peers in the Australian population, where recent comparable population survey data was available.
3. To ascertain whether involvement in a mental health research advisory group has a positive effect on young people.

The study achieved these objectives using a longitudinal survey administered at 6-month intervals, commencing shortly before applicants were advised of their acceptance or non-acceptance into the YBT. The outcome variables on which change was assessed were selected based on the limited previous work in the area and the results of the preceding studies in the project. The measures used to answer each objective are outlined in Figure 7.1. Objective 3 involved testing these hypotheses which are described below.

		Objective 2 (Population comparison)	Objective 3 (Change over time)
Demographic characteristics	☐	☐	
Educational Attainment	☐	☐	
Personality	☐		
Technology Use	☐		
Activities undertaken online	☐		☐
Civic participation	☐		☐
Experience of mental ill health	☐	☐	☐
Psychological distress	☐		☐
Experience of help-seeking	☐	☐	☐
Likelihood to seek help from specific sources	☐		☐
Awareness of others' mental ill health	☐		☐
Depression literacy	☐		☐
Depression stigma	☐		☐

Figure 7.1 Measures used to answer each objective of survey of advisory group members

The study draws on two specific areas of literature as described in Chapter 2. The characteristics of the young people who are involved were described in Sections 2.5.1 and 2.6.4. The experiences that young people have reported when they are involved were reviewed in Sections 2.5.3 and 2.6.4.

A key study which informed the design of the present study was the evaluation of Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011). It is one

of the few to date to examine experiences of involvement using quantitative measures. The measures used here, and the outcome variables on which change over time were examined, were informed by that study in particular.

Young people and consumers have reported that involvement offers opportunities to gain new skills (Case et al., 2014; S. Chen et al., 2007; Collin, Rahilly, et al., 2011; Coser et al., 2014; Mclaughlin, 2011; Powers & Tiffany, 2006; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Where specific types of skills have been reported, these are related to the topic of the involvement activity. Because it was not practical to examine the development of skills in an online survey, the related concepts of ‘knowledge about an area and activities within it’ were examined as a proxy. The skills chosen (activities online, awareness of others’ mental ill health and depression literacy) were chosen based on the research of the CRC and what the YBT was likely to discuss. Because of heightened awareness of online activities, it was anticipated that the accepted group would increase the number of activities they undertook online. The specific hypotheses posited were:

- Activities undertaken online: compared to the young people who were **not-accepted**, those who were **accepted** into the YBT would, over the year increase the number of activities they undertook online.
- Awareness of others’ mental ill health: young people who were **accepted** into the YBT would, compared to those who were **not-accepted**, increase their awareness of others’ mental ill health over the year.
- Depression literacy: young people who were **accepted** into the YBT would report an increase in their depression literacy over the year, compared to those who were **not-accepted**.

Previous studies examining young people’s involvement in mental health service delivery and research have suggested that involvement may lead to improvements in young people’s mental health and the likelihood that they will seek help (Case et al., 2014; Collin, Rahilly, et al., 2011; Ramey & Rose-Krasnor, 2015). Within the specific area of youth involvement in mental health research area, exposure to other young people who had experienced mental ill health was posited by some of young people to be related to improvements in their own, as they realised that others had been through similar experiences (Howe et al., 2011). In addition, young people who had been involved in the Reachout.com Youth Participation Program associated their participation with increased understanding of when and how to seek help in

regards to their mental health issues (Collin, Rahilly, et al., 2011). These findings were used as the basis for hypotheses in two broad areas (experience of mental ill health and help seeking for mental ill health), which were tested using four measures. The measures and hypotheses were:

- **Actual experience of mental ill health:** Compared to the young people who were **not-accepted** into the YBT, young people who were **accepted** would experience fewer episodes of mental ill health or behavioural problems over the year.
- **Psychological distress (K10):** Young people who were **accepted** into the YBT would experience a decrease in psychological distress over the year, as measured by the K10, compared to those who are were **not-accepted**.
- **Actual help seeking for mental ill health:** Young people who were **accepted** into the YBT would be more likely to seek help for mental ill health over the year compared to those who are were **not-accepted**.
- **Likelihood to seek help from specific sources:** Young people who were **accepted** into the YBT would experience a decrease in psychological distress, as measured by the K10, over the year compared to those who were **not-accepted**.

Young people who have been involved in research (Howe et al., 2011), and mental health service delivery (Collin, Rahilly, et al., 2011), have reported that they have increased involvement in their broader communities. In particular, social connectedness was the most significant benefit found in the cross sectional survey of young people who had been part of Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011). These findings formed the basis of the civic participation hypothesis, which was:

- **Civic participation:** compared to those who were **not-accepted** into the YBT, young people who were **accepted** into the YBT would increase the number of activities they reported participating in over the year.

The present chapter follows the structure established in the previous three chapters: the rationale for the study is described, followed by the design, results, and limitations. The chapter concludes with a discussion of the findings.

7.1.2 Study rationale

Young people's involvement in mental health research is an under-explored area. In particular, no attempt has been made to either compare the characteristics and experiences of young people who are interested in being involved with those who are involved, or to use quantitative measures to ascertain if young people change over time as a result of their involvement. The present study aimed to do by examining young people over the course of one year of their involvement in the YBT. The outcome variables on which change was assessed (described in detail below, Section 7.2.4 measures), were chosen based on previous literature in which young people have described their experiences of involvement.

7.2 Design

7.2.1 Choice of method

Survey methods, and online delivery in particular, reduce the ability to identify respondents. This was considered an important factor to minimise potential bias arising from participants responding differently if they believed the researcher could identify them (deVaus, 2002).

Because the researcher's membership of a previous cohort of the YBT meant that there was potential for a pre-existing relationship with potential participants (see Section 3.6), online surveys were used to preserve participants' privacy.

Surveys also afford comparison with previous research, through the use of standardised measures, also enabling comparison with comparable populations (deVaus, 2002). Finally, longitudinal surveys were used to achieve Aim 3 of the project. The use of this technique enabled comparison of the experiences of young people who had been involved with those who had not.

7.2.2 Human Research Ethics approval

The Australian National University's Science and Medical Delegated Ethics Review Committee approved the ethical aspects of this study (Approval number 2013/502, see Appendix 7.1).

7.2.3 Participant selection and description of involvement in the YBT

The potential participants for this study were applicants to the 2013 cohort of the YBT who were aged between 18 and 25. As described in Section 3.3.3, 20 young people between the ages of 12 and 25 years were involved in each cohort of the YBT.

The proportion of that group aged between 18 and 25 varied between each cohort. The selection criteria used by the CRC to select participants varied and was not formally recorded.

7.2.4 Procedure

All applicants were invited to participate in the first survey (the pre-acceptance survey) following their application, but prior to their acceptance or rejection from the YBT. Participants who responded to the pre-acceptance survey were surveyed at 6 and 12 months following the first survey. The areas examined in each survey are shown in Table 7.1 and are detailed further in Section 7.2.5. The full text of the survey can be found in Appendix 7.2.

Table 7.1 *Survey of YBT applicants: question areas*

Area examined	Pre-acceptance	6-month	12-month
Previous applications to the YBT	✓		
Acceptance into the YBT		✓	
Participant characteristics	✓		
Educational attainment	✓		
Personality	✓		
Technology use	✓		
Activities undertaken online	✓	✓	✓
Experience of mental ill health	✓	✓	✓
Experience of help seeking	✓	✓	✓
Awareness of others' mental ill health	✓	✓	✓
Depression literacy	✓	✓	✓
Depression stigma	✓	✓	✓
Civic participation	✓	✓	✓

A number of measures were employed to protect participants' confidentiality. A researcher who was not the primary researcher managed the contact details and sent the invitation emails to the participants, including the survey URLs. Additionally, the email invitations included a letter from the Youth Participation Officer at the CRC reassuring participants that only researchers at the ANU would have access to individual level data, and that their participation would not affect their chance of being selected into the YBT. One important implication of this was that if participants did not respond to the 6-month survey, it was not possible to ascertain if they had been **accepted** into the YBT.

The surveys were piloted with other researchers, including the supervisory panel. The results of this pilot found that the measures were acceptable in length, and that the content made sense to the researchers.

The pre-acceptance survey was distributed in September 2013, in the week following participants' submission of their applications to the YBT. Two emails, an

initial invitation and a follow up reminder email, were sent. An invitation to participate in the 6-month survey was emailed to all initial applicants in February 2014. This survey included a question asking if applicants were accepted into the YBT. This question was used to group participants into the **accepted** and **not-accepted** groups for analysis. These emails can be seen in Appendix 7.3.

The surveys were administered using Limesurvey version 2.06+, an online survey application, which was securely hosted on web servers at the Centre for Mental Health Research. Each of the surveys took approximately 10-15 minutes and could be completed anywhere the participants could access the internet, and at a time that was convenient to them. Participants accessed the survey via an individualised URL in the email they were sent, which was linked to a token through which their responses to the three surveys could be linked. The URL led to the study home page, on which the study information sheet and consent form were presented (Appendix 7.4). Participants consented to taking part by clicking ‘agree’ to a statement that they had read and understood the study’s information sheet and agreed to the risks involved in their participation.

7.2.5 Measures

Pre-existing psychometrically validated measures were used where available, with a preference given to the list of Standard Measures developed by the CRC (the CRC Standard Measures) and provided to researchers for use in each of their projects (Young and Well Cooperative Research Centre, 2013). Researcher-devised questions were employed where these instruments either were not available or were not practical to use.

Participant characteristics

Participant characteristics were measured at the pre-acceptance time point. These measures included age (open-ended); gender (‘male’, ‘female’ and ‘other’); their membership of a list of groups that the CRC had identified as being of interest (e.g. being from a ‘culturally and linguistically diverse background’, being a ‘carer’ or having a ‘chronic illness or disability’); their main activities (e.g. ‘full time work’, ‘attending school’, ‘home duties’); and how many times they had previously applied to be a member of the YBT (‘0’, ‘1’ or ‘2’). These characteristics were chosen based on those that have previously been reported in youth involvement in mental health research, and those which have been identified as influencing rates of mental ill health, civic participation or volunteering.

Educational attainment

Educational attainment was measured in the pre-acceptance survey. Participants were asked to report their highest level of pre-tertiary schooling, and the highest level of post-secondary or tertiary schooling that they had completed ('trade/apprenticeship', 'other certificate', 'associate or undergraduate diploma', 'bachelor's degree' or 'higher degree'). Those who had completed six years of secondary school were asked to indicate their score within a range of options on Australia's university entrance score systems: either their Australian Tertiary Admissions Rank (ATAR) or University Admissions Index (University Admissions Centre, 2016).

Personality

Participants' core personality traits were measured in the pre-acceptance survey using the Big Five Inventory (BFI; Rammstedt, 2007). The 10-item version of the BFI (BFI-10; Rammstedt & John, 2007) was selected on the basis of its brevity and acceptable psychometric properties. The optional additional 'agreeableness' item noted in Rammstedt & John (2007) was included, resulting in an 11-item scale. Previous work has reported the Cronbach alpha coefficients of the five scales as: 'extraversion' $\alpha=0.68$, 'agreeableness' $\alpha=0.40$, 'conscientiousness' $\alpha=0.50$, 'emotional stability' $\alpha=0.73$ and 'openness to experience' $\alpha=0.45$ (Rammstedt & John, 2007). Internal consistency scores for the scales in the present study were as follows: 'extraversion' $\alpha=0.77$, 'agreeableness' $\alpha=0.13$, 'conscientiousness' $\alpha=0.71$, 'emotional stability' $\alpha=0.86$, and 'openness to experience' $\alpha=0.19$. Due to the poor coefficients found for the 'agreeableness' and 'openness to experience' scales in the current study, these were judged to be unreliable and are consequently not reported. The results of the three scales which were found to have acceptable coefficients—'extraversion', 'conscientiousness' and 'emotional stability'—are reported.

Technology use

The type of technology that participants used, and how frequently they did so, was measured by asking participants the following questions from the CRC Standard Measures (Young and Well Cooperative Research Centre, 2013). These questions were asked in the pre-acceptance survey only.

- How often do you use the internet? ('every day or almost every day', 'once or twice a week', 'once or twice a month', 'less than once a month')

- Approximately how much time would you spend using the internet on a normal school or work/non school or work day? (Open-ended)
- How many days a week do you go online after 11pm at night? (0-7 days)
- Which of the following technologies do you use on a more-or-less daily basis (e.g. a 'smart phone', a 'television', 'other handheld portable device')
- Where do you most commonly access the internet? (e.g. 'anywhere via my smart phone or tablet', 'work', 'school', 'TAFE or university')

Activities undertaken online

The number and type of activities that young people had undertaken online in the previous month were measured at all three time points. The question was drawn from the CRC Standard Measures (Young and Well Cooperative Research Centre, 2013). The text of the question was: 'Please select from the following list all the things that you have done online in the past month:'

- Accessed chat rooms
- Accessed health information online
- Accessed online virtual worlds (e.g. Second Life)
- Accessed social network websites (e.g. Facebook)
- Checked email
- Gambled
- Listened to, downloaded or uploaded music (e.g. iTunes, Spotify, Songle)
- Made or received Voice Over Internet Protocol (VOIP) phone calls (e.g. Skype)
- Used online or email counselling
- Played games alone
- Played games with others over the internet
- Posted or viewed photos (e.g. Flickr, dropshots, Pinterest, Instagram)
- Read a blog entry
- Read or watched the news
- Searched for new friends
- Used a webcam
- Used an instant messenger (e.g. MSN or Gmail messenger)

- Used eBay, auction sites, Internet shopping facilities
- Used forums, bulletin boards, or discussion groups
- Used the Internet for school, study or work
- Used Twitter
- Watched, downloaded or uploaded video clips, cartoons, movies, etc., e.g. YouTube
- Written a blog or online diary
- Accessed pornography
- Sexted (sent or received nude or semi-nude photos of yourself or others)

In order to report the number of participants who had undertaken these activities at the pre-acceptance survey, the items were grouped into the following categories:

- Health related activities: ‘used online or email counselling’
- Commerce related activities: ‘used eBay, auction sites, Internet shopping facilities, gambled’
- Sexual pleasure: ‘accessed pornography,’ ‘sexted’
- Social networking: ‘accessed chat rooms,’ ‘accessed online virtual worlds,’ ‘accessed social network websites,’ ‘checked email,’ ‘searched for new friends,’ ‘used an instant messenger,’ ‘used forums, bulletin boards or discussion groups,’ ‘used twitter,’ ‘watched, downloaded or uploaded video clips’
- Entertainment: ‘listened to, downloaded or uploaded music,’ ‘played games alone,’ ‘played games with others over the internet,’ ‘read a blog entry,’ ‘read or watched the news’
- Spoken communication: ‘made or received VOIP calls,’ ‘used a webcam’
- School or work: ‘used the internet for school, study or work’
- Written or produced content: ‘posted or viewed photos,’ ‘written a blog or online diary’

Experience of mental ill health

Actual experience of mental ill health was measured by the question: ‘Have you ever had mental health or behavioural issues?’ at the pre-acceptance survey. In the subsequent surveys, the question was modified to ask: ‘In the last six months, have you experienced a mental health or behavioural problem?’ The text of the pre-acceptance

survey question was drawn from the CRC Standard Measures. Where these questions were compared to examine change over time, the binary nature of this question presented a limitation. The implications of this are discussed in Section 7.5.3 (limitations).

The Kessler-10 (K10; Kessler et al., 2002) was used at all three surveys to measure psychological distress. This scale comprises ten items measuring non-specific psychological distress in the past four weeks, and includes items such as ‘did you feel hopeless?’ and ‘did you feel so sad that nothing could cheer you up?’ Items are rated on a 5-point Likert-type scale ranging from 1 (‘none of the time’) to 5 (‘all of the time’). A total scale score is calculated by summing item scores, with total scale scores ranging from 10 to 50. Higher scores are indicative of greater psychological distress. The scale demonstrates strong validity, excellent reliability, and has been shown to be sensitive to change (Kwan & Rickwood, 2015), including in adolescent populations ($\alpha=0.83-0.90$; Dao et al., 2006). At the pre-acceptance time point of the present study, internal consistency was high with a Cronbach’s alpha coefficient of 0.95 ($n=43$).

The Adult Mental Health Continuum short form (Lamers, Westerhof, Bohlmeijer, ten Klooster, & Keyes, 2011) was employed to measure psychological wellbeing. Due to an error in how the Likert scale labels were entered in the survey, the data from this scale were not analysed (see Section 7.5.3).

Help seeking for mental ill health

If participants reported an experience of mental ill health by indicating that they had previously had mental health or behavioural issues, they were asked if they had sought help for this experience in the period the survey pertained to. A single item measure drawn from the CRC Standard Measures was used. At the pre-acceptance survey the question was: ‘have you ever sought treatment for a mental health or behavioural problem?’. In the follow up surveys participants were asked: ‘in the last six months have you sought treatment for a mental health or behavioural problem?’

The General Help Seeking Questionnaire (GHSQ; Wilson, Deane, Ciarrochi, & Rickwood, 2005) was used to measure the likelihood that young people would seek help from a range of sources for a personal or emotional problem. It was asked of all participants in all three surveys. Participants indicated how likely they were to do this on a 7-point Likert type scale ranging from ‘extremely unlikely’ to ‘extremely likely.’ The sources were:

- Partner (e.g. significant boyfriend or girlfriend)

- Friend (not related to you)
- Parent
- Other relative/family member
- Mental health professional (e.g. school counsellor, psychologist, psychiatrist)
- Phone help line (e.g. Lifeline, Kids Help Line)
- Family doctor/ GP
- Teacher (year advisor, classroom teacher, university lecturer)
- The internet
- Someone else not listed above (please describe who this was)
- I would not seek help from anyone

Internal consistency was not calculated for this scale as the items are treated individually (Wilson et al., 2005).

Awareness of others' mental ill health

Participants' awareness of others' mental ill health was measured in all surveys using researcher-devised items. In the pre-acceptance survey, participants were asked: 'have any of your close friends or close family members ever experienced a mental health problem?' In the follow up surveys, the question used was: 'in the last six months have any of your close friends or close family members experienced a mental health problem?'

Depression literacy

Depression literacy was measured using the 11-item version of 22-item Depression Literacy scale (D-Lit; Griffiths, Crisp, Christensen, MacKinnon, & Bennett, 2010; Griffiths, Jorm, & Christensen, 2004). The scale assesses mental health literacy specific to depression. Respondents answer each item with one of three options – 'true', 'false' or 'don't know'. Each correct response receives one point. Incorrect and don't know responses receive zero points. Higher scores indicate higher mental health literacy for depression. The short form of the scale, as used by Griffiths et al. (2010), was chosen to reduce participant burden.

Psychometric properties of the shortened version of the scale have not been published. However, the 22-item scale has been reported to have good internal consistency ($\alpha=.71$; Griffiths, Christensen, & Jorm, 2008; Griffiths, Jorm, et al., 2004). The Cronbach's alpha coefficient for the present study was 0.67 ($n=43$). While 0.70 is

conventionally considered the desirable coefficient alpha for it to be acceptable, lower coefficient levels will result from use of shorter scales (Cortina, 1993; Lance, Butts, & Michels, 2006). This, and a visual inspection of the data, were used to conclude that the shortened version of the scale used in this study was sufficiently internally consistent for the results to be a reflection of participants' depression literacy.

Depression stigma

Depression stigma was measured using the Depression Stigma Scale (DSS; Griffiths et al., 2008; Griffiths, Jorm, et al., 2004), which was designed to assess stigmatising attitudes towards depression. The DSS comprises two 9-item sub-scales—personal and perceived stigma (Griffiths et al., 2008). The personal scale was used in this and the following study because of the focus on young people's own experiences, rather than their perceived experiences of the broader population. Items on the DSS-personal include: 'people with depression could snap out of it if they wanted' and 'people with depression are unpredictable.' Two of the items on the scale: 'I would not vote for a politician if I knew they had been depressed' and 'I would not employ someone if I knew they had been depressed' were not included as these items were thought to have less relevance to young people. Items are rated on a 5-point Likert scale ranging from 0 ('strongly disagree') to 4 ('strongly agree'). A total score on the scale is calculated by summing scores, with total scores on the version used ranging from 0 to 28. Higher scores are indicative of greater stigma. The full-length DSS has been reported as having moderate to high internal consistency ($\alpha = 0.72-0.82$; Griffiths et al., 2008; Griffiths, Jorm, et al., 2004). However, in the present study a Cronbach's alpha of 0.47 ($n=43$) was found. Because a poor level of internal consistency indicates that the scores reported by participants on individual scales were not highly correlated with each other, it could not be assumed that participants' scores were an accurate representation of their level of depression stigma. Consequently, the results of this scale are not reported.

Civic participation

Participants' civic participation was measured at all three time points using the 22-item Civic participation scale (Vromen, 2003). The items on the scale are:

- An online community group (e.g. eBay, Myspace or Facebook, TakingITGlobal, VibeWire.net)
- A support group

- Mental health organisation (e.g. beyondblue, Create Foundation)
- A local library
- A human rights, development or aid organisation
- A group or club based at your school, TAFE or university
- A local sporting or recreational group
- A band, artistic collective or other creative network
- Some other political or activist organisation
- A youth club
- An environmental organisation
- Organisations or groups concerned with women's or gender issues
- Any type of group related to a specific ethnic group in the community
- A citizen's association
- A church group
- A conservation or heritage organisation (e.g. National Trust, or National Parks and Wildlife)
- Made a donation
- Volunteered time
- Signed a petition
- 'Buycotted' or boycotted a product
- Written a letter to the editor or contributed to talk back radio discussion or commented on an online article
- None of these
- Other

Participants respond to the scale by indicating in which of the list of groups or activities they have been involved. The scale has previously been used in an evaluation of Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011). Reachout.com was the lead partner organisation in the CRC.

7.3 Analysis

7.3.1 Overview

For all statistical analyses in this study, the critical P value used was .01. This was chosen in preference to the more conventionally used .05 to reduce the Type 1 error risk because of the large number of comparisons carried out. Exact P values are reported, with the * symbol used to denote statistically significant effects.

Data were analysed using SPSS v 23 for Mac (IMB Corp, 2015). Only surveys that had been formally submitted were included in the analysis. The variables employed in the study were at either the categorical, ordinal or continuous level of measurement. Age was treated as continuous. Demographic variables, other than age, were categorical. Consistent with their use elsewhere, scales which used Likert scales (D-Lit, DSS, the BFI-10 scales, GHSQ and K10) were treated as continuous data. The civic participation scale, and the activities young people had undertaken online, employed 23 and 25 categorical variables respectively. These scales are reported in two ways—as a series of individual categorical variables, and as a continuous variable calculated by summing the number of items endorsed by participants. As noted above, the internal consistency of the psychometrically validated scales used in the study varied. For the scales with very poor internal consistency (BFI-‘agreeableness’ and ‘openness to experience’, and the DSS), the results are not reported because it cannot be confidently assumed that participants’ responses were indicative of the concept the scale was measuring.

7.3.2 Description of characteristics and comparison between accepted and not-accepted subgroups (Objective 1) and comparison of applicants to population (Objective 2)

The proportion of missing data was examined for each variable during data screening and checking. Missing data ranged from 1-2 cases per variable. Cases that were missing items on key variables were excluded from that analysis. As such, the sample size may vary between analyses.

Chi-square and Mann-Whitney U tests were used to compare the **accepted** and **not-accepted** subgroups (Objective 1), and to compare applicants to their peers in the Australian population (Objective 2). The chi-square test was used for Objectives 1 and 2 to compare categorical data. The variables used for the chi-square analyses met the assumptions of this test, i.e. independence of observations and that the variables consist of two or more categorical, independent groups (Tabachnick & Fidell, 2013). An important limitation of these comparisons is that the chi-square test has reduced accuracy when the differences between the sizes of the samples being compared are large, as occurred when the sample for this study was compared to the population (Tabachnick & Fidell, 2013).

For the participant characteristics which were measured using continuous variables, both the independent samples t-test and the Mann-Whitney U test were

considered. Preference was given to the independent samples t-test because it has greater statistical power. However, the variables for which it was considered were either non-normally distributed, or the variances were not homogeneous. Thus, the Mann-Whitney U test was used. The assumptions of the Mann-Whitney U test are:

1. One dependent variable measured at the continuous or ordinal level;
2. One independent variable which consists of two categorical, independent groups;
3. Independence of observations; and
4. The distribution of scores for both groups on the independent variable have the same shape.

The first three assumptions were met in the design of the study. Assumption 4 was tested in each use of the analysis and was met in all uses of the test.

7.3.3 Change over time (Objective 3)

Objective 3 aimed to ascertain if young people changed as a result of their involvement on a range of measures. Some of these measures were continuous, and others categorical. In order to use analyses appropriate to the measurement level, two styles of analysis were carried out. Prior to analysis, patterns of missingness were examined to understand if there were any systematic differences between participants who chose to respond to each of the surveys: pre-acceptance, 6-month and 12-month.

Examination of patterns of missingness

Logistic regressions were conducted to determine if there were any systematic differences in responses between the surveys. The variables which were examined were: participant characteristics for which there was more than one respondent at the pre-acceptance survey, actual experience of mental ill health and the number of previous applications to the YBT. At both 6 and 12 months, missingness was not significantly related to any of the participant characteristics, actual experience of mental ill health or the number of previous applications to the YBT. Table 7.2 shows the results of the logistic regression analyses.

Table 7.2 *Advisory group survey: examination of patterns of missingness*

Variable	Survey	Odds Ratio	95% CI	Significance level
Gender	6-month	0.63	0.17–2.42	$p=.502$
	12-month	0.48	0.11–2.14	$p=.336$
Lives with a chronic illness or disability	6-month	1.14	0.26–5.03	$p=.860$
	12-month	0.35	0.04–3.18	$p=.349$
From a culturally or linguistically diverse background	6-month	0.40	0.07–2.30	$p=.295$
	12-month	0.41	0.04–3.83	$p=.436$
Identifies as LGBTI	6-month	1.47	0.26–8.27	$p=.664$
	12-month	0.62	0.06–6.05	$p=.683$
Main occupation	6-month	1.22	0.99–1.22	$p=.067$
	12-month	1.13	0.89–1.44	$p=.324$
Highest level of pre-tertiary schooling	6-month	0.68	0.12–3.85	$p=.664$
	12-month	1.60	0.17–15.63	$p=.683$
Highest level of tertiary education	6-month	1.67	0.97–2.87	$p=.063$
	12-month	1.46	0.84–2.56	$p=.184$
Previous applications to the YBT	6-month	1.78	0.53–5.92	$p=.349$
	12-month	0.56	0.11–2.77	$p=.472$
Psychological distress (K10) at pre-acceptance survey	6-month	0.99	0.93–1.06	$p=.854$
	12-month	0.99	0.92–1.07	$p=.881$
Actual experience of mental ill health prior to pre-acceptance survey	6-month	0.94	0.26–3.42	$p=.927$
	12-month	0.38	0.09–1.61	$p=.189$

Choice of analytical method – continuous variables

A mixed models repeated measures analysis of variance (MMRM ANOVA) was used to ascertain if YBT membership had an impact on the continuous outcome measures over time. Measurement occasion (time) was used as the within-groups factor, and acceptance into the YBT as the between-groups factor. The continuous outcome measures were: the number of activities undertaken on the internet, the number of activities young people had participated in in their communities (civic participation), psychological distress (K10), likelihood to seek help from specific sources (GHSQ individual items) and depression literacy (D-Lit).

MRMM ANOVA was chosen because it allows for retention of participants with missing data (Gueorguieva & Krystal, 2004). The covariance matrix used was ‘compound symmetry.’ This choice was made because of the small number of observations at each survey and a visual inspection of the variance of scores at each survey, which showed that the variance between times was approximately equal.

Choice of analytical method – categorical variables

The remaining variables for which change over time was measured were categorical. This limited the available analytical methods because change over time analyses assume the dependent variable is either normally distributed and continuous (e.g. repeated measures ANOVA), or non-normally distributed and continuous or

ordinal (e.g. Friedman's test). While MRMM ANOVA can be used when the dependent variable is categorical (Gueorguieva & Krystal, 2004), the software used to do so is highly specialised and was not available for this analysis.

Consequently, statistical analyses that compare the difference between two proportions were considered. These analyses could be used to analyse how young people changed over time through the creation of specific new variables which denoted within-participant change between surveys on the dependent variable. These 'change over time' variables allowed within-participant change to be compared to group membership through a test of association.

This resulted in two potential methods remaining: binomial logistic regression (BLR), and chi-square. An assumption of BLR is that there is a minimum of 15 cases per independent variable. This assumption was met for the **pre-acceptance to 6-month** period but violated for the **6-month to 12-month** and **pre-acceptance to 12-month** periods. Due to this, BLR was used to examine change over the **pre-acceptance to 6-month** period, and chi-square was used to examine change between the **6-month to 12-month period** and the **pre-acceptance to 12-month** period.

An important limitation of analyses other than the MRMM approach is that they are unable to include participants with missing data. Imputation methods were not implemented because, other than last observation carried forward (LOCF), they are not suitable for categorical data. LOCF was considered, but not used because of the large proportion of missing cases at the 12-month survey relative to the 6-month survey (7 missing cases, or 58%, of the 6-month survey sample was missing at the 12-month survey). The use of LOCF may have resulted in incorrect inferences being drawn because it would have resulted in a high level of assumption that no change over time had occurred.

Consequently, analyses were carried out on the smallest number of participants who responded to one of the two surveys under consideration. This resulted in n=18 for the **pre-acceptance to 6-month** analyses, and n=10 for the **pre-acceptance to 12-month** and the **6-month to 12-month** periods.

Correct use of BLR is dependent on seven assumptions being met. The first three of these (dichotomous dependent variable, independent variables measured at continuous or nominal scales, and independence of observations) are related to study design. These were met in the design of the study.

Assumption 4 of binomial regression analyses is that there is a minimum of 15 cases per independent variable. This assumption was met for the pre-acceptance and 6-

month surveys, but not the 12-month survey. Because of this violation, the chi-square test was used for the 12-month time point.

Two of the remaining three assumptions for binomial analyses (absence of collinearity, and a linear relationship between the independent variable and the logit transformation of the dependent variable) apply only when a continuous independent variable is used. The independent variables used in all of the analyses for this study were dichotomous. Consequently, they do not apply. The final assumption, no significant outliers, high leverage points or highly influential points (Laerd Statistics, 2018), was tested by examining studentised residuals. None were found in any of the analyses for this study.

Creation of change over time variables to analyse categorical variables

Change over time variables were created to capture within-participant change over time in a single variable, to allow group level difference between participants to be compared. These variables grouped participants into two categories: those whose experiences had changed in the direction anticipated (positive change), and those who had not changed or changed in the opposite direction to what had been anticipated (no positive change). How change was grouped varied depending on the hypothesis pertaining to the variable and is described below.

Participants who were **accepted** into the YBT were expected to report fewer episodes of mental ill health or behavioural problems over the year compared to those who were **not-accepted**. A participant who indicated that they had experienced mental ill health in one survey, but had not in a subsequent survey (e.g. ‘yes’, ‘no’), was classified as having experienced a ‘positive change’. Conversely, if a participant had reported that they had not experienced mental ill health in one survey, but in a subsequent survey reported that they had (e.g. ‘no’, ‘yes’), or reported the same experience in subsequent surveys (e.g. ‘yes’, ‘yes’), they were classified as ‘no positive change’.

Young people who were **accepted** into the YBT were expected to be more likely to seek help for mental ill health through the year compared to those who were **not-accepted**. Participants who reported that they had sought help in one survey, but had not in a subsequent survey (e.g. ‘yes’, ‘no’), or reported the same behaviour in consecutive surveys (e.g. ‘no’, ‘no’), were classified as having ‘no positive change’. ‘Positive change’ was classified as having occurred if participants reported not having

sought help in one survey and having sought help in a subsequent survey (e.g. ‘no’, ‘yes’).

Finally, young people who were **accepted** into the YBT were expected to increase their awareness of others’ mental ill health over the year—to change from not being aware of others, to being aware. Participants were classified as having ‘no positive change’ where they reported no change between time points (e.g. ‘no’, ‘no’ or ‘yes’, ‘yes’), or where they went from being aware of others to not being aware of others between surveys (e.g. ‘yes’, ‘no’). If a participant reported that they were not aware of others’ mental ill health in one survey, but then reported that they were in a subsequent survey (e.g. ‘no’, ‘yes’), they were classified as ‘positive change’.

Calculation of effect sizes

Effect sizes were measured using Hedge’s g , which is a correction of the commonly used Cohen’s d for small sample sizes ($n < 20$). The formula used was that described by Lakens (2013):

$$\frac{\bar{M}_1 - \bar{M}_2}{\sqrt{\frac{(n_1 - 1)SD_1^2 + (n_2 - 1)SD_2^2}{n_1 + n_2 - 2}}} \times \left(1 - \frac{3}{4(n_1 + n_2) - 9}\right)$$

The thresholds for size applied to it are those commonly used for the interpretation of Cohen’s d , as described by Cohen (1988)—0.8 being a large effect, 0.5 moderate and 0.2 small.

Both within and between-group effect sizes were calculated. Within-group effect sizes were for the **pre-acceptance to 6-month** period, the **pre-acceptance to 12-month** period and the **6-month to 12-month** period. Between-group effect sizes were between the **accepted** and **not-accepted** groups at the 6-month and 12-month surveys.

For the categorical variables, Cramer’s V was used to measure the strength of the association.

7.4 Results

7.4.1 Participant flow

Figure 7.2 presents the participant flow. Participants who did not respond to the 6-month time point were excluded because it was necessary to know if they had been accepted into the YBT or not.

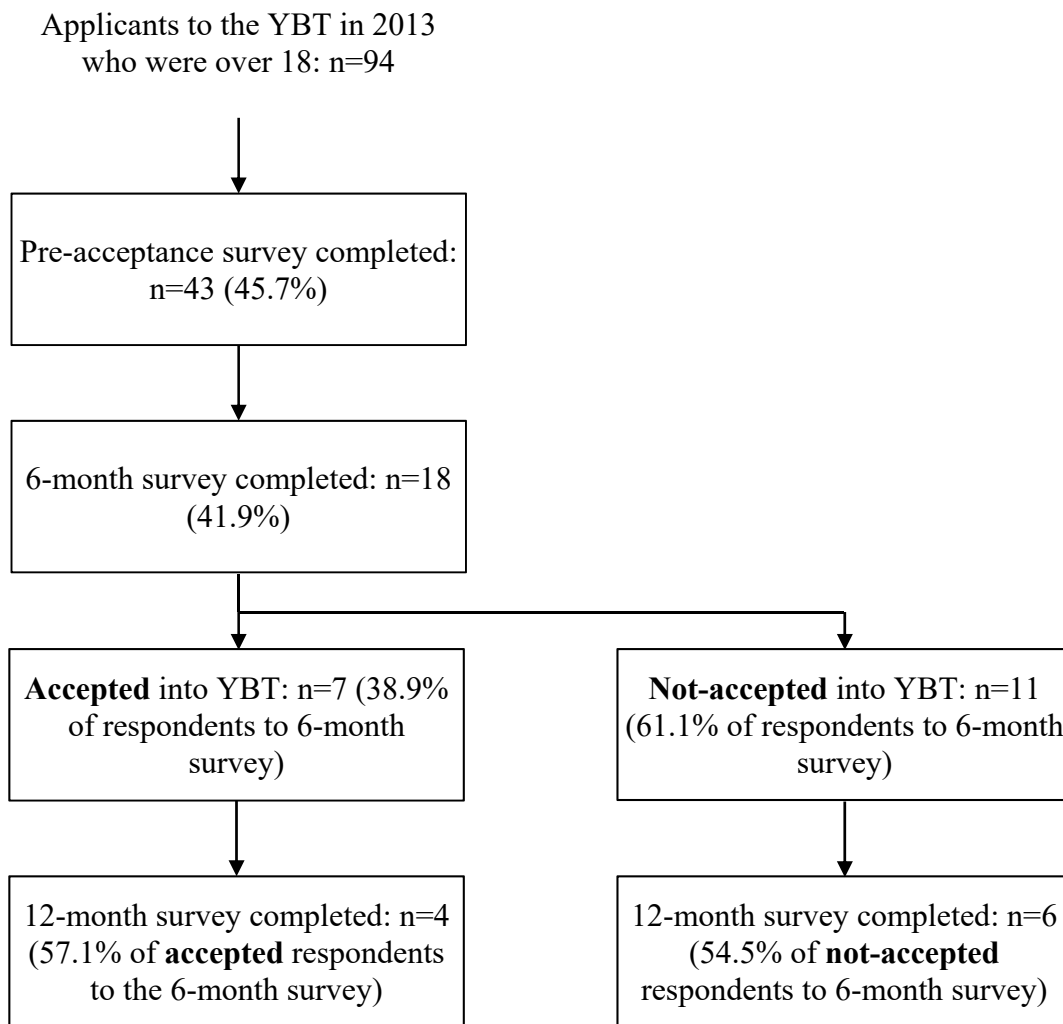


Figure 7.2 Participant flow: survey of advisory group applicants

7.4.2 Participant characteristics and comparison between accepted and not-accepted groups (Objective 1)

The majority of applicants (n=30, 70%) had not applied to the YBT before 2013. Of those who had applied, 27% (n= 12) had applied to the YBT once before and one had applied twice before.

Of the young people who were **accepted** into the YBT, 43% (n=3) had applied once before, and 57% (n=4) had not previously applied. Of the young people who were **not-accepted** into the YBT, 36% (n=4) had applied once before, and 64% (n=7) had not applied previously. A chi-square test showed that this difference was not significant ($\chi^2(1) = 0.08, p = .583$).

Participant characteristics

Participants' ages ranged from 18 to 24 years. The mean age of applicants was 21.4 years (SD 2.06, n=43). The mean age of the **accepted** group was 20.5 (SD 2.01, n=7). The mean age of the **not-accepted** group was 20.3 (SD 2.14, n=11). The Mann-

Whitney U test showed that the difference between the **accepted** and **not-accepted** subgroups was not significant ($U=47.0$, $p=.479$, range 18-24).

Table 7.3 presents the demographic characteristics of applicants, the **accepted** and **not-accepted** subgroups, and the results of the chi-square tests between the subgroups. Of the population groups of interest, the most common group with which the **whole sample** identified was 'lives with a chronic illness or disability' (20.9%, $n=9$ of the **whole sample**). The same proportion (14%, $n=1$) of the **accepted** group identified with four of the groups: 'lives with a chronic illness or disability,' 'has an experience of homelessness,' 'from a culturally and linguistically diverse background,' and 'identifies as LGBTI.' The most frequently identified group by the **not-accepted** subgroup was 'lives with a chronic illness or disability' (27%, $n=3$). No young people who identified as 'a newly arrived migrant or refugee' responded to the survey.

The majority of all groups reported that their main activity was being a student (**whole sample**: 52%, $n=23$; **accepted**: 86%, $n=6$, **not-accepted**: 64%, $n=7$).

Table 7.3 Demographic characteristics of YBT applicants

Characteristic	Whole sample (N= 43)		Accepted (N= 7)		Not-accepted (N=11)		Test of significance (accepted v not-accepted)
	n	%	n	%	n	%	
Gender							
Female	31	72	3	42.9	9	18.2	$\chi^2(1)=2.92, p=.141$
Male	12	28	4	57.1	2	81.8	
Population groups of interest							
Aboriginal or Torres Strait Islander	1	2.3	0	0	1	9.1	$\chi^2(1)=0.67, p=.611$
Lives with a chronic illness or disability	9	20.9	1	14.3	3	27.3	$\chi^2(1)=0.42, p=.485$
Has an experience of homelessness	2	4.7	1	14.3	0	0.0	$\chi^2(1)=1.66, p=.389$
From a culturally and linguistically diverse background	8	18.6	1	14.3	1	9.1	$\chi^2(1)=0.12, p=.641$
Identifies as LGBTI	6	14.0	1	14.3	2	18.2	$\chi^2(1)=0.05, p=.674$
Main occupation ^a							$\chi^2(2)=4.41, p=.110$
Student	23	52.4	6	85.7	7	63.6	
Employed full time	7	16.7	1	14.3	0	0	
Employed part time	10	23.8	0	0	4	36.4	
Not in the workforce	1	2.4	0	0	0	0	
Volunteer	2	4.8	0	0	0	0	
Educational attainment							
Highest level of pre-tertiary schooling							$\chi^2(1)=0.05, p=.674$
Some secondary school	6	14.0	1	14.3	2	18.2	
Six years of secondary school	37	86.0	6	85.7	9	81.8	
Highest level of tertiary education ^b	N=37		N=7		N=6		$\chi^2(2)=1.27, p=.529$
None	10	23.3	4	57.1	3	46.2	
Diploma or below	6	14.0	0	0	1	16.7	
Bachelor's degree	16	37.2	3	42.9	2	33.3	
Higher degree	2	4.7	0	0	0	0	

Note: % is of valid responses within each participant group, ^a Missing cases= 1, ^b Only participants who had completed six years of secondary education were presented with this item.

Educational attainment

Table 7.3 presents the educational attainment of participants. The comparison of the **accepted** and **not-accepted** subgroups shows that the educational attainment of the subgroups was similar. There was a high level of educational attainment across all participant groups, with the **accepted** subgroup having the highest proportion that had obtained a bachelor's degree (43%, n=3).

Only participants who had completed six years of secondary school (n=37) were asked about their tertiary education levels and the tertiary entrance rank they obtained. Of the 25 in the **whole sample** who had received a tertiary entrance rank, 56% (n=14) had received a score above 91 out of a possible score of 99.

Within the **accepted** subgroup, four participants (57.1%) had received a tertiary entrance rank. Of this group, 75% (n=3) had received a score of more than 91%. This was similar to the **not-accepted** group, of which 6 participants (55%) had received a tertiary entrance rank, and 50% (n=3) had received a score of over 91%. A chi-square test showed that this difference was not significant ($\chi^2(3)=3.75, p=.290$).

Personality

Table 7.4 presents the participants' self-reported personality traits. As noted in Section 7.2.5, two of the five personality factors are not reported due to low internal consistency. The median scores on all scales were above the scale mid-point, although the wide ranges indicate that there was variability within the sample. The highest median score of the scales reported was 'conscientiousness' for all groups. The differences in the scores reported by the **accepted** and **not-accepted** subgroups were not significant, as determined by Mann-Whitney U test.

	Median	Range	Median	Range	Median	Range	
Conscientiousness	4.00	2.50–5.00	4.50	3.00–5.00	4.00	2.50–5.00	U=47.00, $p=.479$
Extraversion	3.25	1.50–5.00	3.50	1.50–4.50	3.00	1.50–5.00	U=34.50, $p=.724$
Emotional stability	3.25	1.50–5.00	3.50	1.50–5.00	3.00	1.50–5.00	U=34.50, $p=.722$

Technology use

Table 7.5 presents the technology use of participants. Nearly all of the **whole sample** had used a ‘computer’ on a daily basis (95.3%, n=41). Other than computers, the most frequently used technology by both subgroups were smartphones (85% n=6, of the **accepted** subgroup and 82%, n=9 of the **not-accepted** subgroup). A low proportion of both the **accepted** (29%) and **not-accepted** subgroups (36%) reported using a non-internet enabled mobile phone on a daily basis.

Participants in the **accepted** and **not-accepted** subgroups reported that they had used the internet for the same amount of time on ‘school or work days’, and ‘non-school or work days’ (75% of each group having used the internet for less than 5 hours on both types of days).

Table 7.5 Technology use of YBT applicants

	Whole sample (N= 43)		Accepted (N= 7)		Not-accepted (N=11)		Test of significance (accepted v not-accepted)
	n	%	n	%	n	%	
Type of technology used on a daily basis							
Computer	41	95	7	100	11	100	Not applicable ^a
Smartphone	38	88	6	86	9	82	$\chi^2(1)=0.05, p=.674$
Entertainment device	31	72	3	43	8	73	$\chi^2(1)=1.61, p=.220$
Non-internet enabled mobile phone	11	26	2	29	4	36	$\chi^2(1)=0.12, p=.572$
Amount of time spent on the internet on school or work days ^b							$\chi^2(1)=0.00, p=.764$
Less than 5 hours	17	50	3	75	6	75	
More than 5 hours	17	50	1	25	2	25	
Amount of time spent on the internet on non-school or work days ^c							$\chi^2(1)=0.00, p=.764$
Less than 5 hours	23	68	3	75	6	75	
More than 5 hours	11	32	1	25	2	25	

Note. % is of sample, ^a Because 100% of the both groups had used computers on a daily basis, the chi-square test was not calculated, ^b Missing cases: Whole sample= 9, Accepted= 3, Not-accepted= 3; ^c Missing cases: Whole sample=9, Accepted= 3, Not-accepted= 3

Internet use

Table 7.6 presents the internet use of YBT applicants. The location from which participants most frequently accessed the internet was varied, with the majority of the **whole sample** accessing it from a 'mobile device' (42%, n=18). A majority of the **accepted** and **not-accepted** subgroups most frequently accessed the internet from their 'own home' (86%, n=6 and 55%, n=5 respectively). The difference between where the two subgroups most frequently accessed the internet was not statistically significant.

The majority of the **whole sample** (56%, n=24) reported that they used the internet after 11pm on 0-3 days per week. When the **accepted** and **not-accepted** subgroups were compared, the converse was found— the majority of the **accepted** group, had used the internet after 11pm for between four and seven days (71%, n=5). A chi-square test showed that the difference between the **accepted** and **not-accepted** subgroups was not significant (see Table 7.6).

The activity that the internet had been used for most frequently by the **whole sample** was 'social networking' (100%, n=43). Those who were **accepted** also reported high use of this (100%, n=7), as well as 'school or work' (100%, n=7) and 'entertainment' (100%, n=7). The majority of those who were **not-accepted** had used the internet for 'entertainment' (100%, n=11), school or work (73%, n=8), 'social networking' (100%, n=11) and had 'wrote or produced content' (82%, n=9).

Of the two groups, the median number of activities that the **accepted** subgroup had participated in was greater (median=11, range 8-16, n=7) than the **not-accepted** subgroup (median=9, range 5-15, n=11). A Mann-Whitney U test showed that the difference between the subgroups was not statistically significant ($U=54.50, p=.151$).

Table 7.6 Internet use of YBT applicants

	Whole sample (N= 43)		Accepted (N= 7)		Not-accepted (N=11)		Test of significance (accepted v not-accepted)
	n	%	n	%	n	%	
Location from which the internet was most frequently accessed							$\chi^2(1)=1.87, p=.199$
Mobile device	18	42	1	14	5	46	
Own home	17	40	6	86	6	55	
School or work	7	16	0	0	0	0	
Public place	1	2	0	0	0	0	
Number of days the internet was used after 11pm							$\chi^2(1)=5.10, p=.039$
0-3 days	24	56	2	29	9	82	
4-7 days	19	44	5	71	2	18	
Activity that the internet had been used for in the past month							
Commerce related activities	23	54	3	43	5	46	$\chi^2(1)=0.01, p=.648$
Entertainment	42	98	7	100	11	100	Not applicable ^a
Health related activities	2	5	0	0	1	9	$\chi^2(1)=0.67, p=.611$
School or work	33	77	7	100	8	73	$\chi^2(1)=2.29, p=.202$
Sexual pleasure	10	23	3	43	3	27	$\chi^2(1)=0.47, p=.428$
Social networking	43	100	7	100	11	100	Not applicable ^b
Spoken communication	18	42	4	57	3	27	$\chi^2(1)=1.61, p=.220$
Wrote or produced content	33	77	5	71	9	82	$\chi^2(1)=0.27, p=.515$

Note. % is of valid responses within each participant group. ^a Because 100% of both the accepted and not accepted groups had used the internet for entertainment purposes in the past month, the chi-square test was not calculated; ^b Because 100% of the sample had used the internet for social networking in the past month, the chi-square test was not calculated.

Previous experience of mental ill health

The majority of the **whole sample** reported that they had experienced a mental health or behavioural problem at some point in their lives (67%, n=29). This was also true of the **accepted** (71%, n=5) and **not-accepted** (64%, n=7) subgroups. A chi-square test showed that the difference between the two subgroups was not significant ($\chi^2(1)=0.12, p=.572$).

Psychological distress at time of application (K10)

The median level of psychosocial distress of the **whole sample**, as measured by the K10, was high (median=22.00, range 10-40, n=42). The median score reported by the **not-accepted** subgroup was the same as the **whole sample** (median=22.00, range=12-39, n=11). The median score reported by the accepted subgroup was moderate (median=16.00, range=10-36, n=7). The difference between the subgroups was not statistically significant, as determined by the Mann-Whitney U test ($U=27.00, p=.328$).

Previous experience of help seeking for mental ill health

Of the 29 the **whole sample** who reported that they had previously experienced a mental health or behavioural problem, 93.1% (n=27) had sought treatment for this. The majority of both subgroups had sought help from professional sources— 80% (n=4) of the **accepted** subgroup and 63.6% (n=7) of the **not-accepted** subgroup. A chi-square test showed that the difference between the two subgroups was not statistically significant ($\chi^2(1)=1.53, p=.417$).

The proportion of the **whole sample** who had sought help from self-help sources was lower than from professional sources. Only one participant had used self-help (3%) at the pre-acceptance survey. This participant did not respond to the 6-month survey. Consequently, no participants in either the **accepted** or **not-accepted** group sought help from self-help sources.

Likelihood of seeking help from specific sources (GHSQ)

Table 7.7 presents the results of the General Help Seeking Questionnaire (GHSQ) from the pre-acceptance survey. It shows that among all groups (**whole sample, accepted** and **not-accepted**), the ‘internet’ was the least preferred source from which to seek help for mental ill health, and that ‘friends’ were the preferred source at the pre-acceptance survey. However, the wide ranges on most items indicates that there

Table 7.7 Likelihood that YBT applicants would seek help from specific sources

Source of help	Whole sample (N=43)		Accepted (N=7)		Not-accepted (N=11)	Test of significance (accepted v not accepted)
	Median	Range	Median	Range		
Family doctor/GP	5.00	1-7	5.00	1-7	5.00	U=31.0, $p=.536$
Friend (not related to you)	5.00	1-7	6.00	3-7	6.00	U=37.5, $p=.925$
I would not seek help from anyone	5.00	1-7	4.00	1-7	4.50	U=31.5, $p=.536$
Mental health professional	4.00	1-7	2.00	1-6	4.00	U=33.5, $p=.659$
Other relative/family member	5.00	1-7	5.00	1-7	5.00	U=39.0, $p=.963$
Parent	2.00	1-7	2.00	1-5	3.00	U=31.0, $p=.536$
Partner	4.00	1-7	3.00	1-7	5.00	U=26.0, $p=.285$
Phone help line	2.00	1-7	2.00	1-6	3.00	U=37.5, $p=.930$
Teacher	4.50	1-7	4.00	2-7	5.00	U=46.0, $p=.536$
The internet	1.00	1-7	2.00	1-7	4.00	U=46.0, $p=.438$
Someone else not listed above	2.00	1-7	4.00	1-7	2.00	U=27.5, $p=.328$

Awareness of others' mental ill health

A large proportion of the **whole sample** reported that they knew of friends or family who had experienced mental ill health (n=41, 95%) at the pre-acceptance survey. This was also true of the **accepted** (91%, n=10) and **not-accepted** (86%, n=6) subgroups at the pre-acceptance survey. The difference between these proportions was not statistically significant, as indicated by a chi-square test ($\chi^2(1)=0.12, p=.641$).

Knowledge about mental ill health (depression literacy)

The median depression literacy score of the **whole sample** at the pre-acceptance survey was 7.0 (range 1-10, n=42). The median score reported by those who were **accepted** was 7.0 (range 3-10, n=7) and the median score reported by those who were **not-accepted** was 8.0 (range 4-10, n=11). The difference between the subgroups was not statistically significant, as determined by Mann-Whitney U test ($U=35.5, p=.791$).

Participation in their broader communities (Civic participation)

The median number of types of civic activities that the **whole sample** had participated in, at the pre-acceptance survey, was 8.0 (range 0-18, n=42). The median number of activities reported by those who were **accepted** was 7.0 (range 5-18, n=7) and the median number of activities reported by those who were **not-accepted** was 7 (range 2-16, n=11). A Mann-Whitney U test determined that the difference between the two subgroups was not statistically significant ($U=48.0, p=.387$).

The **whole sample** group was actively participating in their local communities, as shown by the high rates of participation in groups based at their 'school, TAFE or university' (65%, n=28). They were interested in helping other young people, as evidenced by their life experiences including the large number (88%, n=38) who had volunteered with other groups prior to applying to the YBT. They had primarily volunteered or been engaged within the mental health field (67%, n=29 had volunteered with a 'mental health organisation' and 42%, n=18 had been involved in a 'support group').

When the **accepted** and **not-accepted** subgroups were compared, there were no statistically significant differences. However, there were some proportional differences. Of note is that a greater proportion of the **accepted** subgroup had been involved in a mental health organisation than those who were **not-accepted** (**accepted** 86%, n=6 and **not-accepted** 46%, n=5).

Table 7.8 *Civic participation of YBT applicants*

Civic participation activity	Whole sample (N= 43)		Accepted (N= 7)		Not-accepted (N=11)		Test of significance (accepted v not-accepted)
	n	%	n	%	n	%	
An online community group	21	49	5	71	4	36	$\chi^2(1)=2.10, p=.167$
A support group	18	42	2	29	3	27	$\chi^2(1)=0.01, p=.676$
A mental health organisation	29	67	6	86	5	46	$\chi^2(1)=2.92, p=.112$
A local library	12	28	4	57	2	18	$\chi^2(1)=2.92, p=.117$
A human rights, development or aid organisation	17	40	2	29	6	55	$\chi^2(1)=1.17, p=.278$
A group or club based at your school, TAFE or university	28	65	6	86	8	73	$\chi^2(1)=0.42, p=.485$
A local sporting or recreation group	24	56	5	71	6	55	$\chi^2(1)=0.51, p=.417$
A band, artistic collective or other creative network	16	37	3	43	3	27	$\chi^2(1)=0.47, p=.428$
Some other political or activist organisation	11	26	1	14	3	27	$\chi^2(1)=0.42, p=.485$
A youth club	15	35	4	57	5	46	$\chi^2(1)=0.23, p=.500$
An environmental organisation	8	19	1	14	3	27	$\chi^2(1)=0.42, p=.485$
Organisations or groups concerned with women's or gender issues	14	33	0	0	5	46	$\chi^2(1)=4.41, p=.054$
Any type of group related to a specific ethnic group in the community	7	16	1	14	0	0	$\chi^2(1)=1.66, p=.389$
A citizen's organisation	1	2.3	0	0	0	0.0	Not applicable ^a
A church group	9	21	4	57	2	18	$\chi^2(1)=2.92, p=.117$
A conservation or heritage organisation	1	2	1	14	0	0	$\chi^2(1)=1.66, p=.389$
Made a donation	32	74	5	71	9	82	$\chi^2(1)=0.27, p=.515$
Volunteered time	38	88	6	86	9	82	$\chi^2(1)=0.05, p=.674$
Signed a petition	35	81	6	86	10	91	$\chi^2(1)=0.12, p=.641$
'Boycotted' or boycotted a product	8	19	1	14	0	0	$\chi^2(1)=1.66, p=.389$
Written a letter to the editor or contributed to talk back radio or commented on an article online	18	42	3	43	3	27	$\chi^2(1)=0.47, p=.428$

Note. % is of valid responses within each participant group, ^a Not calculated because there were 0 participants in the subgroups compared.

7.4.3 Comparison of applicants to their peers in the Australian population (Objective 2)

Objective 2 of the study was to compare the characteristics of the young people who apply to mental health advisory groups to their peers in the Australian population, where recent comparable population survey data was available. Only characteristics which have been recently measured in comparable population level surveys are reported. Where possible, the Australian Census of Population and Housing has been used (Australian Bureau of Statistics, 2016). Where the questions asked in the study do not align with questions asked in the census, other Australian Bureau of Statistics studies have been used and are noted in Table 7.9, below.

Participant characteristics

Chi-square tests showed that none of the differences were significantly different, which indicates that the samples are likely to be drawn from the same population.

Educational attainment

When compared to their peers in the Australian population, there were fewer young people in the sample who had not completed any tertiary education, and proportionally more who had completed bachelor's degrees. The proportion of the **whole sample** who had completed a bachelor's degree (36.4%, n=16) was statistically significantly different to that of the Australian population for the same age range at the last Australian census (Australian Bureau of Statistics, 2016).

Actual experience of mental ill health

The proportion of the **whole sample** who had experienced a mental health or behavioural problem (67%, n=29) was statistically significantly different to the 16.3% of the 18 to 25 year old Australians who have experienced a mental health or behavioural problem ($\chi^2=38.27$, $p=.001$ Australian Bureau of Statistics, 2014b).

Experience of help seeking

A statistically significant higher proportion of young people in the sample had sought help for mental ill health (93%, n=27) than their peers in the Australian population (23.3%; $\chi^2=24.39$, $p=.001$ Australian Bureau of Statistics, 2007).

Table 7.9 Comparison of demographic characteristics of YBT applicants to population proportions

Characteristic	Whole sample (N= 43)		Population	Comparison to population
Population groups of interest				
Aboriginal or Torres Strait Islander	1	2.3	12.5	$\chi^2(1) = 3.50, p=.038$
Lives with a chronic illness or disability	10	23.2	41.4 ^a	$\chi^2(1) = 4.46, p=.026$
Has an experience of homelessness	2	4.6	11.0 ^b	$\chi^2(1) = 1.18, p=.228$
Main occupation				
Student	23	53	44	$\chi^2(1) = 1.11, p=.184$
	7	16	32	$\chi^2(1) = 5.37, p=.016$
	10	23	30	$\chi^2(1) = 1.14, p=.183$
	1	2	7	$\chi^2(1) = 1.58, p=.167$
Volunteer	2	5	19	$\chi^2(1) = 5.13, p=.017$
Educational attainment – highest level of pre-tertiary schooling				
Some secondary school	6	14	19	$\chi^2(1) = 1.83, p=.119$
Six years of secondary school	37	86	78	$\chi^2(1) = 1.03, p=.206$
Educational attainment - highest level of tertiary education				
None	N=37			
Diploma or below	10	23	61	$\chi^2(1) = 0.64, p=.278$
Bachelor's degree	6	14	23	$\chi^2(1) = 0.61, p=.291$
Higher degree	16	36	14	$\chi^2(1) = 15.09, p=.000^*$
	2	3	2.0	$\chi^2(1) = 2.57, p=.150$

Note: % is of sample; ^aAustralian Bureau of Statistics. (2009). *Disability, ageing and carers, Australia: summary of findings*, cat. no. 4430.0. Canberra; ^b Australian Bureau of Statistics. (2014). *General Social Survey: Summary Results*, cat. no. 4159.0. Canberra

7.4.4 Change over time (Objective 3)

Objective 3 of the study was ‘to ascertain whether involvement in a mental health advisory group has positive effects on young people.’ Eight different outcome variables were assessed: internet use, actual experience of mental ill health, psychological distress (K10), actual help seeking, likelihood to seek help from specific sources (GHSQ), awareness of others’ mental ill health, depression literacy and civic participation. Depending on the measurement level of the dependent variable, analyses were conducted using either MMRM ANOVA or binomial logistic regressions and chi-square tests. Effect sizes were calculated using either *Hedges g* or *Cramer’s V*, depending on the level of measurement.

Internet use

Table 7.10 presents the mean number of activities that young people had undertaken on the internet in the last month for the **accepted**, and **not-accepted** subgroups at each survey. Figure 7.3 shows how these changed over time and the differences between subgroups.

Table 7.10 Means and standard deviations for internet use (number of online activities per month) at pre-acceptance, 6-month and 12-month

Group	Survey								
	Pre-acceptance			6-month			12-month		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Accepted	11.5	3.0	7	14.0	2.2	7	16.8	4.1	4
Not-accepted	9.5	3.1	11	10.3	3.4	11	11.3	2.6	6

MRMM ANOVA indicated that for the number of activities undertaken online in the last month, the overall interaction of YBT membership and time was not significant ($F [2, 24.58] = 0.99, p = .385$). The between-group effect sizes were: $g = 1.20$ at 6 months and $g = 1.50$ at 12 months. These are large effect sizes. The relative increase indicates that the size of the effect increased over the year of involvement.

The within-group effect sizes for the participants who were **accepted** were: **pre-acceptance to 6-month** $g = -.87$; **6-month to 12-month** $g = -.85$; and **pre-acceptance to 12-month** $g = -1.39$. These are large to very large effect sizes.

The within-group effect sizes for the **not-accepted** group were smaller than the **accepted** group. They were: **pre-acceptance to 6-month** $g = -.22$; **6-month to 12-month** $g = -.32$; **pre-acceptance to 12-month** $g = -.58$. The effect sizes for the 6-month periods were small, and the effect size for the 12-month period (**pre-acceptance to 12-month**) was medium.

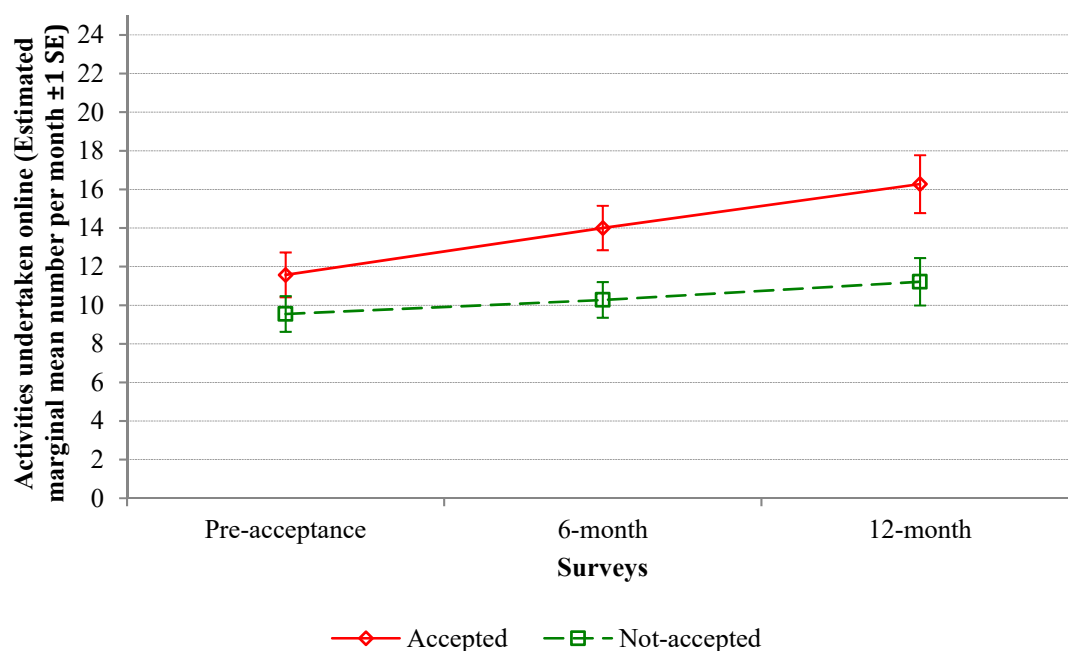


Figure 7.3 Estimated marginal means and standard errors (± 1 SE) for internet use (number of online activities per month)

Actual experience of mental ill health

Figure 7.4 presents the proportion of participants who had a mental health or behavioural problem prior to each survey for both subgroups. At the pre-acceptance survey, a higher proportion of the participants who were **accepted** reported that they had ever experienced mental health or behavioural problems than those who were **not-accepted** (71%, $n=5$ compared to 64%, $n=7$). This trend was reversed at the 6-month survey, at which 29% ($n=2$) of the participants who were **accepted** reported that they had experienced mental health or behavioural problems in the last 6 months, compared to 64% ($n=7$) of those who were **not-accepted**. At the 12-month survey, 25% ($n=1$) of participants who were **accepted** and 50% ($n=3$) of participants who were **not-accepted** reported that they had experienced mental health or behavioural problems in the last 6 months.

Binomial logistic regression was used to ascertain that the change reported by participants who were **accepted**, between the **pre-acceptance** and **6-month** surveys, was not statistically significantly different to participants who were **not-accepted** (OR 7.50, 95% CI 0.59 – 95.38, $p=.120$).

Between 6 and 12 months, the change reported by participants who were **accepted** was not statistically significantly different to the change reported by participants who were **not-accepted** ($\chi^2(1)=1.68$, $p=.400$). The effect size was $V=.41$.

The changes reported by the **accepted** and **not-accepted** subgroups between the **pre-acceptance and 12-month** surveys were also not statistically significant ($\chi^2(1)=1.68, p=0.333$). The effect size was the same as the previous test ($V=.41$).

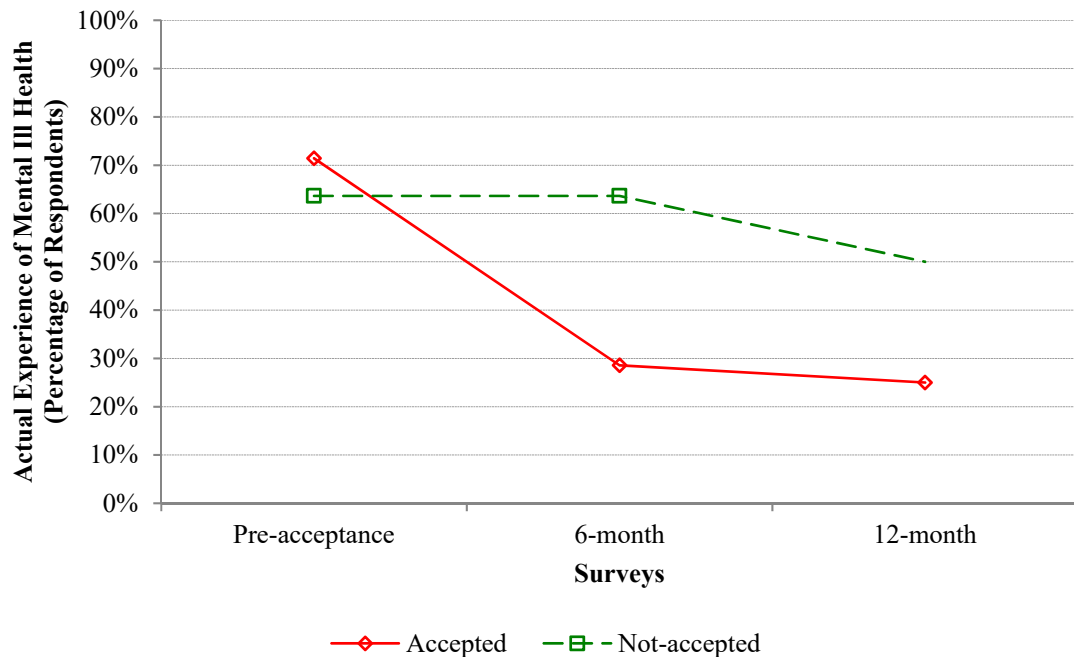


Figure 7.4 Percentage of participants who had experienced mental ill health

Psychological distress (K10)

Table 7.11 presents the mean K10 scores for the **accepted** and **not-accepted** subgroups at each survey. Figure 7.5 shows how these changed over time, and the differences between subgroups.

Table 7.11 Means and standard deviations for psychological distress (K10) at pre-acceptance, 6-month and 12-month

Group	Survey								
	Pre-acceptance			6 months			12 months		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Accepted	20.0	10.1	7	18.9	9.4	7	17.0	7.4	4
Not-accepted	23.7	8.9	11	23.0	9.2	11	26.7	7.8	6

MRMM ANOVA indicated that for psychological distress (K10), there was not a significant interaction between YBT membership and time ($F[2, 24.34] = 0.03, p=.973$).

The effect size of the differences between the **accepted** and **not-accepted** subgroups (between-groups effect size) at 6 months was $g=-.43$, which is a small effect size. At 12 months the between-groups effect size was $g=-1.14$, which is a large effect size. The within-group effect sizes for the **accepted** subgroup were: **pre-acceptance to 6-month** $g=.11$; **6-month to 12-month** $g=.19$; and **pre-acceptance to 12-month**

$g=.29$. The 6-month effect sizes were very small, and the 12-month effect size was small.

The within-group effect sizes for the **not-accepted** group were: **pre-acceptance to 6-month**: $g=.08$, which was a very small effect size. Effect sizes were small for **6-month to 12-month** period ($g=-.40$), and **pre-acceptance to 12-month** period ($g=-.32$).

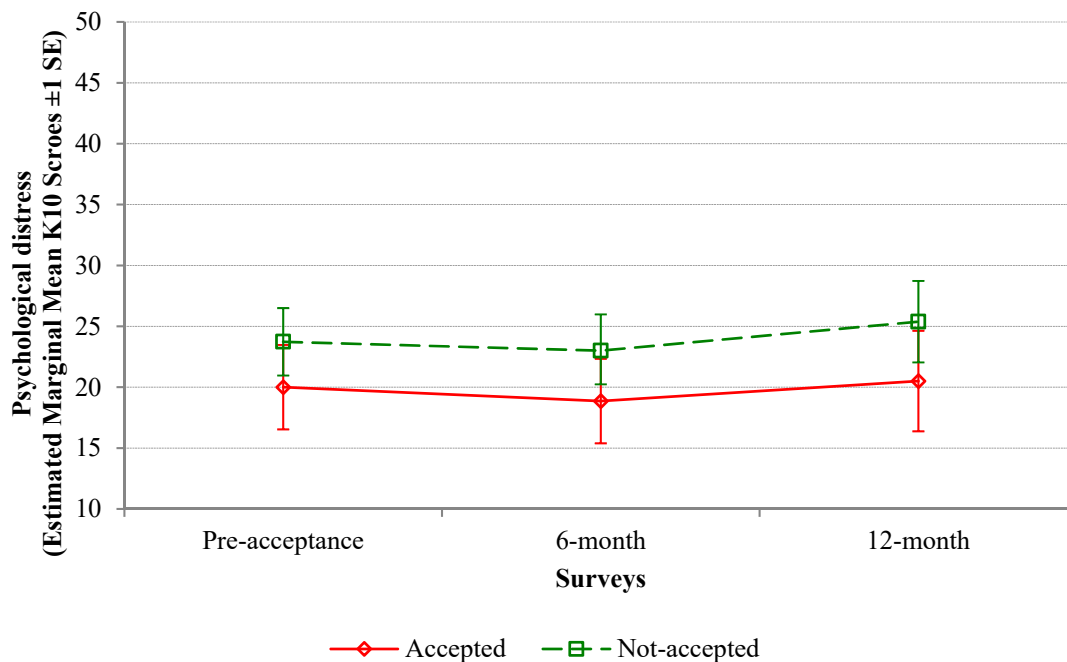


Figure 7.5 Estimated marginal means and standard errors (± 1 SE) for psychological distress (K10)

Actual help seeking

Figure 7.6 shows the proportion of participants who had sought help for mental ill health prior to each survey and the differences between subgroups. At all three time points, the proportion of young people who had sought help was higher in the **not-accepted** subgroup than in the **accepted** subgroup.

The creation of the change over time variables showed that, while the proportion of respondents seeking help had changed, no individual participants had gone from not seeking help to having sought help between surveys. The change in proportion arose due to the decreasing number of respondents to the 6 and 12-month surveys. Consequently, no change over time analyses could be conducted, as there were no differences between groups to compare.

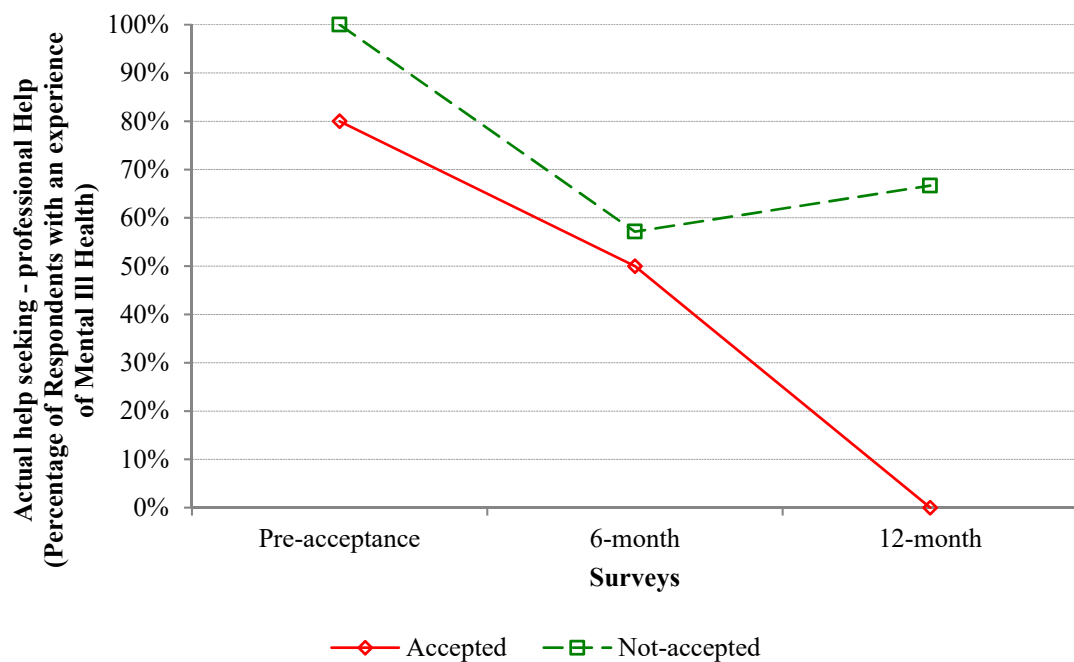


Figure 7.6 *Percentage of respondents with an experience of mental ill health who reported seeking professional help*

Likelihood to seek help from specific sources

Table 7.12 presents the mean likelihood that young people would seek help from each of the sources listed as part of the GHSQ, at each survey, for both subgroups. The results of the MRMM ANOVA and figures showing how these changed over time and the variance within subgroups are presented sequentially following the table.

Table 7.12 Means and standard deviations 'likelihood to seek help from particular sources' at pre-acceptance, 6-month and 12-month

Source	Subgroup	Survey					
		Pre-acceptance			6-month		
		Mean	SD	n	Mean	SD	n
Doctor	Accepted	3.71	2.63	7	3.71	2.63	7
	Not-accepted	4.27	2.83	11	4.18	2.44	11
Friend	Accepted	5.29	1.38	7	4.86	1.07	7
	Not-accepted	5.27	1.49	11	4.45	1.29	11
No one	Accepted	4.00	2.00	7	3.86	1.77	7
	Not-accepted	4.64	2.25	11	4.55	2.02	11
Mental health professional	Accepted	3.00	1.73	7	3.57	2.37	7
	Not-accepted	3.45	1.97	11	2.73	1.49	11
Another relative	Accepted	4.71	1.98	7	4.71	1.60	7
	Not-accepted	4.82	1.60	11	4.00	1.55	11
Parent	Accepted	2.57	1.72	7	3.00	1.91	7
	Not-accepted	3.00	1.26	11	2.36	1.75	11
Partner	Accepted	3.57	1.99	7	3.57	1.72	7
	Not-accepted	4.36	1.12	11	3.18	1.78	11
Phone helpline	Accepted	2.71	1.70	7	2.86	1.77	7
Internet	Not-accepted	4.36	1.57	11	4.00	2.05	11
	Accepted	2.86	1.77	7	2.29	1.38	7
Someone else	Not-accepted	2.09	1.70	11	1.27	0.47	11
	Accepted	2.86	1.57	7	2.71	1.38	7
	Not-accepted	3.82	2.04	11	2.73	1.56	11
	Accepted						

Likelihood to seek help from a doctor

Figure 7.7 presents the mean likelihood that participants would seek help from a doctor at each time point, and how this varied between the **accepted** and **not-accepted** subgroups. MRMM ANOVA indicated that for this, the overall interaction of YBT membership and time was not significant ($F [2, 24.57] = 1.31, p=.287$).

At the 6-month survey, the between-group effect size was $g=-.18$ and at the 12 month survey, the effect size was $g=.38$. The within-group effect sizes for the **accepted** subgroup between the **pre-acceptance** and **6-month** surveys was $g=-.00$. The within-group effect sizes for the **6-month to 12-month** and the **pre-acceptance to 12-month** periods were the same, $g=-.76$.

The within-group effect size for the **not-accepted** subgroup for **pre-acceptance to 6-month** was $g=.033$, for **6-months to 12-month** was $g=-.12$, and for **pre-acceptance to 12-month** was $g=-.08$.

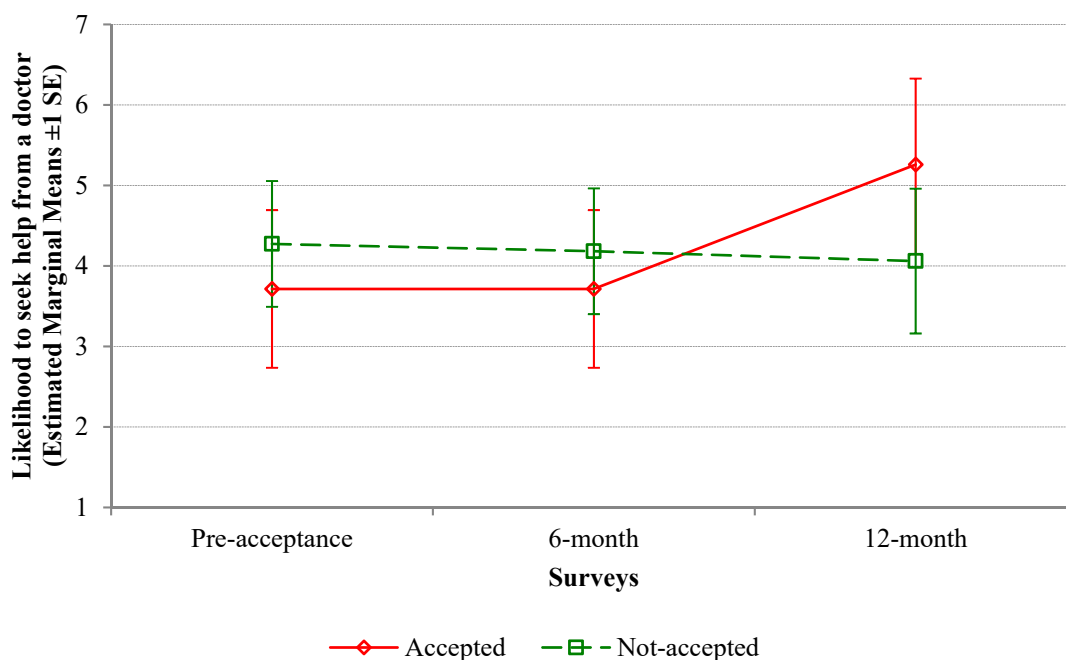


Figure 7.7 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a doctor (GHSQ)

Likelihood to seek help from a friend

The mean likelihood that participants would seek help from a friend at each time point, and how this varied between subgroups, is presented in Figure 6.8. Using MRMM ANOVA, the overall interaction of YBT membership and time was found to be not significant ($F [2, 27.34] = 0.69, p=.511$).

The between-group effect sizes were: 6 months $g=0.32$ and 12 months $g=-.56$. For participants who were **accepted** the within-group effect sizes were: **pre-acceptance to 6 months** $g=0.33$; **6-month to 12-month** $g=-.11$; and **pre-acceptance to 12-month** $g=-.19$. For participants who were **not-accepted** the within-group effect sizes were: **pre-acceptance to 6-month** $g=.57$; **6-month to 12-month** $g=-1.00$; and **pre-acceptance to 12-month** $g=-.29$.

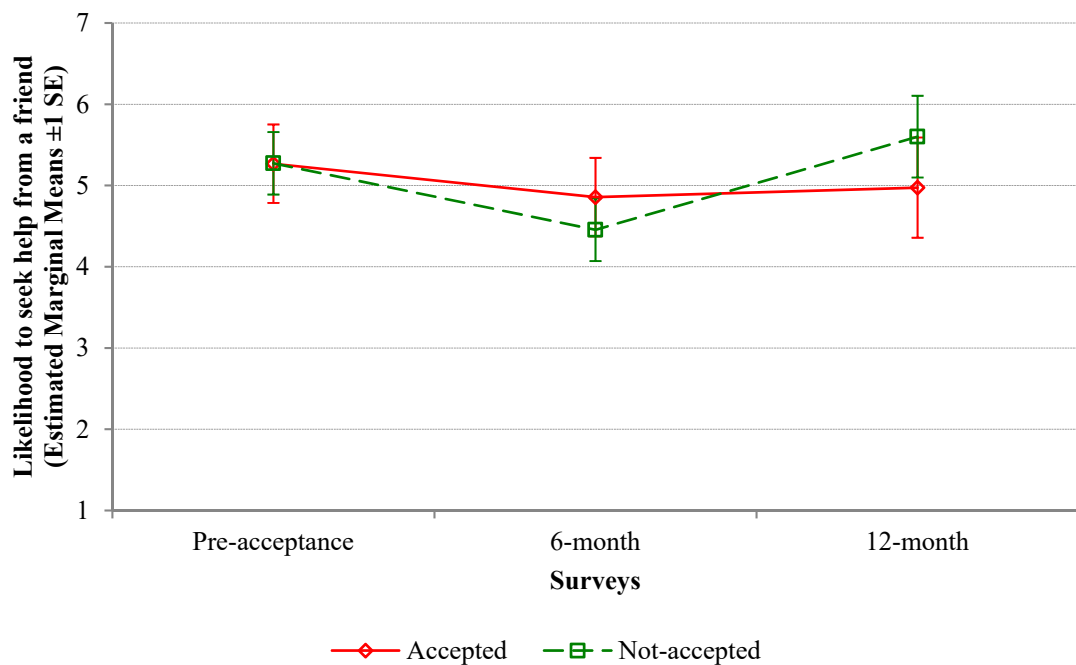


Figure 7.8 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a friend (GHSQ)

Likelihood to seek help from no one

Figure 7.9 presents the mean likelihood that participants would seek help from no one at each time point, and how this varied between participants who were **accepted** and **not-accepted**. MRMM ANOVA indicated that for the likelihood that participants would seek help from no one, the overall interaction of YBT membership and time was not significant ($F [2, 24.85] = 0.09, p=.912$). The absence of a significant result indicates that there was not a significant difference in the patterns of change of likelihood to seek help from no one, based on YBT membership.

The between-group effect sizes were: 6 months $g=.34$ and 12 months $g=.53$. The within-group effect sizes for the **accepted** subgroup were: **pre-acceptance to 6-month** $g=-.07$; **6-month to 12-month** $g=-.38$; and **pre-acceptance to 12-month** $g=-.26$. The within-group effect sizes for the **not-accepted** subgroup were **pre-acceptance to 6-month** $g=.04$; **6-month to 12-month** $g=.44$; and **pre-acceptance to 12-month** $g=.47$.

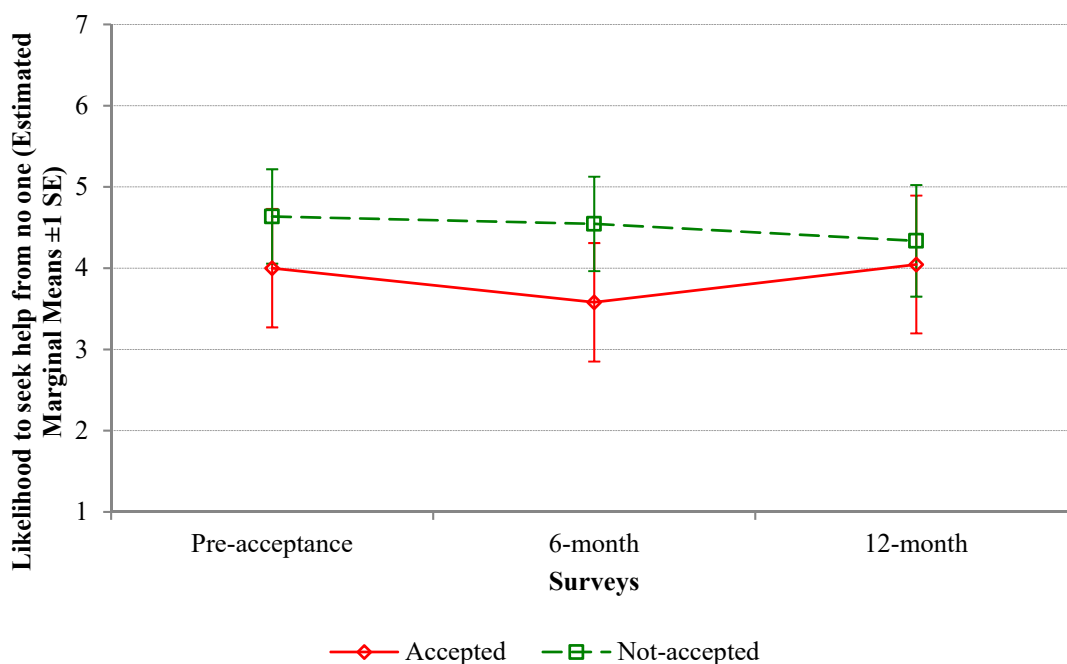


Figure 7.9 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from no one (GHSQ)

Likelihood to seek help from a mental health professional

Figure 7.10 presents the likelihood that participants would seek help from a mental health professional at each time point, and how this varied between subgroups. The results of the MRMM ANOVA show that the overall interaction of YBT membership and time was not significant ($F [2, 24.37] = 2.52, p = .101$).

At 6 months, the between-group effect size was $g = .43$. At 12 months, it was $g = 0.17$. For participants who were **accepted** the within-group effect sizes were: **pre-acceptance to 6-month** $g = -.28$; **6-month to 12-month** $g = .23$; and **pre-acceptance to 12-month** $g = -.00$. For participants who were **not-accepted** the within-group effect sizes were: **pre-acceptance to 6-month** $g = .41$; **6-month to 12-month** $g = -.40$; and **pre-acceptance to 12-month** $g = .07$.

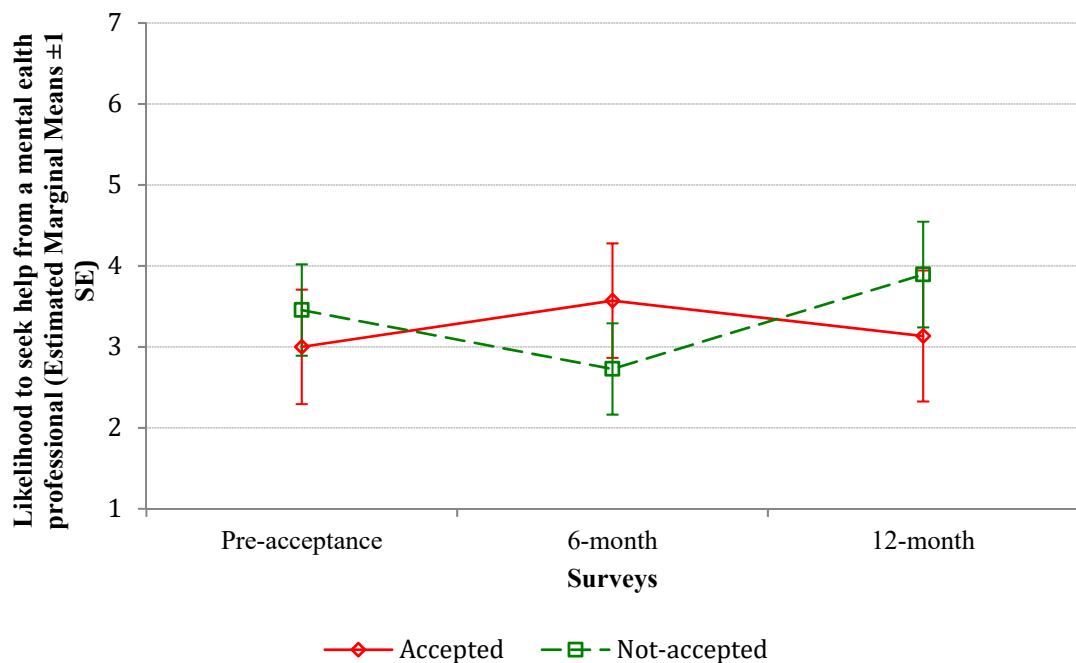


Figure 7.10 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a mental health professional (GHSQ)

Likelihood to seek help from another relative

The mean likelihood that participants from each subgroup would seek help from another relative at each survey is presented in Figure 7.11. MRMM ANOVA indicated that the overall interaction of YBT membership and time was not significant ($F [2, 24.86] = 0.67, p = .552$).

The between-group effect sizes were: 6 months $g = .43$ and 12 months $g = -.18$. The within-group effect sizes for the **accepted** subgroup were: **pre-acceptance to 6-month** $g = .00$; **6-month to 12-month** $g = .48$; and **pre-acceptance to 12-month** $g = .43$. The within-group effect sizes for the **not-accepted** subgroup were: **pre-acceptance to 6-month**: $g = .50$; **6-month to 12-month**: $g = -.09$; and **pre-acceptance to 12-month** $g = .34$.

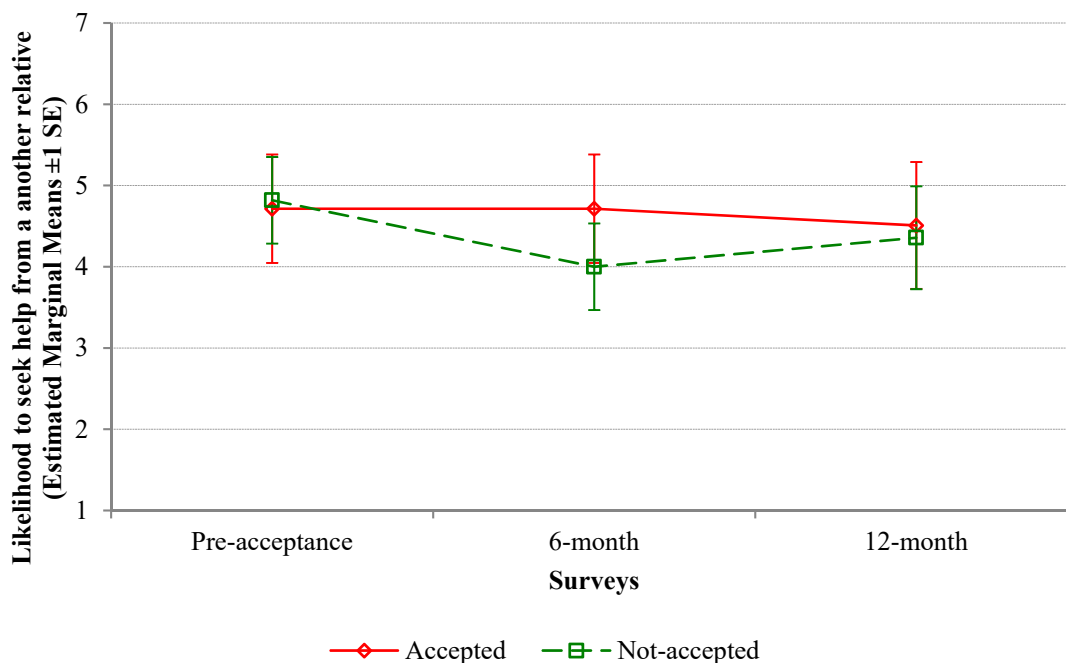


Figure 7.11 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from another relative (GHSQ)

Likelihood to seek help from a parent

Figure 7.12 presents the likelihood that participants would seek help from a parent at each survey, and how this varied between subgroups. MRMM ANOVA showed that the overall interaction of YBT membership and time was not significant ($F[2, 24.64] = 1.05, p = .37$).

The between-group effect size at 6 months was $g = .34$ and at 12 months it was $g = -.43$. The within-group effect sizes for the **accepted** subgroup were: pre-acceptance to 6 months $g = -.22$; **6-month to 12-month** $g = .11$; and **pre-acceptance to 12-month** $g = -0.09$. For the **not-accepted** subgroup, the within-group effect sizes were: **pre-acceptance to 6-month** $g = .40$; **6-month to 12-month** $g = -.71$; and **pre-acceptance to 12-month**: $g = -.44$.

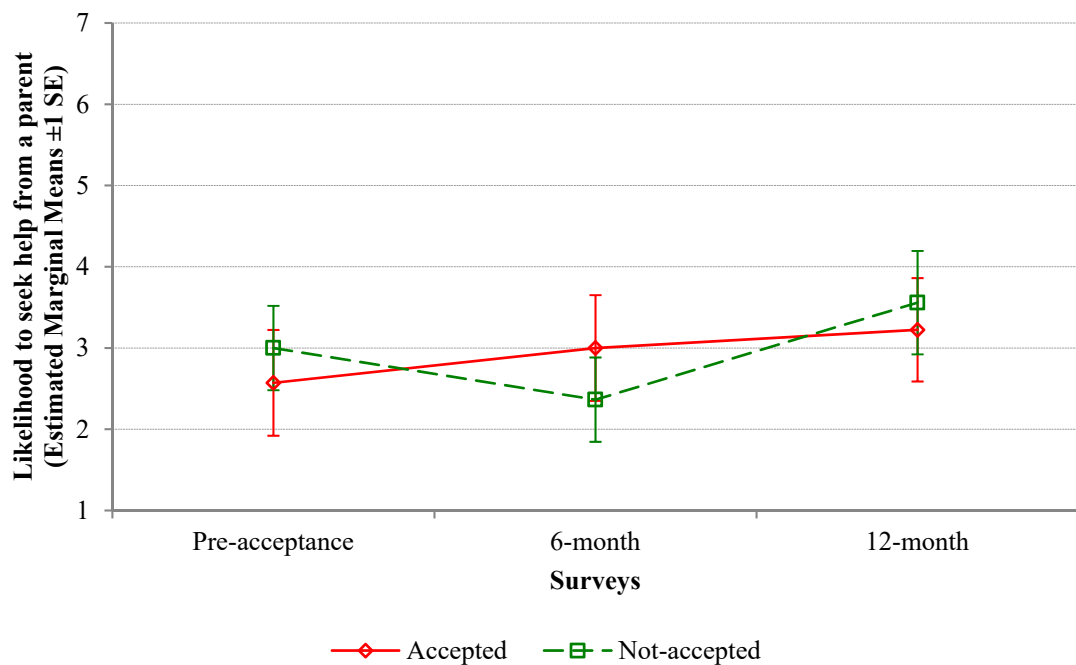


Figure 7.12 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a parent (GHSQ)

Likelihood to seek help from a partner

The mean likelihood that participants from each subgroup would seek help from a partner at each survey is presented in Figure 7.13. The results of the MRMM ANOVA indicated that for this help seeking source, the overall interaction of YBT membership and time was not significant ($F [2, 24.96] = 1.07, p=.360$).

At 6 months, the between-group effect size was $g=.21$. At 12 months, the between- group effect size was $g=-.16$. For the **accepted** participants, the within-group effect sizes were **pre-acceptance to 6-month**: $g=.00$; **6-month to 12-month** $g=.04$; and **pre-acceptance to 12-month** $g=.03$. For the **not-accepted** participants the within-group effect sizes were: **pre-acceptance to 6-month**: $g=.76$; **6-month to 12-month** $g=-.34$; and **pre-acceptance to 12-month** $g=.36$.

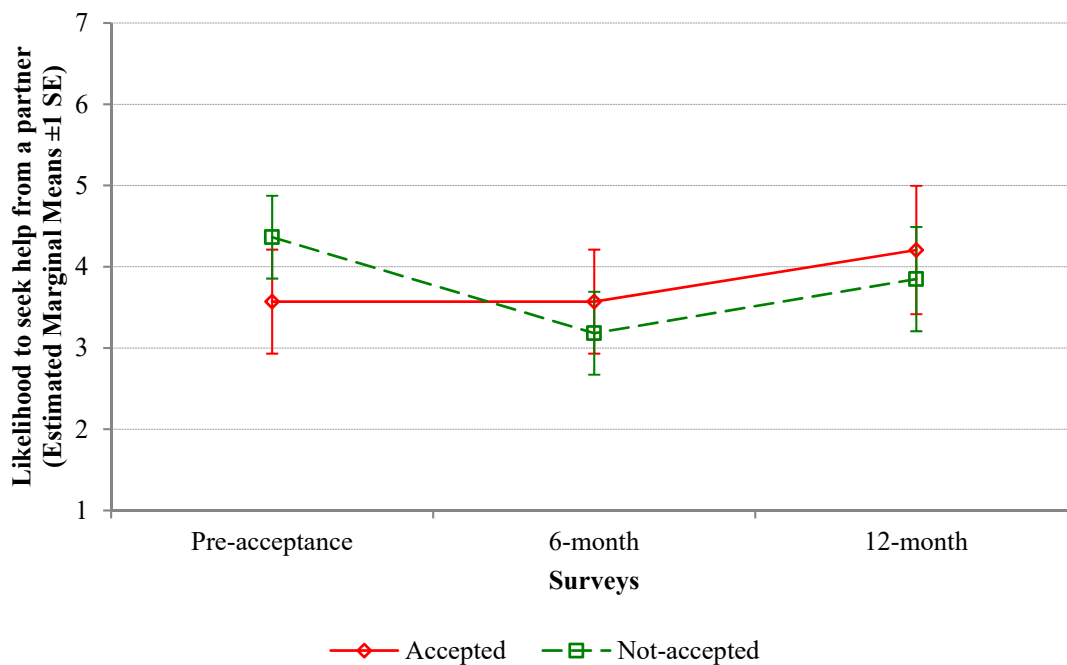


Figure 7.13 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a partner (GHSQ)

Likelihood to seek help from a phone help line

Figure 7.14 presents the mean likelihood that, at each survey, participants from each group would seek help from a phone help line. Using MRMM ANOVA, the overall interaction of YBT membership and time was found to be not significant ($F [2, 24.21] = 1.44, p = .258$). This result indicates that for phone help lines as a help seeking source, there was no significant difference in the patterns of change based on YBT membership.

The between-group effect size at 6 months was $g = .42$ and at 12 months the effect size was $g = -.73$. The within-group effect sizes for the **accepted** participants were: **pre-acceptance to 6-month** $g = -.09$; **6-month to 12-month** $g = .99$; and **pre-acceptance to 12-month** $g = -.94$. The within-group effect sizes for the **not-accepted** participants were: **pre-acceptance to 6-month** $g = .45$; **6-month to 12-month** $g = -.05$; and **pre-acceptance to 12-month** $g = -.52$.

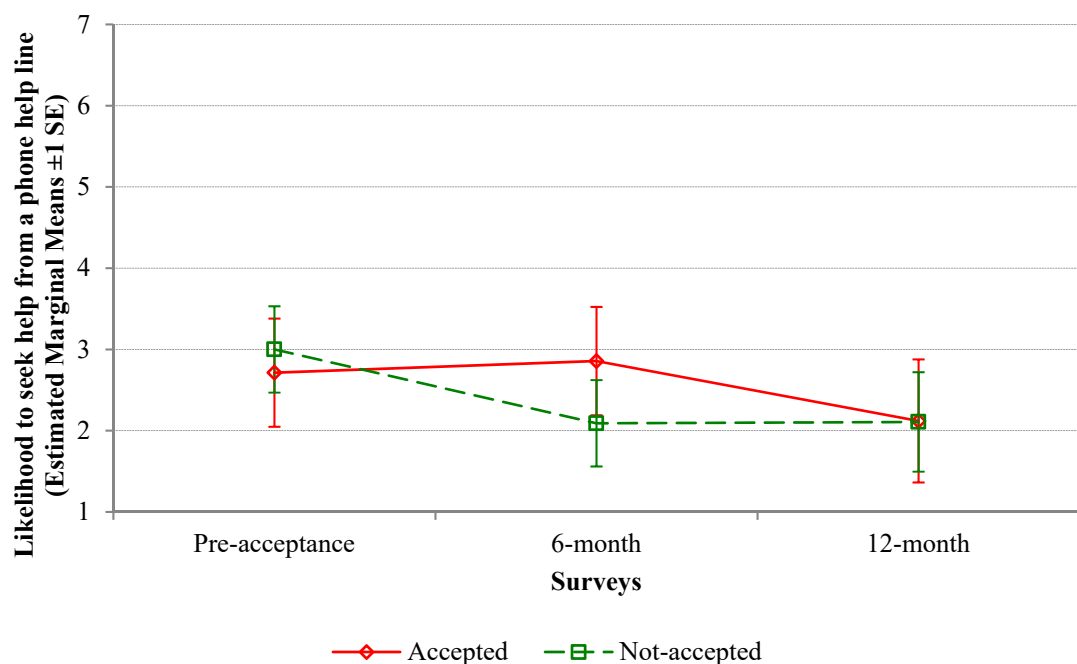


Figure 7.14 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a 'phone help line' (GHSQ)

Likelihood to seek help from a teacher

The mean likelihood that participants would seek help from a teacher at each survey is presented in Figure 7.15. MRMM ANOVA indicated that the overall interaction of YBT membership and time was not significant $F [2, 24.21] = 1.44$, $p = .258$. This absence of significant result shows that there was no significant difference in the patterns of change in likelihood to seek help from a teacher, based on YBT membership.

At 6 months the between-group effect size was $g = .95$ and at 12 months it was $g = .85$. For the **accepted** participants the within-group effect sizes were: **pre-acceptance to 6 months** $g = -.58$; **6-month to 12-month** $g = .15$; and **pre-acceptance to 12-month** $g = -.35$. The within-group effect sizes for the **not-accepted** participants were: **pre-acceptance to 6-month** $g = .19$; **6-month to 12-month** $g = -.09$; and **pre-acceptance to 12-month** $g = .12$.

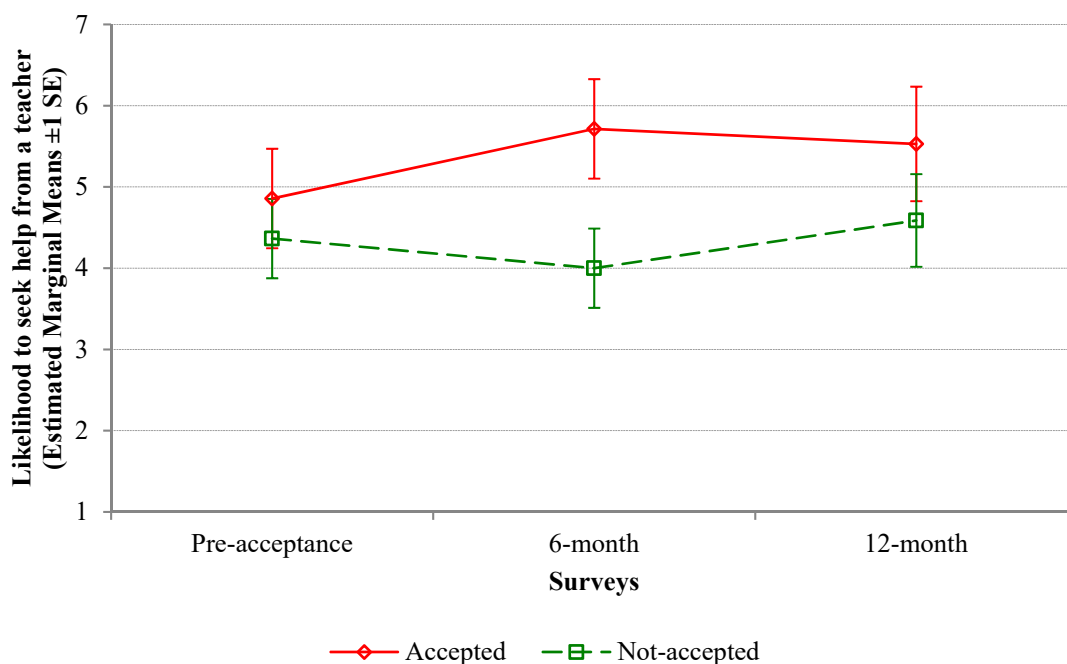


Figure 7.15 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from a 'teacher'

Likelihood to seek help from the internet

Figure 7.16 presents the mean likelihood that participants would seek help from the internet at each survey. MRMM ANOVA indicated that the overall interaction of YBT membership and time was not significant ($F [2, 23.91] = 0.08, p = .922$). This result shows that there was no significant difference in patterns of change of likelihood to seek help from the internet over time, based on YBT membership.

The between-group effect sizes were: 6 months $g = 1.05$ and 12 months $g = .38$. The within-group effect sizes for the **accepted** group were: **pre-acceptance to 6-month** $g = .34$; **6-month to 12-month** $g = .38$; and **pre-acceptance to 12-month** $g = -.60$. The within-group effect sizes for the **not-accepted** group were: **pre-acceptance to 6-month**; $g = .63$, **6-month to 12-month** $g = .12$; and **pre-acceptance to 12-month** $g = .51$.

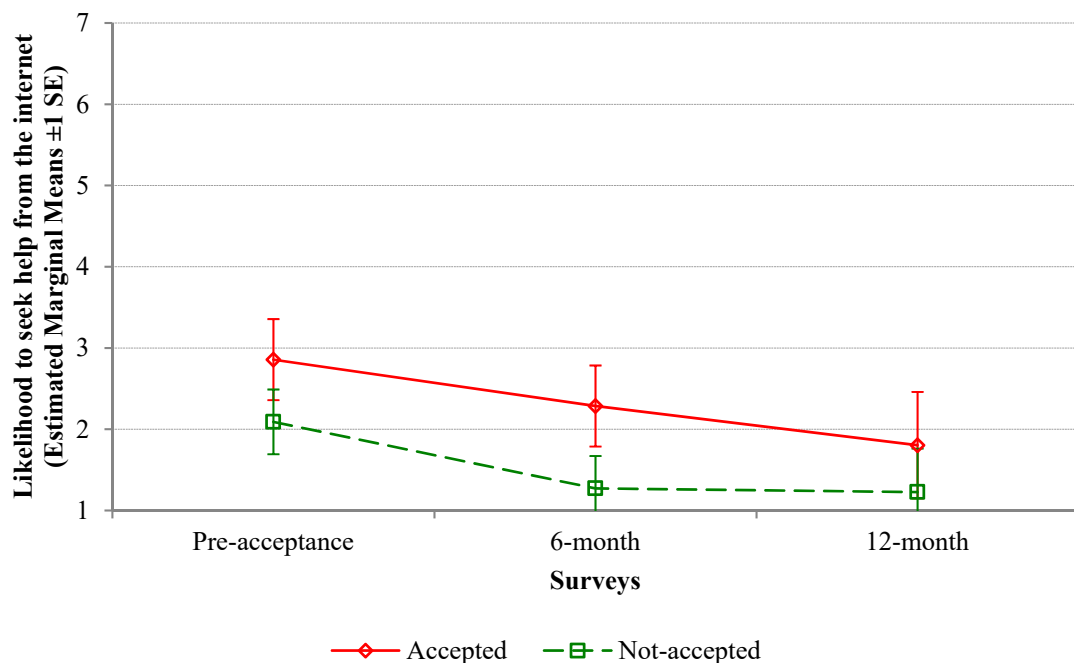


Figure 7.16 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from 'the internet' (GHSQ)

Likelihood to seek help from someone else

Figure 7.17 presents the mean likelihood that participants would seek help from someone else at each time point and how this varied between subgroups. Using MRMM ANOVA, the overall interaction of YBT membership and time was found to be not significant ($F [2, 25.38] = .44, p = .647$). This result indicates that there was no significant difference between the patterns of change of likelihood to seek help from someone else over time, based on YBT membership.

At 6 months, the between-group effect size was $g = -.01$ and at 12 months was $g = -.25$. For the **accepted** participants, the within-group effect sizes were: **pre-acceptance to 6-month** $g = .09$; **6-month to 12-month** $g = .23$; and **pre-acceptance to 12-month** $g = .30$. For the **not-accepted** participants, the within-group effect sizes were: **pre-acceptance to 6-month** $g = .58$; **6-month to 12-month** $g = -.06$; and **pre-acceptance to 12-month** $g = .48$.

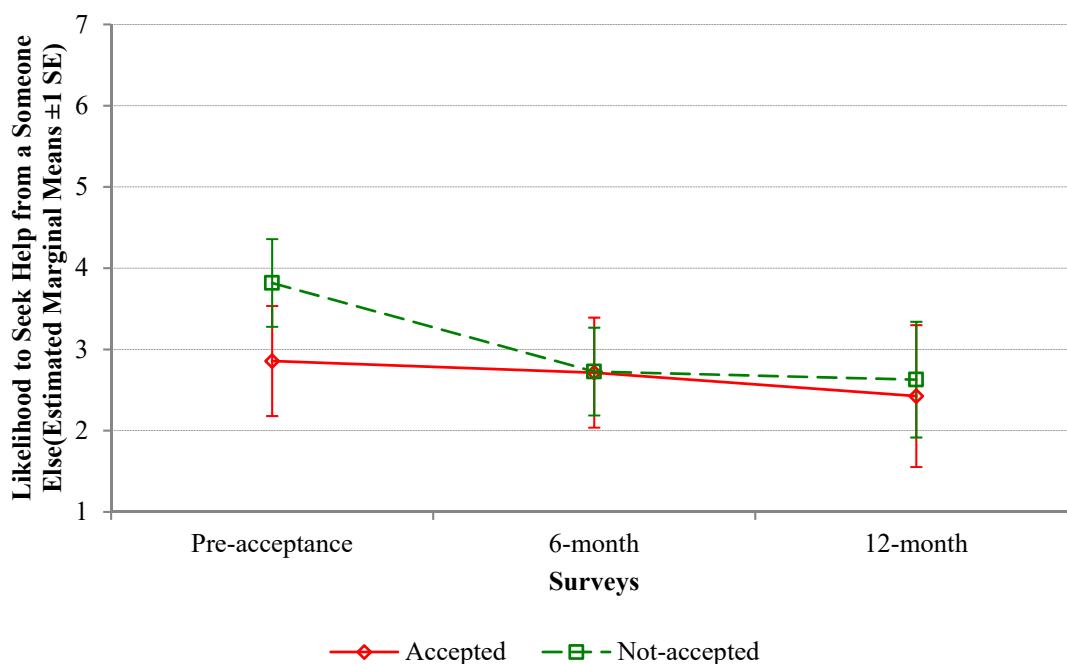


Figure 7.17 Estimated marginal means and standard errors (± 1 SE) for likelihood to seek help from 'someone else' (GHSQ)

Awareness of others' mental ill health

Figure 7.18 presents how participants' awareness of others' mental ill health changed over time and how this varied between participants who were **accepted** and those who were **not-accepted**. The figure shows that participants in both subgroups had a high level of awareness at the pre-acceptance survey.

At 6 months, the proportion of all participant groups who knew of someone who had experienced mental ill health was less than at the pre-acceptance survey. A higher

proportion of the **not-accepted** participants (82%, n=9) compared to the **accepted** participants (71%, n=5) reported that they knew someone. At 12 months only one participant, who was **not-accepted**, reported that they did not know anyone who had an experience of mental ill health.

Because of the high proportion of awareness at the pre-acceptance survey, the number of participants who could change in the anticipated direction (from not knowing to knowing) was limited and analyses were not conducted to examine change between any of the time points.

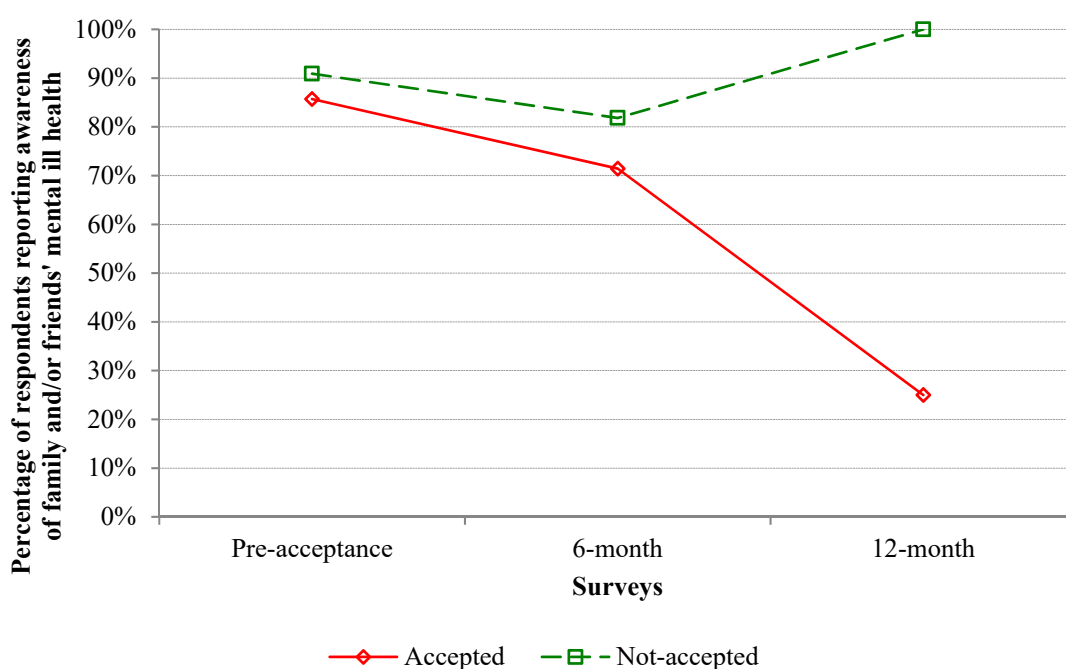


Figure 7.18 *Percentage of Respondents reporting awareness of other's mental ill health*

No significant differences were found between the proportion of participants in the **accepted** and **not-accepted** subgroups who became aware of other's mental ill health over the **pre-acceptance 6-month** period ($\chi^2(1)=.58, p=.647$) or over the **6-month to 12-month** period ($\chi^2(1)=0.74, p=.600$). No participants changed in the anticipated direction over the **pre-acceptance to 12-month** period and as a result the calculation could not be conducted.

Depression literacy

Table 7.13 presents the mean depression literacy score for the **accepted** and **not-accepted** subgroups. Figure 7.19 shows how these changed over time and the variance within subgroups.

Table 7.13 Means and standard deviations for depression literacy at pre-acceptance, 6-month and 12-month

Group	Survey								
	Pre-acceptance			6-month			12-month		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Accepted	6.7	2.6	7	7.0	2.8	7	5.5	4.9	4
Not-accepted	7.1	1.9	11	6.9	2.0	11	7.7	1.0	6

MRMM ANOVA indicated that for depression literacy, the overall interaction of YBT membership and time was not significant ($F [2, 24.57] = 1.12, p=.345$). The between-group effect size at 6 months was $g=.04$ and at the 12 months was $g=-.63$.

The within-group effect sizes for the **accepted** subgroup were: **pre-acceptance to 6-month** $g=-.11$; **6-month to 12-month** $g=.41$; and **pre-acceptance to 12-month** $g=.34$. For the **not-accepted** group, the within-group effect sizes were: **pre-acceptance to 6-month** $g=.09$; **6-month to 12-month** $g=-.44$; and **pre-acceptance to 12-month** $g=-.35$.

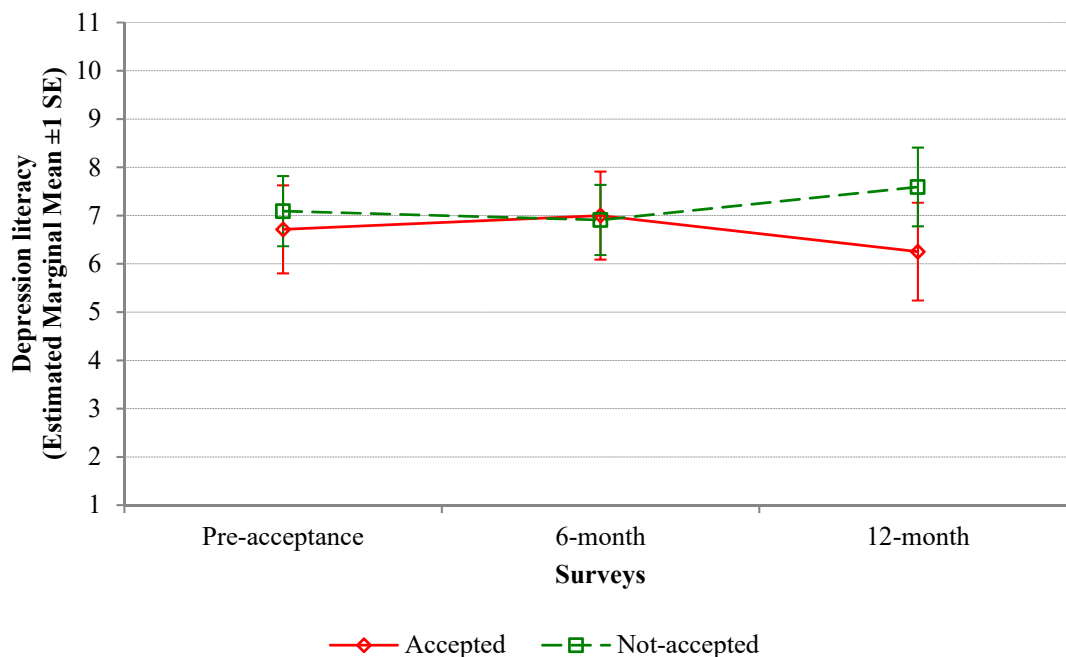


Figure 7.19 Estimated marginal means and standard errors (± 1 SE) for depression literacy

Participation with their broader communities (Civic participation)

In order to ascertain if young peoples' participation in their communities had increased because of their membership of the YBT, the number of activities they had participated in during that time were summed. This method does not show whether the young people were participating in the same activities over the six months, or the depth of their participation in a particular area, only the number of activities. What it does show is whether the number of activities increased or decreased.

Table 7.14 presents the mean number of activities participated in at each survey for the **accepted** and **not-accepted** subgroups. Figure 7.20 shows how these changed over time and the variance within subgroups.

Table 7.14 Means and standard deviations for civic participation (number of civic participation activities) at pre-acceptance, 6-month and 12-month

Group	Survey								
	Pre-acceptance			6-month			12-month		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Accepted	9.4	4.6	7	10.3	4.0	7	7.8	4.5	4
Not-accepted	7.8	3.9	11	8.4	3.5	11	7.5	3.0	6

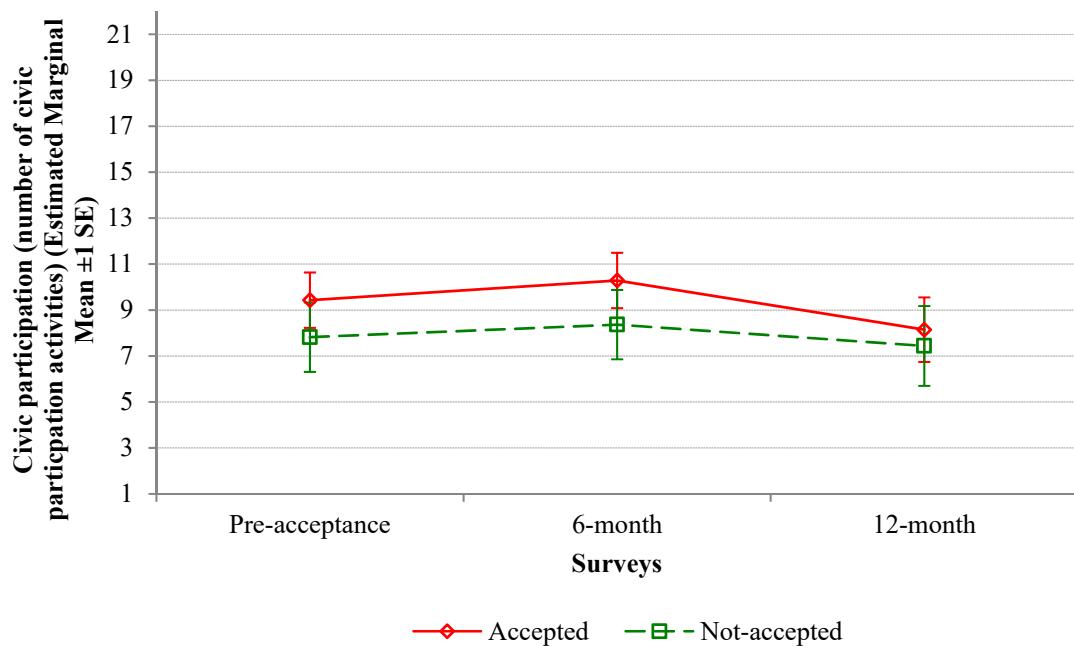


Figure 7.20 Estimated marginal means and standard errors (± 1 SE) for civic participation (number of civic participation activities)

MRMM ANOVA indicated that for the number of civic activities that young people had undertaken, the overall interaction of YBT membership and time was not significant ($F [2, 24.11] = 0.21, p = .811$). The between-group effect sizes were: 6 months $g = .50$ and 12 months $g = .06$. For the **accepted** subgroup, the within-group effect sizes were: **pre-acceptance to 6-month** $g = -.20$; **6-month to 12-month** $g = .61$; and **pre-acceptance to 12-month** $g = -.37$. For the **not-accepted** subgroup, the within-group effect sizes were **pre-acceptance to 6-month** $g = -.15$; **6-month to 12-month** $g = -.26$; and **pre-acceptance to 12-month** $g = .09$.

7.5 Discussion

The findings of this study show that applicants to youth advisory groups are similar to their peers in the Australian population on the majority of demographic

characteristics measured. The characteristics in which they significantly differ are: their experience of mental ill health, the likelihood that they have sought help for this, and their rates of tertiary education. The results of this study suggest that they do not experience improvements to their mental health or levels of civic participation, on any of the dimensions examined, as a result of being involved in a mental health research advisory group.

7.5.1 Applicant characteristics and comparison between accepted and non-accepted groups (Objective 1) and comparison of applicants to population (Objective 2)

Objectives 1 and 2 of the study examined the differences between the young people who were accepted into the YBT and those who were not, and the differences between the young people who applied and their peers in the Australian population. No significant differences were found between the accepted and not accepted groups. Significant differences were found between the young people who applied and the Australian population on three measures. These measures were the proportion of young people who had obtained a bachelor's degree, the proportion who had experienced an episode of mental ill health at some point in their lives, and the proportion who had sought help for mental ill health at some point in their lives.

This study has shown that on the majority of demographic factors, including population sub-groups, the proportion of young people who apply are not significantly different to their peers in the Australian population. The exception to this was the proportion who had obtained bachelor's degrees, which was higher in the applicant sample than the general population. As noted above, no previous work exists to which these findings can be compared. The bias toward higher rates of educational attainment indicates that young people who are interested in taking part in these groups may be more educated than the general population. This may be advantageous for researchers in general, as a university educated sample could be more likely to be familiar with academic concepts and research methods. However, if researchers require young people to provide input about a project which is to be used by the general population, this bias may be a challenge which should be considered at the recruitment stage. One way in which this could be overcome would be for researchers to ensure that they have ongoing relationships with organisations who also work with less well educated young people, or those not currently attending university. The importance of relationships such as these was identified by participants in Study 1 (university student focus groups)..

The proportion of young people who applied who had experienced mental ill health, and sought help for it, was significantly higher than the Australian population. This finding is particularly interesting given that an experience of mental ill health was not mentioned as a desirable attribute in the CRC's recruitment media. Where previous work has described the mental health characteristics of young people who apply, this has been limited to studies which have selected young people with particular mental health characteristics. These include having used mental health services and other attributes (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Monshat et al., 2012; Wadley et al., 2013). No attempt has been made in these, or other, studies to compare the young people who apply with the general population. The preceding studies in this project have suggested similar findings—young people who are interested in being involved in youth mental health research have high rates of mental ill health and help seeking (Study 1, university student focus groups; Study 2, researcher interviews; and Study 3, analysis of advisory group applications). This bias may be due to young people with these experiences being more interested in and motivated to take part in this type of work. In the future, active recruitment of individuals without these experiences would need to take place in order to rectify this situation. One option would be to ask young people with experience of mental ill health to identify others who do not and encourage them to take part. Another would be to co-ordinate with researchers in other fields to attract a less skewed group of participants. Such action may be particularly important for projects that aim to increase rates of help seeking among young people with a mental illness who have not previously sought help, or projects targeted to the general population.

An important consideration when interpreting the differences between this sample and their peers in the Australian population is whether researchers should involve young people who are suitable for the particular project they are contributing to. The additional insights and expertise which can be gained from an experienced and informed sample of participants on a key area of interest may be ideal for some researchers or purposes. A higher level of knowledge of mental ill health and help seeking may allow young people to better inform the work in which they are participating. Thus, these results should not necessarily be considered problematic, nor do they cast doubt on the output of previous research. Rather, they should be noted by researchers as a bias, and future selection processes altered or tailored if a non-targeted sample is required for a specific project. The final study in the project extends these comparisons further by comparing these results to those of young people who have

participated in their communities in other ways. The objectives of this final study include to ascertain which of these similarities or differences are attributable to involvement in youth mental health research, or other factors.

7.5.2 Young people's experiences as a result of being part of the YBT (Objective 3)

Young people's experiences of being involved in mental health research (Aim 3) was explored in this study by attempting to understand if changes that young people experienced could be attributed to their involvement in the YBT. Previous studies in the area have suggested that there are perceived changes in young people's lives as a result of their participation. However, no attempt has yet been made to use quantitative measures to ascertain if this is directly attributable to experiences of involvement. The present study attempted to do this. Given the absence of previous quantitative work in the area, the choice of measures was guided by the CRC Standard Measures, previous qualitative research in the area and the researcher's lived experience. A limitation of this lack of previous quantitative work was that some binary (yes/no) measures were used to measure change over time. This limitation is discussed further in the following section (7.5.3 limitations).

As described in detail in the following paragraphs, no significant differences were found between changes reported by the young people who were part of the YBT and those who were not. While the findings do not establish that positive changes occur on any of the dimensions examined, this absence does not necessarily indicate that young people do not experience positive changes as a result of their involvement. One explanation for this absence of statistically significant change may be because of the limited number of compulsory activities in the YBT. Due to the low intensity of young people's involvement with the YBT. The only compulsory activity for YBT members was a group weekend which occurred within the first 6 months of their year-long association. When compared with other youth advisory groups, this was a relatively low intensity experience. For example, the young people in the 'Youth Speak' advisory group met on a monthly basis to discuss research priorities, to feedback information from local and national conferences, and to collaborate with academics and clinicians (Mawn, Welsh, Stain, et al., 2015). Young people who take part in groups such as this, which offer a higher intensity of involvement, may be more likely to experience the positive mental health effects which have been reported by young people in previous qualitative work. Future studies should consider examining these groups using similar

questions and analyses to those in the present study. Such examination could ascertain if the lack of significant findings in this study was a result of the low-intensity of the intervention, or if young people's belief that they will gain positive mental health effects from their involvement is merely a perception, and not a reality.

However, while some results may be able to be explained or expanded upon if a different group is examined, or if different measures are used in future, some results in this study may also be attributable to different response biases. For example, the accepted group reported a decrease in awareness of friends' or family mental ill health between the 6 and 12 month surveys. Given the personal nature of these questions, social desirability bias may have impacted on people's responses. Alternatively, this example in particular may have been impacted by a reduced rate of engagement with the survey at the 12 month time point. As noted above, at the 12 month time point even those young people accepted into the YBT would have not had a high level of engagement with the group and may no longer have been involved with the CRC unless involved through other mechanisms than the YBT. This may have meant that they did not consider their responses thoroughly.

It was hypothesised that young people who were involved in the YBT would report that they had experienced fewer episodes of mental ill health, and that they would be more likely to report that they had sought help for it than young people who were not part of the YBT. These hypotheses were based on two areas of previous work. Firstly, the findings from the group interview described by Howe et. al., (2011) in which young people reported that their involvement had helped them to realise that other young people had been through similar experiences. Secondly, the broader involvement in mental health service delivery and research literature. Specifically, young people who had been involved in the Reachout.com Youth Participation Program associated their participation with increased understanding of when, and how, to seek help in regards to their mental health issues (Collin, Rahilly, et al., 2011). The present study is the first to try and quantitatively examine if these changes occur. Because of the limited previous work, four measures were used: actual experience of mental ill health, actual experience of help seeking, psychological distress and likelihood to seek help from specific sources. No significant effects were found, and the size of the effects ranged from very small to medium, as determined using Cohen's thresholds (1988). As discussed above, one reason for this absence of finding may have been the low intensity of the YBT. Other reasons may be attributable to the measures used, or the very low sample size.

In choosing a measure by which this can be understood in future, it may be challenging to find one which is sufficiently isolated. Consideration should also be given to when an effect is measured. For example, administering the K10 between one and three weeks after the weekend away may have provided a more accurate reflection of the impact of the YBT. In the case of ‘intentions to seek help,’ measures chosen could be based on the content discussed at the workshop or the subject of the research. One item on the GHSQ concerns help seeking from the internet, which was an attempt to ask about a source of help seeking that may have been related to the content examined or discussed by the YBT. However, the absence of any significant finding may indicate that this was not specific enough.

In previous work, young people have reported that they perceive that involvement offers opportunities to gain new skills (Case et al., 2014; S. Chen et al., 2007; Collin, Rahilly, et al., 2011; Coser et al., 2014; McLaughlin, 2011; Powers & Tiffany, 2006; Ramey & Rose-Krasnor, 2015; Tarpey, 2006). Where specific types of skills have been reported, these were related to the type of activity that young people are involved in. Young people were keen to gain research skills when offered mentoring and training through the youth advisory group described by Mawn, Welsh, Stain et al., (2015). In the present study, three areas were examined as a proxy for development of skills: activities undertaken online, knowledge of others’ mental ill health and depression literacy. While no significant differences were found between how the accepted and not accepted groups changed over time, the effect sizes for these measures ranged from medium to large. In particular, at the 12-month survey, the between-group effect size for the number of activities that young people had undertaken in the last month was very large. When considered in light of the small sample size, which limited the likelihood that a significant effect could have been found, this difference may merit future investigation. It suggests that young people who were involved did use the internet in more ways than those who were not accepted, and it is possible that this difference was related to their YBT involvement.

It was also anticipated that young people would take part in an increased number of civic activities as a result of being a member of the YBT. This was based on previous findings in which young people have reported a belief that participation will increase their involvement with their communities (Howe et al., 2011; Oliver et al., 2006). Researchers have also expressed a belief that young people will be able to increase their connections with the broader community through involvement (Powers & Tiffany, 2006). The changes over time to young people’s civic participation were analysed and

found to be not significant. Similar to the above, the absence of significant findings may be due to the relative low-intensity of the YBT compared to other youth advisory groups or involvement in research activities. For this finding specifically, this absence may be because the measure used in this study was of breadth, not depth. Being involved in a national level advisory group may have meant that young people chose to reduce the number of other activities they participated in, while deepening their involvement in a more select range of activities. If a significant effect had been found, this would have indicated that a low-intensity intervention is able to produce substantial changes to the breadth of young people's behaviour. That this was not found suggests that either such an effect cannot be produced by involvement, or that a higher intensity may be required.

7.5.3 Limitations

An important consideration when interpreting the results of this study is that they are based on one example of an advisory group. Because of this, it is important to note that the findings may not be able to be generalised to other advisory groups or uses of involvement processes. In addition, several specific limitations should be considered.

The proportion of participants who responded to the follow up surveys was low. Only 43.2% and 22.7% of respondents to the pre-acceptance survey responded to the 6 and 12-month surveys respectively. While the mixed model repeated measures analyses used are flexible enough to still be robust when used with high levels of missingness, these small sample sizes may have limited the ability of the analyses to detect change. One reason for the low follow-up rates may have been the ethical requirement to mediate the researcher-participant relationship through a third party, which constrained the ability for follow-ups to be made. Had greater effort been able to be expended in following participants up, higher numbers may have responded to the 6 and 12-month surveys.

The measures used to detect change over time were chosen based on previous qualitative, not quantitative, findings. One impact of this was that the measures were general in nature and may not have been specific enough to detect small amounts of change over time. For example, the K10 measures distress in the month preceding the survey. Given the low intensity of the intervention, this period may have been inappropriate. Future work should take these findings into consideration when choosing both measures, and when to deliver them. Another impact of this is that some of the change over time measures were based on binary (yes/no) responses. For example,

participants who responded ‘no’ at one time point and ‘yes’ at another to the question about experience of mental ill health were concluded to have experienced an episode of mental ill health. Had continuous measures been used for these dimensions, the conclusions could have been drawn with more confidence.

When the Likert scale for the Mental Health Continuum Short form was entered into the online software used to administer the survey, the same label was entered for two of the options. Participants’ intended meaning when they responded was thus unclear; as a result, the scale could not be analysed. This scale is a dimensional measure of young people’s wellbeing, and as such may have shown more nuanced changes over time to their experience of mental ill health than the categorical questions analysed.

The version of the BFI which was used in this study is the shortest available version. While the scale has acceptable psychometric properties, and the short length contributed to reducing participant burden in this study, the creators of the scale note that this version of the scale has less validity than the standard 40-item version (Rammstedt, 2007).

7.6 Summary

The fourth study in the YIMHR project has shown that young people who apply to take part in a youth involvement advisory group are statistically significantly more likely to have had an experience of mental ill health, and have sought help for this experience, than the comparable Australian population. Those who are accepted to be part of high level governance groups do not report that they have changed through their experience.

The findings from this study will help address concerns about the breadth of young people who are involved in youth mental health research, by discerning specific areas in which these biases may occur. The implication of these findings is that researchers can counter existing biases by actively seeking and selecting participants who do not have these characteristics. Where this is not feasible, they should attempt to use other mechanisms, such as comparing their findings with other studies, to ensure these biases do not have a significant impact on their work. The findings also help demonstrate that, if researchers wish to provide young people with an experience which changes them, they may need to focus on creating opportunities which are intensive or provide specific training to develop young people in particular ways.

8 Study 5 Survey of community members

8.1 Introduction

8.1.1 Overview

The preceding four studies in the Youth Involvement in Mental Health Research (YIMHR) project have established that young people who are involved in youth mental health research have a broader range of characteristics, motivations and experiences of involvement than have been previously documented. The final study in the project builds on these findings. It compares the young people who have been involved in research and their communities with their non-involved peers on measures of their characteristics, attitudes to and knowledge of depression, and the reasons that they choose to be involved or volunteer in other ways. It also examines the experiences of the young people who were involved in the work of the Young and Well CRC (the CRC) in detail.

The CRC, as described in Section 3.3, was an overarching research organisation which funded and coordinated 31 research projects conducted by universities and industry across Australia. All of the projects involved young people who were between the ages of 12 and 25, and conducted research in the areas of young people, technology, and wellbeing. As one of the four ‘pillars of success’ of the CRC, it was an expectation that youth involvement was to be part of all of the research projects in the CRC.

This study contributes to all three of the project aims. The characteristics and motivations of young people who were involved in the work of the CRC are compared to those who are involved or participate in their communities in other ways (Aims 1 and 2). The experiences of young people who self-reported that they had been involved in the CRC are explored through an analysis of their experiences (Aim 3).

The study explored these aims through three objectives. These objectives, and the measures used to explore them, can be seen in Figure 8.1 below. The measures are described in detail in Section 8.2.5.

	YIMHR Project aim	Objective	Measures
1	To identify the characteristics of young people who are involved in youth mental health research, to compare these with other young peoples' characteristics, researchers' beliefs about these characteristics	To understand how young people who are involved in the CRC differ from other young people	• Participant characteristics • Experience of mental ill health
2	To compare the self-reported motivations of young people involved in mental health research to both researchers' perceptions of these motivations and the motivations that other groups of young people report for similar activities	To compare the self-reported motivations of young people involved in the CRC to the motivations reported by young people who take part in research and who are involved and participate in their communities in other ways	• Volunteer Functions Inventory sub-scales • Self-reported reasons for volunteering
3	To compare young people's actual and desired experiences of involvement in mental health research, and to compare this with how researchers involve young people	To describe the experience of young people who were involved in the CRC and to show how this differed from how they would have liked to be involved	• Questions about young people's involvement with the CRC

Figure 8.1 Alignment of objectives and measures to YIMHR project aims

The findings from the study will contribute to improvements in the practice of youth involvement by providing assurances as to the adequacy of current recruitment practices and insights into the motivations of young people. Researchers can use these results to optimise the recruitment of young people. It will help by providing suggestions as to which research stages and media young people desire to be involved in and thus improve their experience of being involved. The present chapter follows the same structure as the preceding four chapters – the design of the study, analysis, and results are described. The chapter concludes with a discussion of the findings of the study.

In addition to the findings of the previous studies, the present study draws on a range of the areas which were reviewed in Chapter 2. Firstly, the demographic characteristics of young Australians, including their mental health and volunteering (Section 2.2). Secondly, the characteristics, motivations and experiences of consumers and young people who are involved in research and mental health service delivery (Section 2.5), and the characteristics, motivations and experiences of young people who are involved in mental health research specifically (Section 2.6).

8.1.2 Study rationale

Previous work which has described the young people who are involved in mental health research, their motivations and their experiences is limited. In particular, to date no attempt has been made to compare the characteristics or experiences of young people who are involved in mental health research with those in their broader communities.

Where previous work has directly focused on young people's involvement in research and mental health service delivery, including mental health research, this has predominately been via studies which have reported on one instance of involvement. While these findings provide a useful basis for understanding young people's involvement in mental health research, a wide range of areas remain under-examined. These include how the young people who choose to be involved in youth mental health research are different to other groups in the Australian population (Objective 1); why young people volunteer in mental health research specifically (Objective 2); and what young people's experiences of being involved are, and how this differs from their desired experiences of being involved (Objective 3). It is therefore clear that further research is required to address these limitations in the extant literature. The present study aims to address this gap by collecting primary data from young people from both the general population and those who have been involved in mental health research. The data collected addresses their characteristics (Aim 1), motivations (Aim 2), and when they have been involved in mental health research, their experiences of being involved (Aim 3).

8.2 Design

8.2.1 Choice of method

To meet the proposed objectives, a method was required which could access a large sample of young people from a variety of backgrounds, including young people

who had previously been involved with the CRC. It also needed to preserve the anonymity of participants.

Online cross-sectional surveys allow for larger populations to be sampled than alternative methods, particularly paper-based or qualitative methods (deVaus, 2002). This facet allowed the large target group—all young people in Australia aged between 18 and 25, including the young people who had been involved in the CRC (estimated to be 1000)—to be accessed.

Cross-sectional surveys allow for the use of statistical significance tests through which formally stated hypotheses can be tested (J. Chen, Kingston, Tiemann, & Gu, 2010). This aspect was used to ascertain if the CRC group was significantly different to the broader population on a range of pre-determined characteristics. These comparisons enabled the work of previous studies and the broader literature to be built upon.

Finally, online surveys reduce the likelihood that participants will be able to be identified (deVaus, 2002). As was the case in all studies in the project, the potential pre-existing relationship between some of the potential participants and the researcher made this factor a relevant consideration, as participants may have responded differently if they believed that they could be identified.

8.2.2 Human Research Ethics Approval

The Australian National University's Science and Medical Delegated Ethics Review Committee approved the ethical aspects of this study (Approval number 2014/569, see Appendix 8.1).

8.2.3 Participant selection

There were two target participant groups for the study: young people aged 18 to 25 years who resided in Australia and had been involved in the CRC (**CRC**), and those who had not been involved in the CRC (**non-CRC**). The following section describes how an estimate of the number of young people who had taken part in CRC projects was derived. The methods used to recruit the both the **CRC** and **non-CRC** young people to the study are described in Section 8.2.4.

The CRC was an organisation which worked with and funded a collective of investigators to research young people's mental health, wellbeing, and technology use. As noted in Section 3.3, the degree to which individual research projects interacted with, or were supported by, the CRC head office varied considerably between projects. This variation had two implications for the current study. Firstly, projects differed in

how they interpreted the direction from the CRC head office to involve young people throughout their work. While all project plans, which were submitted to the CRC head office for approval prior to funding being released and work commencing, had youth involvement as a critical component, the extent to which this occurred in practice varied between projects. Secondly, the loose collective structure of the CRC meant that at the planning stages of the YIMHR project the CRC head office was only able to provide an estimate of the number of young people who had been involved in youth involvement activities of the CRC.

Thus, in order to recruit young people who had been involved in the CRC into the current study, a series of investigations were required to ascertain the number involved, and through what mechanisms they had been involved. In order to reach the broadest range of young people who had been part of the CRC in any way, the more general terms ‘participation’ and ‘volunteering’ were used instead of ‘engagement’ or ‘involvement.’ These terms were used when communicating with CRC researchers about the study and within the text of the survey itself.

The first stage involved emails sent by the head of CRC Projects and Partnerships to the lead researchers for each of the CRC projects (see Appendix 8.2), as identified on the CRC website. These emails introduced the researcher (RR) and asked for any details of the study which were unclear from the CRC website, or about which there was perceived ambiguity. The details of this investigation are shown in Figure 8.2.

This exercise identified that participants from eight of the 31 projects of the CRC would not be able to be included in the study. This was either because the study had not commenced recruitment and was unlikely to in the period that the survey was being conducted (n=1); the participants in the study were all under 18 years of age (n=3); or because the project had not collected participants’ details (e.g. had used an anonymous, online cross-sectional survey) (n=4).

8.2.4 Recruitment

Recruitment of the CRC participant group

The 23 projects in the CRC which had involved young people over the age of 18 years, and had been designed in such a way that the young people involved could be recontacted, were included through to the next stage of investigation. At this stage, prior to Human Research Ethics Committee (HREC) approval being sought, an ethics expert was consulted about how to best approach the ethical challenges posed by the study. Specifically: of contacting young people, who had previously been involved in CRC

projects, to invite them to participate in the current study. It was suggested that for each project in the CRC with existing ethics approval, a variation would need to be sought from the committee which had provided it to allow an invitation e-mail to be sent to the participants. The application to the ANU Science & Medical Delegated Ethics Review Committee (DERC) for the survey included this detail. The DERC approval required that variations to other universities' ethics protocols also be approved by the chair of the DERC, prior to submission to the original approving committee. Thus, participants were only recontacted after approval from both the DERC and, where applicable, the original HREC had been granted.

Following ethics approval, an email was sent to the lead researchers of the 23 CRC projects which were considered at this stage. This email was accompanied by an email from the head of CRC Projects and Partnerships to indicate the support of the CRC head office. Seventeen researchers responded to this email or a follow up email. The results of this investigation are outlined in Figure 8.2 and below.

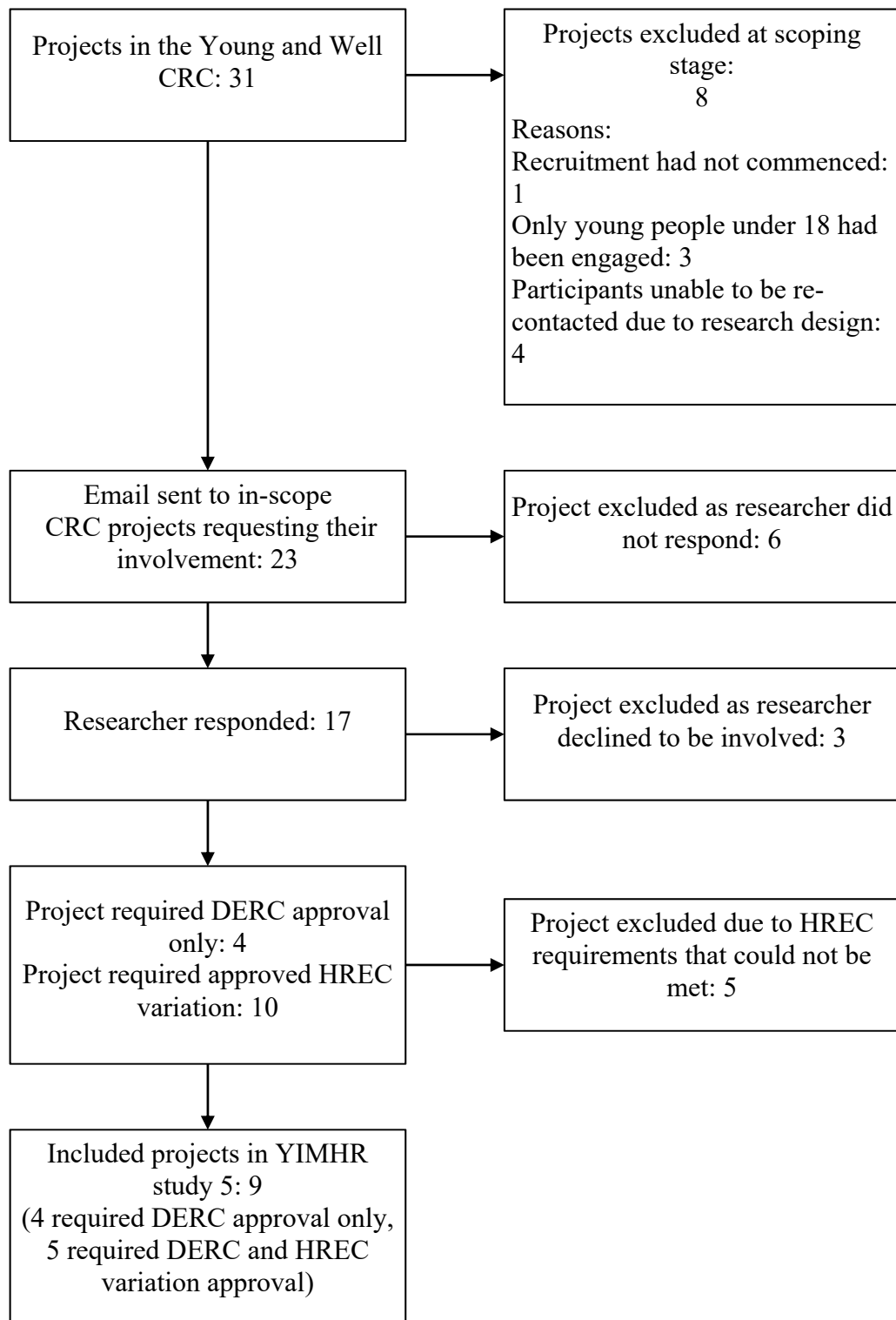


Figure 8.2 Recruitment of CRC projects to survey of community members

The lead researcher on three of the projects declined to take part in the study. Of the 14 remaining studies, four industry-led projects had not used an HREC approval process. This absence of prior approval allowed young people who had been involved to be recruited to the present study based solely on the DERC approval.

Ethics variations were submitted by the researcher to the approving HREC for the remaining ten projects. In five cases, the committees approved these variations, and in the other half they were rejected, and the committees requested that full applications be submitted. Full applications were outside the scope and means of the current project; they would have incurred costs to the project which were outside of available resources and required the time and cooperation of the original researchers. In total, nine of the 31 CRC studies were included in this study. The number of young people who had been involved in these nine studies was not disclosed to the researcher by the project investigators.

Following inclusion of the CRC studies into the present study, a survey URL was sent to the potential participants. In the majority of cases this was done via email; however, for participants from one study the link was sent via SMS, as mobile numbers not email addresses, had been collected.

Recruitment of the non-CRC participant group

Concurrently to the above, young people who had not been part of the CRC, the **non-CRC** participant group, were recruited. A probability sampling strategy was not practical for this study due to financial and other limitations. A four-arm snowball sampling strategy was used. The arms of the strategy were:

1. Distributing the survey via Facebook pages liked by Australian peak youth organisations (see below)
2. Distributing the survey via posts on the study's Facebook page
3. Distributing the survey to the researcher's Facebook friends
4. Inviting survey participants to share the survey with their friends

These four arms of the snowball strategy are described in order in the following section.

The following eight Australian peak youth organisations' Facebook pages were identified in September 2014, and the 638 Facebook pages that they had liked were compiled to create a list of organisational pages relevant to Australian young people.

- Youth Affairs Network of Tasmania
- Youth Action and Policy Network NSW

- Northern Territory Youth Affairs Network
- Youth Affairs Council of Western Australia
- Youth Affairs Council of South Australia
- Youth Coalition of the ACT
- Youth Affairs Council Victoria
- Australian Youth Affairs Coalition

Thirty-four organisations were excluded at this stage, as they were either: not Australian-focused (24 organisations), not youth focused (five organisations), or they lacked contact information (five organisations). The remaining 602 organisations were contacted by either email or Facebook messaging. Of these, 91 pages replied within four months of the initial messages saying they would share the survey, five requested that the researcher post it to their pages and twelve shared it with non-Facebook networks. This process is shown in Figure 8.3.

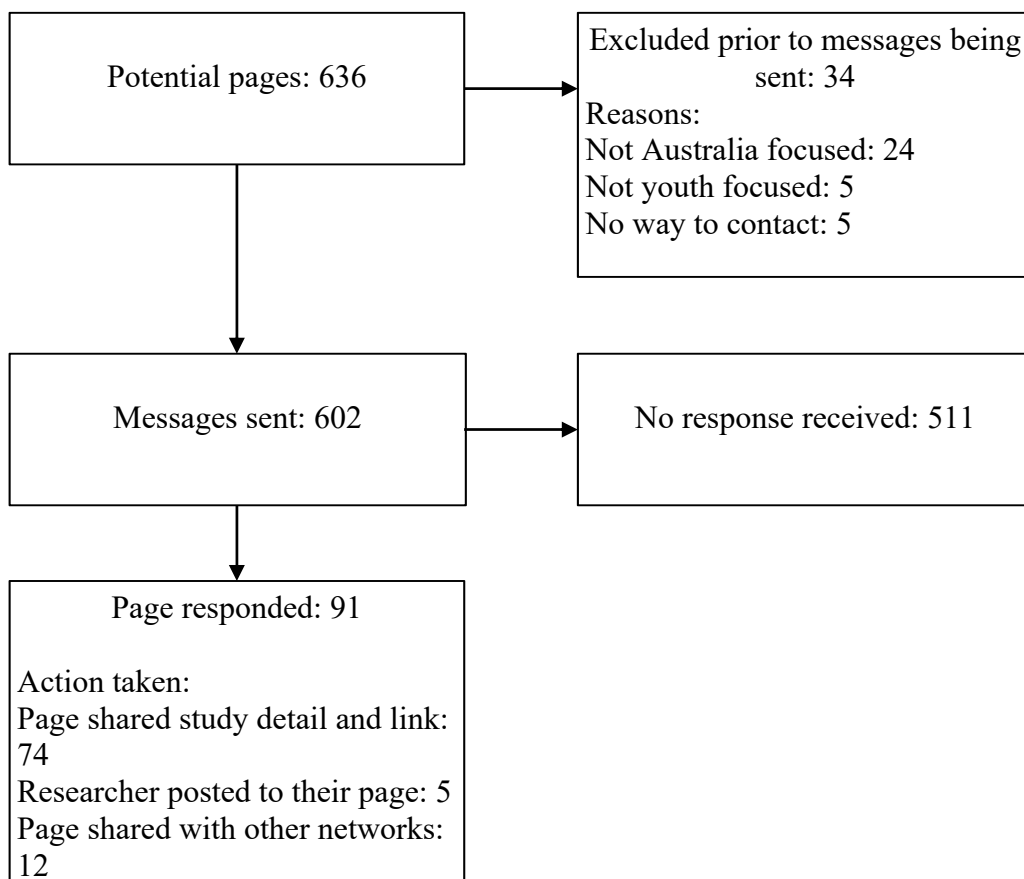


Figure 8.3 Recruitment for survey of community members - flow chart of results of contacting the Facebook pages liked by youth peak bodies.

A Facebook community page was used to facilitate the above strategies and to extend the potential reach of the survey (Figure 8.4). This page displayed six rotating

posts, posted at approximately two-day intervals from October 2014 to May 2015 (Figure 8.5).



Figure 8.4 Screenshot of the about section of the survey of community members Facebook page



Figure 8.5 Screenshots of the text of the six posts employed in the recruitment phase for the survey of community members Facebook page

The researcher's Facebook friends who fulfilled eligibility criteria (aged 18- 25 years and located in Australia) were sent an invitation by the researcher to complete the

survey, share the survey on their Facebook page, and/or share it to any Facebook groups or networks to which they belonged. The message text can be seen in Appendix 8.3. A total of 198 friends were identified and messaged in October 2014. Of these, 53 shared the survey on their page within three weeks of the message being sent.

The final element of the snowball sampling strategy was a message which appeared on the final page of the survey. This message asked participants to share the link to the survey with two or three of their eligible friends.

Participants provided indicated consent to participating by clicking ‘agree’ to a statement that they had read and understood the study’s information sheet and agreed to the risks involved in their participation.

8.2.5 Measures

The information sheet for the study can be found in Appendix 8.4. The full text of the survey can be seen in Appendix 8.5. The questions asked are described below. Their relationship to the project aims, study objectives, and measures is shown in Figure 8.1, above.

The surveys were piloted with other researchers, including the supervisory panel. The results of this pilot found that the measures were acceptable in length, and that the content made sense to the researchers.

Participant characteristics

Young people’s age (open-ended numerical) and gender (‘male’, ‘female’, ‘other’) were recorded to ascertain if there were any biases in the groups, and to allow the data to be compared to other populations. The wording and categorical response options for gender were drawn from the CRC Standard Measures (Young and Well Cooperative Research Centre, 2013).

The postcode of the respondent’s usual residence was measured (open-ended numerical), to enable classification of their remoteness based on the Australian Statistical Geography Standard (Australian Bureau of Statistics, 2013). The Standard classifies postcodes into major cities, inner regional, outer regional, remote, and very remote. For the purpose of analysis, this categorical variable was grouped into ‘major cities’ and ‘other areas’ because of a strong bias toward major cities in the responses.

Cultural diversity was measured by asking whether English was the only language they spoke (‘yes’, ‘no’), and if not, which other languages they spoke (open-ended). In addition to this, participants were asked whether or not they were a member of a range of population subgroups identified by the CRC as being of interest to the

organisation. Participants indicated if they were a member of each of the following groups ('yes', 'no'). The wording of these categorical variables was drawn from the CRC's Standard Measures.

- Carer
- Having a chronic illness or disability
- Being from a culturally and linguistically diverse background
- Having an experience of homelessness
- Speaking a language other than English
- Identifying as Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI)

Educational attainment

The measures used to ascertain participants' educational attainment were: their highest level of educational attainment ('no formal education', 'completed or partially completed primary school', 'completed or partially completed junior high school (years 7-10)', 'completed or partially completed senior high school (year 11 and 12)', 'certificate or diploma', 'degree', 'post graduate diploma, masters or PhD', 'no answer') and the highest level of educational attainment of all the people in their home (same categories as previous question). They were also asked about the main activity that they were undertaking at the time ('full time work', 'home duties', 'student attending school', 'student attending university'). As above, the wording of these measures was drawn from the CRC's list of Standard Measures and all were constructed as categorical variables for the purpose of analysis.

Technology use

Participants' technology use was measured using questions from the CRC Standard Measures. The questions used were:

- How often do you use the internet? ('every day or almost every day', 'once or twice a week', 'once or twice a month', 'less than once a month')
- Which of the following technologies do you use on more or less a daily basis ('a smart phone', 'a television', 'other handheld portable device')

Activities undertaken online

The number and type of activities that young people had undertaken online in the previous month were recorded using a question drawn from the CRC Standard

Measures (Young and Well Cooperative Research Centre, 2013). The text of the question was: ‘please select from the following list all the things that you have done online in the past month?’ (e.g. ‘accessed chatrooms’, ‘played games online’, ‘accessed pornography’). For the purpose of analysis and reporting, items were grouped into the same categories as Study 4 (see Section 7.2.5, measures).

Experience of mental ill health, help seeking and knowledge of others’ mental ill health

Participants were asked a series of researcher-devised questions about their experience of mental ill health. These questions were:

- Have you ever had mental health or behavioural issues? (‘yes’, ‘no’)
- Have you sought help for a mental health or behavioural problem? (‘yes’, ‘no’)
- Have any of your close friends or close family members ever sought help for a mental health or behavioural problem? (‘yes’, ‘no’)

Depression Literacy

Participants’ depression literacy was measured using the short-form 11-item version of the Depression Literacy Scale (D-Lit) (Griffiths, Jorm, et al., 2004; Gulliver et al., 2012). An example of an item from this scale is: ‘People with depression should stop taking antidepressants as soon as they feel better.’ Possible scores on the scale range from 0 to 11, with higher scores indicating higher depression literacy. Psychometric properties of the shortened version of the scale have not been published. However, the 22-item scale has been reported to have good internal consistency ($\alpha = .71$; Griffiths et al., 2008; Griffiths, Jorm, et al., 2004). The Cronbach’s alpha for the scale in the present study was 0.617 ($n=625$). As occurred in the previous study, this was lower than the conventionally accepted threshold of 0.70. This lower coefficient level was considered to be acceptable for two reasons: lower coefficient levels can result from shorter scales (Cortina, 1993; Lance et al., 2006); and, based on a visual inspection of the data, the data were deemed to be sufficiently internally consistent for the results to be a reflection of participants’ depression literacy.

Depression stigma

Depression stigma was measured using a shortened version of the personal subscale of the Depression Stigma Scale (DSS; Griffiths et al., 2008; Griffiths, Christensen, et al., 2004). Examples of items on the scale include ‘Depression is a sign

of personal weakness' and 'Depression is not a real medical illness.' Responses to the scale are measured on a five-point scale ranging from zero, 'strongly disagree' to four, 'strongly agree.' Scores on the shortened scale used a range from 0-28. Higher scores indicate higher levels of depression stigma. Items eight and nine of the scale ('I would not employ someone if I knew they had been depressed'; 'I would not vote for a politician if I knew they had been depressed') were removed as they were considered to be of limited relevance to young people. The use of short forms of scales result in lower Cronbach's alpha values than those attained when the full forms of scales are used, even if correlation is identical across all items (Cortina, 1993). Applied to the DSS, the exclusion of the two items above, which have a higher reported correlation compared to the remaining items (Griffiths, Christensen, et al., 2004), would further reduce the alpha values for the DSS relative to studies utilising the full form of the scale. In the present study, a Cronbach's alpha of 0.72 (n=627) was found. The attained value for alpha was considered acceptable in light of the above, and when compared to previously reported values for the scale ($\alpha = 0.72-0.82$; Griffiths et al., 2008; Griffiths, Jorm, et al., 2004).

Research experience

All participants were asked about their experience of participating³ in research other than with the CRC, in the last three years (the duration of the CRC at the time of the survey). The question asked, 'have you participated in research other than with the Young and Well Cooperative Research Centre in the past 3 years?' Where participants responded 'yes' to this question, they were presented with an open-ended question asking them to provide any further details they remembered.

Civic participation

Young people's participation in their communities was measured using the Civic Participation Scale as in Study 4 (Vromen 2003; Section 7.2.4). The scale consists of 22 types of civic participation or types of community groups. Participants select as many of the following options as apply to them. The options presented were the same as Study 4 (see 7.2.5, measures).

³ In order to be as inclusive of experiences of involvement, engagement and participation as possible, the term 'participation' was used. This was thought to be the term which participants would be most familiar with, and thus would cause the least confusion.

Volunteering motivations and experience

Participants who had indicated that they had been involved with the CRC, participated in research other than the CRC, or had taken part in at least one of the civic participation scale items were asked about their motivations for, and experience of, volunteering. Participants who had not done any of these things were asked about their reasons for not volunteering.

The Volunteer Functions Inventory (VFI) was used to investigate the extent to which participants felt that they were motivated to volunteer. The VFI is the most widely used standardised instrument to assess volunteer motivation (Chacón, Gutiérrez, Sauto, Vecina, & Pérez, 2017; Clary et al., 1999). It was originally developed to examine why some people volunteer and others do not. The factors were derived from a review of previous research into people's motivations for volunteering and a consideration of the activities undertaken by volunteers when they volunteer. The functionalist approach, which underpins the scale, involves inquiring about people's motivations from the point of view of the personal and social processes that initiate, direct and sustain action. It posits that different people who take part in the same volunteering activity are motivated by a range of different factors. The creators of the VFI, Clary and Snyder (1999) describe the factors as:

- Career motives —the volunteer has the goal of gaining career-related experience through volunteering
- Enhancement motives— the individual is seeking to grow and develop psychologically through involvement in volunteering
- Protective motives— the individual uses volunteering to reduce negative feelings, such as guilt, or to address personal problems
- Values motives— the person is volunteering in order to express or act on important values, such as humanitarianism and helping the less fortunate
- Social motives— volunteering allows the person to strengthen their social relationships
- Understanding motives —the volunteer is seeking to learn more about the world and/or exercise skills that are often unused

The VFI is available in a number of forms ranging from 13 items to 30. The 13-item version was chosen for its brevity and the consequent reduction in participant burden. In this version of the scale, four items contribute to the 'career' factor, three items contribute to the 'understanding' factor and three items to the 'values' factor. The

‘enhancement’, ‘social’ and ‘protective’ factors are based on one statement each. Seven-point Likert scales are used to measure how important each statement is to participants, ranging from ‘not at all important’ to ‘very important’, with higher scores indicating greater importance. In order to simplify the scale, in this study a 1 (‘not at all important’) -5 (‘very important’) Likert scale was used.

The psychometric properties of the 13-item scale have not been published. However, the 30-item version of the scale has good internal consistency, with the Cronbach’s alpha coefficients reported for each of the scales by Clary et al., (1999) as follows: ‘career’ $\alpha=.89$, ‘enhancement’ $\alpha=.84$, ‘protective’ $\alpha=.81$; ‘social’ $\alpha=.83$, ‘understanding’ $\alpha=.81$, and ‘values’ $\alpha=.80$. In the present study the factors measured by more than one item had acceptable internal consistency with Cronbach’s alpha coefficients of ‘career’ $\alpha=.73$ ($n=585$), ‘understanding’ $\alpha=.73$ ($n=585$), and ‘values’ $\alpha=.84$ ($n=577$).

In addition to the VFI, three open-ended questions were asked about participants’ reasons for volunteering or not volunteering. These researcher-devised questions asked participants to indicate:

- Which organisations have you been involved with?
- What are your reasons for volunteering?
- What are your reasons for not volunteering?

The first and second of these questions were presented only to participants who had volunteered, and final question was presented only to participants who had not volunteered.

CRC involvement

Participants’ previous experience with the CRC was examined using a series of researcher-devised questions. The first question in this series was used to establish whether or not survey participants had taken part in the CRC or any of its projects. Participants were provided with a list of the CRC projects to assist them in identifying if they had been involved with any of these projects. As in the above questions, the term used in this question, ‘volunteered,’ was broad in order to recognise and account for young people’s differing understanding of involvement. This list was developed using the CRC website and was reviewed by members of the CRC head office who provided amendments. The results of this question were used to group the sample into those who had participated in the CRC, and those who had not.

Using survey skip logic, the remaining questions in this series were asked only of participants who had indicated that they had volunteered with the CRC. These questions examined three areas:

- Their experience of involvement
- Their desired experience of involvement; and
- The use of technology as part of their involvement

The content of the questions was informed by the Reachout.com's Youth Participation Program (Collin, Rahilly, et al., 2011) and an internship evaluation questionnaire developed by the CRC head office (Young and Well Cooperative Research Centre, 2014).

Participants were asked about which stages of research ('deciding what to do', 'deciding how to do it', 'doing it', 'interpreting the findings', 'writing a scientific report on the findings', 'letting the community know the results') they had been involved in and which they would have liked to be involved in. These stages of research were derived from the cycle of consumer participation⁴ in research described by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia in the Model Framework for Consumer and Community Participation in Health and Medical Research (National Health & Medical Research Council and the Consumers Health Forum of Australia, 2005).

They were also asked about the media through which they were involved ('face-to-face', 'online', 'on the phone', 'other'), how many times they were involved in the research (open-ended) and what their involvement entailed (open-ended).

Young people's subjective experiences of being involved were measured through a series of statements about how they had been involved, which were based on the CRC's intern evaluation questionnaire (Young and Well Cooperative Research Centre, 2014). The items on the scale were:

- Support for my participation was given in an approachable and available manner
- I had a clear understanding of my project and my role

⁴ The term participation when used in the NHMRC and CHF model framework connotes a similar level of activity to the meaning of 'involvement' as used by INVOLVE UK and in this thesis.

- I was able to access the people and resources I needed to complete my participation activities
- I knew who to ask for assistance when I needed it
- There was enough flexibility in my participation to allow for unexpected changes in my work or personal life
- I was included in relevant staff activities
- I felt like a member of the project team
- Overall I had a positive experience during my participation

Participants responded using a 5-point Likert-scale ranging from ‘strongly disagree’ (1) to ‘strongly agree’ (5). An open-ended item was included at the end of the scale to allow participants to contribute any further comments regarding their experience of being involved.

The final set of questions in this group examined how technology had been used in their experience of being involved because of the technology-focused nature of the CRC. These questions included ‘do you think technology could have been used differently to improve your experience?’ (‘yes’, ‘no’) and ‘how was technology used to help you participate’ (open-ended).

8.3 Analysis

8.3.1 Overview

Data from the survey were analysed using SPSS v 23 for Mac (IMB Corp, 2015). Only surveys that had been formally submitted were included in the analysis. The following section describes the approach taken to analysis. The objectives which guided the analysis, and the measures which related to them, are described in Figure 8.1.

As described in Section 8.2.5 (Measures), the majority of variables employed were categorical (e.g. experience of mental ill health, membership of population groups). Four measures (D-Lit, DSS, the VFI and the CRC experience of involvement scale) used Likert scales and four questions were open-ended (e.g. reasons for volunteering).

The sample was grouped into the researcher-devised **hierarchy of participation**, which is described in Section 8.3.2 below. Participants in each of the groups on the hierarchy were compared to one another. Where significant differences were found, further investigation was conducted as described below.

The data were treated as normal based on visual inspections of the variables and an application of the central limit theorem which suggests the sampling distribution of large samples (>200 cases) approaches normality (Tabachnick & Fidell, 2013).

The proportion of missing data was examined for each variable during data screening and checking. Missing data ranged from 0-4% per item. This range is below the threshold of 5% suggested by Tabachnick and Fidell (2013) at which missingness is likely to have a large influence on results. Consequently, no further analyses were conducted to identify or substitute missing data.

8.3.2 Grouping of participants

The original design of the study involved grouping the sample into young people who had been involved with the CRC (**CRC**), and the remainder of the sample (**non-CRC**). Due to challenges in recruitment, as described above, these groups involved markedly different sample sizes— $n=35$ (**CRC**) and $n=596$ (**non-CRC**), respectively. Consequently, a grouping strategy was devised to more thoroughly examine if any differences existed within the sample. This strategy involved the categorisation of the **non-CRC** group into a **hierarchy of participation**. The hierarchy consisted of six groups, which were based on known precedents from the literature as described in Chapter 2. The groupings were constructed using responses to three groups of questions in the survey, as described in Section 8.2.4:

1. The ‘CRC involvement’ item
2. The ‘Research experience’ item
3. The Civic participation scale.

All responses to the first two questions listed above were used in grouping the sample. One item (‘volunteered time’) from the civic participation scale was not used in this classification as participants’ meaning when they responded was deemed to be too imprecise to be meaningful. The hierarchy can be seen in Figure 8.6. The detail of the groups and how they were derived is elaborated following the figure.

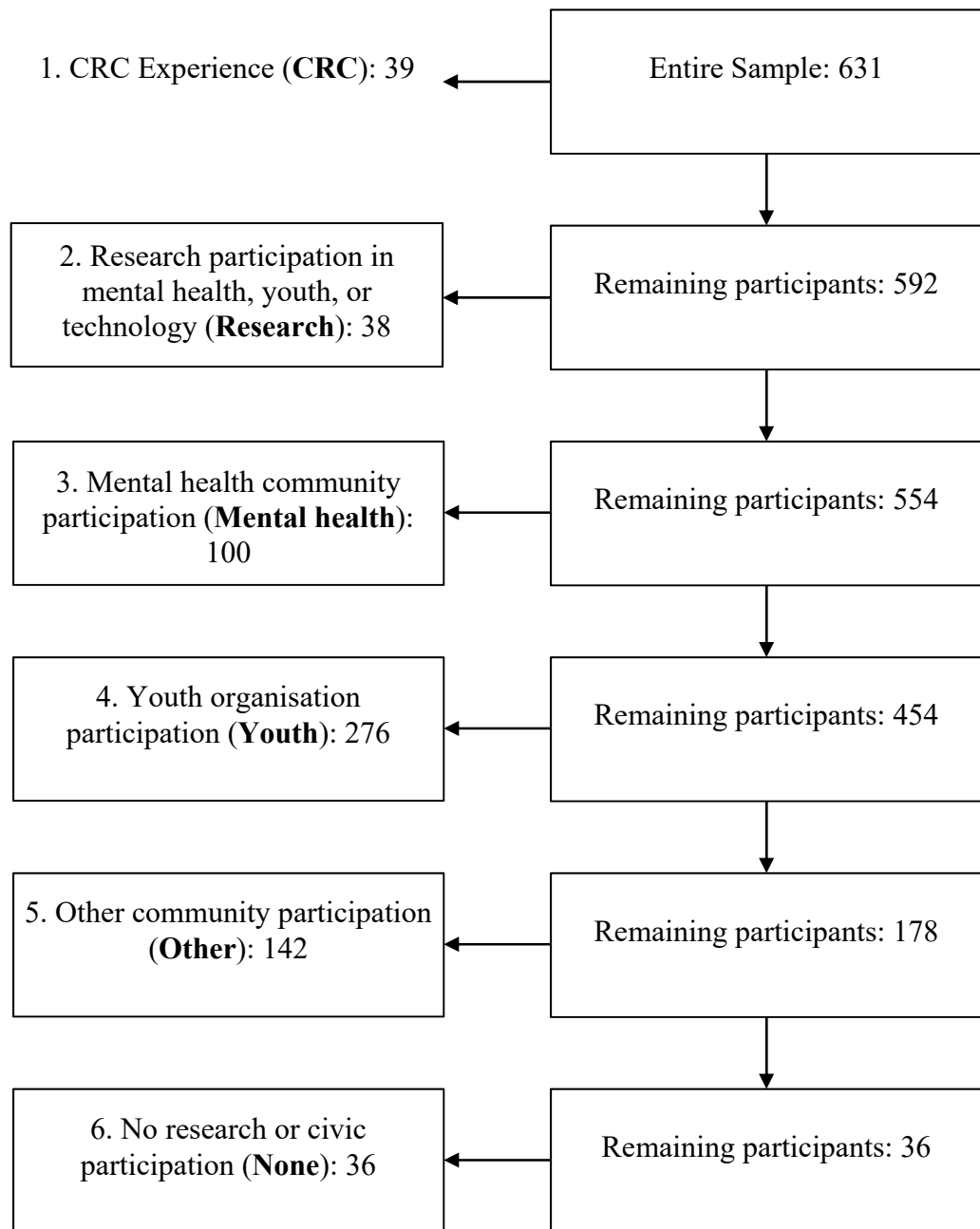


Figure 8.6 Participant grouping: hierarchy of participation

1. CRC experience: ‘CRC’ (n= 39)

The CRC experience group comprised those young people who had responded ‘yes’ to the ‘CRC involvement’ item and participants who responded to the open-ended research question with the name of a CRC project (e.g. *Univirtual Clinic at the ANU*).

2. Research participation in youth, mental health, technology or wellbeing:

‘Research’ (n= 38)

The Research participation in youth, mental health, technology or wellbeing group included those who had described previous research participation in the areas of mental health, youth, and/or technology, but had not been involved in the CRC. Examples of these responses included: *mental health consumer research, research for the Butterfly Foundation, The Inspire Foundation Market Research and Transitions survey at the BMRI through headspace - two interviews, one year apart.*

3. Mental health community participation: ‘Mental health’ (n= 100)

Young people who had identified that they had participated in a mental health organisation or a support group when answering the civic participation scale but had not participated in research in the areas described above, were identified and classified as the Mental health community participation group. This and the following group were selected because of their relationship to one or more of the key topic areas of interest to the CRC (mental health, youth, and technology).

4. Youth organisation participation: ‘Youth’ (n=276)

The fourth group, Youth organisation participation, comprised those participants who identified as having participated in either a ‘youth organisation based at your school/TAFE/university’ or ‘a youth club’ on the civic participation scale.

5. Other community participation: ‘Other’ (n=142)

The second last group, Other community participation, consisted of those participants who were not included in any of the above groups, but who had selected one of the following items on the civic participation scale:

- A local sporting or recreational group
- A band, artistic collective or other creative network
- Some other political or activist organisation
- An environmental organisation
- Organisations or groups concerned with women’s or gender issues

- Any type of group related to a specific ethnic group in the community
- A citizen's association
- A church group
- A conservation or heritage organisation (e.g. National Trust, or National Parks and Wildlife)
- A local library
- An online community group (e.g. eBay, Myspace or Facebook, TakingITGlobal, VibeWire.net)
- Made a donation
- Signed a petition
- 'Buycotted' or boycotted a product
- Written a letter to the editor or contributed to talk back radio discussion or commented on an online article

Endorsement of the above items suggest forms of community participation that are not related to the key areas of interest for the CRC.

6. No research or civic participation: 'None' (n=36)

The final group in the hierarchy were those young people who had not responded to any of the three questions indicating that they had participated in research or civic participation activities, and hence were assessed as having no research participation or civic participation.

8.3.3 Statistical methods

For all analyses, the critical P value used was .01, instead of the more conventional .05 because of the large number of comparisons in this study. As described in the previous chapter (Section 7.3.1), this was chosen in order to reduce Type 1 error risk. Exact P values are reported, with the * symbol used to denote statistically significant effects.

Chi-square tests were used to examine whether there was a significant relationship between groups on categorical measures of participant characteristics (Tabachnick & Fidell, 2013). Comparisons included examination of participants' characteristics according to the **hierarchy of participation**. The variables met the assumptions of the chi-square tests, i.e. independence of observations and that the variables consist of two or more categorical, independent groups (Tabachnick & Fidell,

2013). The choices of variables used in these tests meant that these assumptions were met.

Where a significance level less than the critical value of .01 was found, the strength of the association was calculated and post-hoc tests were used to establish which groups were significantly different from each other (Sharpe, 2015). The strength of the association was measured using Cramer's V . This is a post-hoc test used to measure the strength of the association between one nominal variable with either another nominal variable, or with an ordinal variable when the table is greater than 2 x 2. The statistic varies between 0 and 1, with higher values indicating a stronger association. Thresholds for the strength of the association measured by Cramer's V were described by Cohen (1988) for use in the behavioural and psychological sciences. These are reported following the statistic when it is used. These thresholds are:

- Small: 0.1 - 0.2
- Medium: 0.3 - 0.5
- Large: 0.5 - 0.8

A range of different post-hoc tests can be used with the chi-square test, ranging from visual inspection of proportions, to dividing contingency tables of greater than 2 x 2 into a set of smaller 2 x 2 tables, commonly referred to as partitioning (Sharpe, 2015). The majority of these options involve either having a-priori hypotheses about which specific cells are likely to deviate from each other or having a theoretical basis upon which the contingency table can be collapsed into a 2 x 2 table. Neither of these options were suitable for the present study given its exploratory nature and the decision to retain the levels of the hierarchy. Consequently, the only option of the four described by Sharpe (2015) which was feasible was an examination of the differences between observed and expected frequencies, and the residuals that accompany them.

Expected frequencies are generated when the chi-square statistic is calculated. These are the values which would occur, or be expected, if there was no association between the variables. The expected value for each cell in a table is equal to the row total multiplied by the column total, divided by the total number of observations in the table. Thus, the values vary depending on the variance within the cells of the data being examined.

The differences between the observed and expected frequencies within a table can be quantified, and a measure of this is referred to as residuals. Where expected values are large, residuals are also large. In order to standardise these within tables, cells

are compared using standardised residuals, which are calculated by dividing the raw residual by the square root of the expected value. Residuals calculated in this way can be compared across a contingency table and are used as a comparative measure of how the observed and expected differences differ across the table.

The most commonly accepted threshold for a significant difference between the observed and estimated expected standardised residuals is a value of ± 2 when there are few cells, and ± 3 when there are many cells (Agresti, 2007). Agresti (2007) does not state what constitutes a small or large number of cells. On the basis of the guidance provided by Sharpe (2015) it was decided to treat all of the tables in this study as having a large number of cells. Thus, a standardised residual value of ± 3 or greater was considered to indicate a significant difference.

Comparisons between groups on the hierarchy of participation on the continuous variables of participant characteristics and motivations (the D-Lit, DSS and scales of the VFI) were made using the Kruskal-Wallis H test.

Both the Kruskal-Wallis H test and its parametric equivalent, ANOVA, were considered. Preference was initially given to ANOVA due to the greater statistical power that can be obtained from it. However, on all of the variables it was applied to either the assumption of no significant outliers, or normal distribution within groups on the independent variable, was violated (Howell, 2010). The Kruskal-Wallis H test does not assume either of these characteristics of the data.

The assumptions of the Kruskal-Wallis H test are as follows (Laerd Statistics, 2015):

1. One dependent variable measured at the continuous or ordinal level
2. One independent variable which consists of two or more categorical, independent groups
3. Independence of observations
4. Distribution of scores for each group on the independent variable are equal.

Both assumptions 1 and 2 were met through the choice of variables to be analysed. Assumption 3 was met through the study design, and creation of the **hierarchy of participation**, as each participant only completed the survey once and was assigned to only one of the groups on the hierarchy.

The final assumption is specific to each dependent variable analysed against the independent variable (the group on the **hierarchy of participation**). Where this

assumption is met, the test can be used to draw conclusions about the median scores of each group, using the null hypothesis that the distributions of the scores for all groups are equal. Where this assumption is not met, the test can still be used but a different null hypothesis is posited.

Prior to the use of the test on each dependent variable, the distribution of scores within each group on the hierarchy were examined using boxplots to ascertain if these distributions were equally varied. This visual inspection determined that for all dependent variables, the distribution of groups had equal variance. Consequently, statistically significant differences were interpreted as the median scores of the groups not being equal.

Where the Kruskal-Wallis H test was found to be statistically significant, post-hoc pairwise comparisons were used to determine which specific groups were statistically significantly different to one another. The pairwise comparison procedures used were those described by Dunn (1964) with a Bonferroni adjustment applied to the statistical significance level of .01 (see start of this section for explanation). The procedure used the average rank sum of each group to infer differences between the median scores in each group. A significant result indicates that the differences between the two median scores are statistically significantly different to each other.

Analysis of qualitative data

Responses to open-ended questions (e.g. reasons for volunteering, reasons for not volunteering, CRC involvement) were analysed using thematic analysis, as described in Section 3.6.1. The codes were developed based on the findings of Study 3 (analysis of advisory group applications) and the existing literature.

8.4 Results

The following sections report the findings as they pertain to the project aims and research objectives, as shown in Figure 8.1. Section 8.4.1 reports on the characteristics of the sample. Section 8.4.2 reports the results pertaining to Aim 1 and Objective 1 (to understand how young people who are involved in the CRC differ from other young people). Section 8.4.3 reports the results pertaining to Aim 2 and Objective 2 (to compare the self-reported motivations of young people involved in the CRC to the motivations reported by young people who take part in research, and who are involved and participate in their communities in other ways). The final section, 8.4.4, reports results pertaining to Aim 3 and Objective 3 (to describe the experience of young people

who were involved in the CRC and to show how this differed from how they would have liked to be involved).

8.4.1 Participant characteristics

There were 631 complete responses to the survey. The mean age of participants in the study was 22 years (range of 18-25 years). The majority of the sample was female (78.2%, n=491). They were largely from major cities, with only 16.9% (n=106) reporting that they lived in regional, remote or very remote areas of Australia.

Nearly all participants (98.6%, n=622) reported that they use the internet every day. The technology that they reported using varied, with the majority of the sample reporting using smartphones or tablets (93.7%, n=591) and computers (96.5%, n=609) every day. Substantially fewer reported using non-internet enabled technology on a daily basis, with only 6.8% (n=43) and 10.3% (n=65) using non-internet enabled mobile phones and landline telephones respectively. The most frequent online activities were to communicate with others (100%, n=631), to seek entertainment (98.6%, n=622) and social media (97.5%, n=615). The least frequent activities were accessing pornography (35.8%, n=226), or sending or receiving nude or semi-nude photos of themselves or others (13.0%, n=82). Of relevance to this study was that 72.1% (n=455) had used the internet to access health information or to seek online counselling.

8.4.2 How young people who are involved in the CRC differ from other young people (Objective 1)

Table 8.1 shows the proportion of the participants in each of the groups who reported that they had particular characteristics. There were several missing cases, with the number varying amongst cases as noted in the tables below. There were low overall numbers of both young people who identified as being from an Aboriginal and Torres Strait Islander background (n=5) and being a newly arrived migrant or refugee (n=2). Consequently, these results are not reported in the table below.

Significantly more people in the **mental health** subgroup identified as having a 'chronic illness or disability' than was statistically likely to have occurred if there were no differences between the groups ($\chi^2(5) = 27.35, p = .000$, adjusted standardised residual=3.0). The size of this effect was small (Cramer's $V = 0.21$ (Cohen, 1988)).

Table 8.1 Differences between hierarchy of participation groups: demographic characteristics

	CRC (n=39)		Research (n=38)		Mental health (n=100)		Youth (n=276)		Other (n=142)		None (n=36)	
	n	%	n	%	n	%	n	%	n	%	n	%
Gender ^a (n= 628)												
Female (n=491; 78.1%)	25	65.8	32	84.2	83	83.0	207	75.3	116	82.3	28	77.8
Male (n=130; 20.7%)	11	28.9	6	15.8	15	15.0	67	24.4	23	16.3	8	22.2
Other (n=7; 1.1%)	2	5.3	0	0	2	2.0	1	0.4	2	1.4	0	0.0
Location ^b (n=626)												
Major cities (n=520; 83.1%)	33	86.8	31	81.6	80	80.8	235	85.5	109	77.9	32	88.9
Regional and remote (n=106; 16.9%)	5	13.2	7	18.4	19	19.2	40	14.5	31	22.1	4	11.1
Population groups of interest ^c (n=631)												
Carer (n=36; 5.7%)	7	17.9	2	5.3	6	6.0	13	4.7	7	4.9	1	2.8
Chronic illness or disability (n=96; 15.2%)	11	11.5	11	11.5	25	25.0	34	12.3	14	9.9	1	2.8
Culturally and linguistically diverse background (n=103; 16.3%)	7	6.8	28	73.7	11	10.7	50	18.1	4	3.9	3	2.9
Experience of homelessness (n= 26; 4.1%)	4	10.3	3	7.9	8	8.0	5	1.8	4	2.8	2	5.6
Language other than English spoken (n=153; 24.2%)	14	36.8	11	28.9	18	18.0	78	51.0	25	16.3	7	4.6
Lesbian, Gay, Bisexual, Transgender or Intersex (n=132; 20.9%)	13	33.3	11	28.9	28	28.0	53	19.2	22	15.5	5	13.9

Note: % is of valid responses within each participant group, ^a Missing cases: CRC=1, Youth= 1, Other =1; ^b Missing cases: CRC=1, Mental health=1, Youth=1, Other= 2; ^c Missing cases: CRC=1, Youth= 2, Other =1, None = 1.

Table 8.2 Differences between hierarchy of participation groups: education and main activity

	CRC (n=39)		Research (n=38)		Mental health (n=100)		Youth (n=276)		Other (n=142)		None (n=36)	
	n	%	n	%	n	%	n	%	n	%	n	%
Highest level of education completed – others in home (n=627)^a												$\chi^2(5)=8.34, p=.138$
Senior high or below (n=54; 8.6%)	3	7.7	1	2.6	9	9.1	18	6.6	17	12.1	6	16.7
Diploma to postgraduate (n=573; 91.4%)	36	92.3	37	97.4	90	90.9	256	93.4	124	87.9	30	83.3
Highest level of education completed – self (n=630)^b												$\chi^2(5)=3.34, p=.647$
Senior high or below (n=185; 29.4%)	11	28.9	7	18.4	34	34.0	82	29.8	41	28.9	10	27.8
Diploma to postgraduate (n=445; 70.6%)	28	71.9	31	81.6	66	66.0	193	70.2	101	71.1	26	72.2
Main occupation (n=628)^c												$\chi^2(20)=28.35, p=.101$
Employed full time (n=143; 22.7%)	6	16.2	6	15.8	19	19.0	63	22.9	41	29.1	8	22.2
Employed part time (n=76; 12.1%)	2	5.4	5	13.2	15	15.0	25	9.1	22	15.6	7	19.4
Not in the workforce (n=36; 5.7%)	2	5.4	2	5.3	11	11.0	9	3.3	9	6.4	3	8.3
Student (n=363; 57.8%)	27	73.0	24	63.2	53	53.0	175	63.4	67	47.5	17	40.4
Volunteer (n=10; 1.6%)	0	0.0	1	2.6	2	2.0	4	1.4	2	1.4	1	2.8

Note: % is of valid responses within each participant group. ^a Missing cases: Mental health= 1, Youth= 2, Other= 1; ^b Missing cases: Research= 1, Youth= 1; ^c Missing cases: CRC= 2, Other=1.

Table 8.2, above, shows the educational attainment and main activity of the sample. There were no statistically significant differences between subgroups on any of these measures.

Table 8.3, below, shows young people's experience of mental ill health, their depression literacy and depression stigma, and how this varied between subgroups. As reported in the table, a chi-square test showed a statistically significant difference between subgroup membership and experience of mental ill health. The effect size of this difference was small (Cramer's $V=0.22$ (Cohen, 1988)). Examination of adjusted standardised residuals showed that a significantly higher proportion of young people who had experienced mental ill health had taken part in a mental health organisation (**mental health** subgroup: adjusted standardised residual=4.5) and a significantly lower proportion had taken part in a youth organisation (**youth** group: adjusted standardised residual=-4.7).

A statistically significant difference was also found between subgroup membership and help seeking for mental ill health. The effect size of this difference was small (Cramer's $V=0.21$ (Cohen, 1988)). Examination of adjusted standardised residuals showed that a significantly higher proportion who had taken part in **other community participation** (adjusted standardised residual=3.6) and a significantly lower proportion who had taken part in a **youth** organisation (adjusted standardised residual=-3.7) reported that they had sought help for this experience.

Significant associations were found between group membership and depression literacy (D-Lit) and depression stigma (DSS) using Kruskal-Wallis H tests. Pairwise comparisons were performed using Dunn's (1964) procedure. A Bonferroni correction for multiple comparisons was used to generate adjusted significance levels (exact adjusted significance levels are presented). The results of these post-hoc analyses showed that the statistically significant difference on the D-Lit scale was because the scores reported by the **youth** subgroup (median=5.00) were significantly lower than the **research** subgroup (median=7.00), $p=.006$.

The statistically significant difference on the DSS was due to differences between the **CRC** (median=4.00) and **none** (median=7.00) subgroups ($p=.005$), and between the **mental health** (median=4.00) and **none** (median=7.00) subgroups ($p=.006$). These results indicate that young people who had taken part in the **CRC** and **mental health** organisations reported significantly lower rates of stigma than young people who had not participated in research or in their communities (**none**).

Table 8.3 Differences between hierarchy of participation groups: experiences of, knowledge about and attitudes toward mental ill health

Total sample (n=631)	CRC (n=39)			Research (n=38)			Mental health (n=100)			Youth (n=276)			Other (n=142)			None (n=36)		
	n	%		n	%		n	%		n	%		n	%		n	%	
Previous experience of mental ill health (n=449; 71.6%) ^a	29	74.4		30	78.9		90	90.0		170	61.6		103	72.5		27	75.0	$\chi^2(5)=31.31$, $p=.000^*$
Knows friends or family who have sought help for mental ill health (n=541; 86.2%) ^b	36	92.3		36	94.7		90	90.9		231	86.5		123	89.1		25	71.4	$\chi^2(5)=12.76$, $p=.026$
Participants who had experienced mental ill health (n=449)^c	CRC (n=29)			Research (n=30)			Mental health (n=90)			Youth (n=170)			Other (n=103)			None (n=27)		
Previous help seeking for mental ill health (n=382; 85.0%) ^d	27	93.1		29	96.6		77	85.5		144	84.7		80	77.6		25	75.0	$\chi^2(5)=26.13$, $p=.000^*$
Depression literacy (n=622) ^e	Mdn Rng			Mdn Rng			Mdn Rng			Mdn Rng			Mdn Rng			Mdn Rng		
	6.00	2-10		7.00	2-10		6.00	2-10		5.00	0-10		6.00	0-11		6.00	2-10	$\chi^2(5)=16.44$, $p=.006^*$
Depression stigma (n=627) ^f	4.00	0-13		5.00	0-12		4.00	0-12		5.50	0-28		5.00	0-14		7.00	0-21	$\chi^2(5)=24.11$, $p=.000^*$

Note: % is of valid responses within each participant group: Mdn=Median, Rng=Range ^a Missing cases: Research=1, Youth=2, Other=3 ^b Missing cases: Research=1, Youth=2, Other=4; ^c Only participants who reported that they had experienced mental ill health were asked if they had sought help for it; ^d Missing cases: CRC=1, Mental health=1, Youth=5, Other=2; ^e Missing cases: Mental health=4, Youth=2, Other=3; ^f Missing cases: Mental health=1, Youth=2, None=1.

8.4.3 Young people's self-reported motivations for being involved in the CRC and comparison with motivations of other groups (Objective 2)

As described in Section 8.2.5 (measures), participants who reported that they had not taken part in any of the civic participation activities listed, or had not participated in the CRC, were not presented with questions about motivations for volunteering. Because of this, the total number of participants who were presented with the questions in this section was N=595.

Table 8.4 reports participants' median scores on each of the VFI scales and the proportion of each group who reported specific motivations for volunteering. These were generated from participants' responses to the open-ended question regarding reasons that young people chose to volunteer. Examples of each of the reasons, which were created using thematic analysis, are:

- Connect with other people: e.g. *Opportunities to engage with people, as well as to care for them and share my passions*
- Enjoyment: e.g. *I enjoy contributing to society*
- Give back to the community: e.g. *To assist others and give back to the community where it has given me support in the past*
- Interest or belief in the cause or topic: e.g. *I feel that I align with the set of values espoused by the ALP, at a societal and political level*
- Sense of obligation: e.g. *Feeling that I owe a lot to my communities and to the people that teach me.*
- Something to do: e.g. *To fill in time/have something to do*
- To develop themselves: e.g. *Personal development through service*
- To gain skills and experience: e.g. *To gain experience to eventually find work*
- To make a difference: e.g. *Doing what I can to make a meaningful difference in the world*

Significant results were found on three of the VFI scales: 'enhancement', 'protective' and 'values'. Pairwise comparisons were performed using Dunn's (1964) procedure. A Bonferroni correction for multiple comparisons was used to generate adjusted significance levels (exact adjusted significance levels are presented). The groups on the 'enhancement' and 'protective' scales for which the scores were significantly different reported the same median score. The differences were between

the **mental health** (median=3.00) and **youth** (median=3.00) subgroups, $p=.000$; and between the **mental health** (median=3.00) and **other** (median=3.00) subgroups, $p=.004$. The statistically significant result is likely to be spurious because of the numerous comparisons conducted. This result is likely to not be of practical importance.

Participants who had taken part in a **mental health** organisation (median=3.00) were statistically significantly more likely to report that they had used volunteering to reduce negative feelings, such as guilt or to address personal problems ('protective' scale) than young people in the **other** (median=2.00, $p=.003$) and **youth** (median=2.00, $p=.003$) subgroups.

Higher scores on the 'values' scale indicate that the person is volunteering in order to express or act on important values, such as humanitarianism or helping the less fortunate. This motive was endorsed at significantly higher levels by the **CRC** (median=4.00) and **mental health** subgroups (median=3.66) than the **youth** (median=4.00) and **other** (median= 3.66) subgroups. The specific differences were between the **CRC** and **youth** subgroups ($p=.003$), the **CRC** and **other** subgroups ($p=.003$), the **mental health** and **other** subgroups ($p=.001$) and between the **mental health** and **youth** ($p=.000$) subgroups.

As shown in Table 8.4 below, for the motivations which were participant generated, no significant differences were found between groups.

Table 8.4 Differences between hierarchy of participation groups: motivations for involvement and volunteering

N=595	CRC (n=39)			Research (n=38)			Mental health (n=100)			Youth (n=276)			Other (n=142)		
	Mdn	Rng		Mdn	Rng		Mdn	Rng		Mdn	Rng		Mdn	Rng	
VFI scales															
Career ^a (N= 585)	3.25	1-4		3.00	1-4		2.75	1-4		2.87	1-4		3.00	1-4	$\chi^2(4)=5.89, p=.208$
Enhancement ^b (N=567)	3.00	1-4		3.00	1-4		3.00	1-4		3.00	1-4		3.00	1-4	$\chi^2(4)=23.05, p=.000^*$
Protective ^c (N=565)	3.00	1-4		2.00	1-4		3.00	1-4		2.00	1-4		2.00	1-4	$\chi^2(4)=21.79, p=.000^*$
Social ^d (N= 578)	3.00	1-4		3.00	1-4		3.00	1-4		3.00	1-4		3.00	1-4	$\chi^2(4)=8.88, p=.064$
Understanding ^e (N=586)	3.66	1-4		3.33	1.33-4		3.33	1.33-4		3.33	1-4		3.33	1.67-4	$\chi^2(4)=6.97, p=.138$
Values ^f (N=585)	4.00	1-4		3.66	2.33-4		4.00	2-4		3.66	2-4		3.66	2-4	$\chi^2(4)=30.90, p=.000^*$
Participant generated motivations	n	%		n	%		n	%		n	%		n	%	
Connect with other people (n=75; 12.6%)	6	15.4		5	13.2		11	11.0		39	14.1		14	9.9	$\chi^2(4)=1.88, p=.757$
Enjoyment (n=55; 9.25%)	2	5.1		5	13.2		12	12.0		27	9.8		9	6.3	$\chi^2(4)=3.85, p=.427$
Give back to the community (n=87; 14.6%)	7	17.9		4	10.5		24	24.0		33	11.9		19	13.3	$\chi^2(4)=9.53, p=.049$
Interest or belief in the cause or topic (n=85; 14.3%)	9	23.1		6	15.8		12	12.0		34	12.3		24	16.9	$\chi^2(4)=4.76, p=.313$
Sense of obligation (n=18; 3%)	3	7.7		1	2.6		4	4.0		8	2.9		2	1.4	$\chi^2(4)=4.37, p=.358$
Something to do (n=23; 3.9%)	3	7.7		2	5.3		3	3.0		11	4.0		4	2.8	$\chi^2(4)=4.29, p=.683$
To develop themselves (n=20; 3.36%)	1	2.6		1	2.6		7	7.0		8	2.9		3	2.1	$\chi^2(4)=4.64, p=.327$
To gain skills and experience (n=90; 15.1%)	8	20.5		6	15.8		13	13.0		45	16.3		18	12.7	$\chi^2(4)=2.01, p=.735$
To make a difference (n=152; 25.5%)	11	28.2		10	26.3		33	33.0		73	26.4		25	17.6	$\chi^2(4)=3.85, p=.427$

Note: % is of valid responses within each participant group, Mdn= Median, Rng= Range ^a Missing cases: Research = 1, Mental health = 2, Youth = 2, Other = 5 ^b Missing cases: Research = 1, Mental health = 4, Youth = 12, Other = 11 ^c Missing cases: CRC= 1, Research = 2, Mental health = 5, Youth = 13, Other = 9 ^d Missing cases: Research = 1, Mental health = 2, Youth = 2, Other = 4 ^e Missing cases: Research = 1, Mental health = 2, Youth = 2, Other = 4 ^f Missing cases: Research = 1, Mental health = 1, Youth = 3, Other = 4.

Table 8.5 presents the wide range of organisations that young people nominated that they had participated in, or with. Inductive thematic analysis was used to categorise the responses. This analysis resulted in 11 distinct types of organisations, generated from 611 items by 421 participants. Actions undertaken that did not include the name or a description of the organisation were not included in the analysis (e.g. *led at a youth camp*). Examples of the organisations grouped within each of the categories included:

- Art and performance: e.g. *Canberra City Band*
- Environmental or animal protection: e.g. *Australian Youth Climate Coalition, Tasmania Fire Service, RSPCA, The Cat Protection Society*
- Faith or religion: e.g. *Australian Student Christian Movement, Jewish youth societies*
- Government or legal: e.g. *ACT Youth Advisory Council, Fremantle Community Legal Centre*
- Health and social service: e.g. *Australian Red Cross, Australian Childhood Foundation, Twilight aged care, YouthReach Inc*
- Mental health: e.g. *Headspace, Beyondblue, Black Dog Institute*
- Political: e.g. *Australian Labor party, UNSW Liberal club*
- Refugee or international aid: e.g. *Helping Hands - tutoring students from refugee backgrounds*
- Sexuality or gender: e.g. *One Million Women, All Out, It Gets Better.*
- Sport: e.g. *Local football club*
- Youth: e.g. *Young Scientists of Australia, youth groups*

Table 8.5 Differences between hierarchy of participation groups: types of organisations participants were involved with

Organisation type (N=595)	CRC (n=33)		Research (n=28)		Mental health (n=79)		Youth (n=190)		Other (n=85)	
	n	%	n	%	n	%	n	%	n	%
Art and performance (n=46; 7.7%)	3	8.3	4	14.2	5	6.3	21	11.0	13	16.9
Environmental or animal protection (n= 72; 12.1%)	7	19.4	6	22.2	10	12.7	31	16.3	18	22.2
Faith or religion (n=66; 11.1%)	3	9.4	3	11.1	11	13.8	40	21.5	9	11.1
Government or legal (n=41; 6.8%)	1	3.1	2	7.4	15	18.8	15	8.1	8	9.9
Health and social service (n=117; 19.7%)	14	43.8	11	40.7	25	31.3	45	24.2	18	22.2
Mental health (n=72; 12.1%)	16	50.0	8	29.6	36	45.0	7	3.8	4	4.9
Political (n=64; 10.7%)	6	18.8	6	22.2	13	16.3	31	16.8	8	9.9
Refugee or international aid (n=112; 18.8%)	5	15.6	7	25.9	19	24.1	59	31.7	22	27.2
Sexuality or gender (n=40; 6.7%)	4	12.5	4	14.8	7	8.8	18	9.7	7	8.6
Sport (n=53; 8.9%)	5	15.6	4	14.8	8	10.0	25	13.5	11	13.6
Youth (n=104; 17.5%)	5	15.6	6	22.2	24	30.0	55	29.6	13	16.0
Note: % is of valid responses within each participant group.										

As presented in Table 8.5, a chi-square test showed a significant difference between groups when the proportions of young people who had participated in a ‘mental health’ organisation were compared ($\chi^2(4)=101.29, p=.000^*$). The effect size of this difference was medium (Cramer’s $V=0.50$ (Cohen, 1988)). Post-hoc analyses showed that a significantly higher proportion of young people had participated in a mental health organisation than would have occurred by chance in the **CRC** subgroup (adjusted standardised residual= 5.0) and in the **mental health** subgroup (adjusted standardised residual= 7.2). There were significantly fewer in the **youth** (adjusted standardised residual= -6.7) and in the **other** subgroups (adjusted standardised residual= -3.3).

Participants who indicated that they had not been involved in the CRC, in research or in any of the activities on the civic participation scale, were asked why they had not volunteered. There were 12 responses to this question, which were classified into five discrete reasons. The most frequently mentioned of these reasons were that they ‘feel they do not have time’ (n=4), that they had ‘never thought about it’ (n=3), and that they ‘were not sure where to start or what to do’ (n=3). One participant stated that they felt that volunteering was *too much effort* and another that they were *unable to commit due to illness*.

8.4.4 The experience of young people when they are involved in the CRC and how this differed from how they would have liked to be involved (Objective 3)

This section reports on the questions that were administered to the **CRC** subgroup (n=35) about their experience of being involved in the CRC. It answers study Objective 3: to describe the experience of young people who were involved in the CRC and to show how this differed from how they would have liked to be involved.

The number of participants who responded to the questions reported in this section was lower than those in the **CRC** group of the **hierarchy of participation**. This is because only participants who self-identified as having been part of the CRC projects were presented with questions about their experience with the CRC. The four people who had identified as taking part in research within the CRC, who were included in the **CRC** subgroup, were not presented with these questions.

As noted in Section 8.2.5 (measures), the questionnaire item and recruitment materials that were used to screen participants into this section were intentionally broad, in order to capture as many young people who had been involved, engaged with, or

participated in the CRC as possible. As a consequence of this, participants' experiences encompass the whole spectrum of involvement, participation and engagement– despite the recruitment focusing on young people who researchers and project managers had actively involved in their work. The implications of this for the practice of involvement are discussed later in this chapter (Section 8.5).

Of the 35 young people who were administered the open-ended questions about the nature and frequency of their involvement, 30 provided a response. Table 8.6 shows the results of a content analysis of these responses.

Where participants described more than one type of involvement these were counted as discrete items, resulting in a greater number of types of involvement being counted than the number of participants who responded to the question. The 30 participants who responded to the question described 12 involvement activities in 62 responses. The most frequently nominated types of involvement were 'surveys' (n=23) and 'reviewing research proposals' (n=7), and the least frequent was 'participating in research' (n=1).

Table 8.6 *The nature of young people's involvement in the CRC*

Activity (N=30)	Number of mentions	% of respondents
Survey	23	76.6
Reviewed research proposals	7	23.3
Disseminating results	4	13.3
Focus group	4	13.3
Gave feedback	4	13.3
Interview	4	13.3
Use of an app or intervention	4	13.3
Youth Brains Trust	4	13.3
Workshop	3	10.0
Designing the research	2	6.6
Working group	2	6.6
Participating in research	1	3.3

In addition to the open-ended question about their experiences of involvement, participants were also asked to indicate which research stages they had been involved at, using a pre-determined framework of consumer involvement (see Section 8.2.5, measures). Participants were able to indicate that they had been involved at more than one stage. Figure 8.7 shows the stages that participants reported they had been involved at, plotted against the stages they reported that they desired to be involved with. Young people were most frequently involved in 'doing the research' (n=21), followed by 'deciding how to do it' (n=13) and 'deciding what to do' (n=12). Participants were less frequently involved in 'interpreting the findings' (n=3) and 'writing them into a scientific report' (n=1). However, these were the stages in which there was the greatest

divergence between actual and desired involvement. For example, the number of participants who wanted to be involved at the ‘interpreting the findings’ stage (n=11) was nearly four times as high as the number who had been involved at that stage (n=3). Only one participant reported involvement in ‘writing a scientific report on the findings,’ whereas 13 expressed an interest in being involved with this stage.

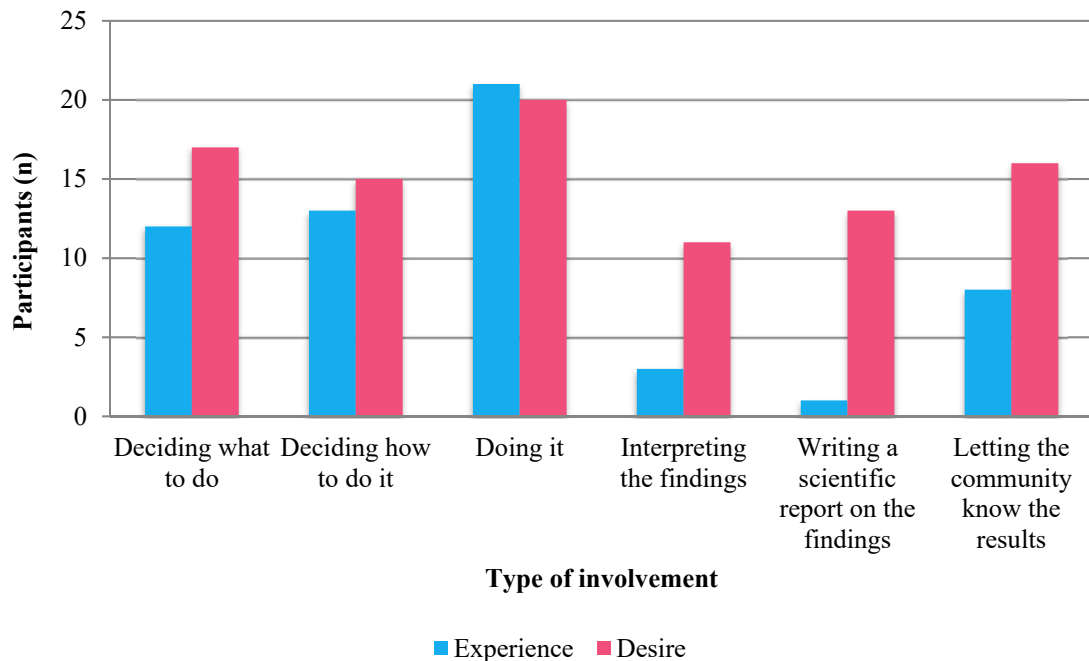


Figure 8.7 Young people who had been involved in the CRC: contrast of experience and desire at the different stages of research

In terms of the media through which they were involved, young people were involved ‘online’ (n=32), ‘face-to-face’ (n=18) and ‘on the phone’ (n=11). Most participants reported being involved through more than one method, with seven participants having been involved ‘face-to-face’ and ‘online’, six ‘online’ and/or ‘on the phone’, and six through all three options.

Participants’ subjective experiences of being involved were explored using both an open-ended question about their experiences, and responses to statements about aspects of their involvement. Table 8.7 shows the median and response range for the ‘experiences of being involved’ statements, answered on a Likert scale of ‘strongly disagree’ (1) to ‘strongly agree’ (5).

There was a wide variance in the experience of the 29 participants who responded to all of the statements. They were least likely to agree that they were ‘included in staff activities’, and most likely to agree that ‘there was enough flexibility in their participation to allow for unexpected changes in their lives’.

Table 8.7 *Experiences of involvement*

Statement (n=29)	Median	Range
Support for my participation was given in an approachable and available manner	4	1-5
I had a clear understanding of my project and my role	4	1-5
I was able to access the knowledge and experience I needed to complete my participation activities	4	1-5
I knew who to ask for assistance when I needed it	4	1-5
There was enough flexibility in my participation to allow for unexpected changes in my personal or work life	5	1-5
I was included in relevant staff activities	3	1-5
I felt like a member of the project team	4	1-5
Overall I had a positive experience during my participation	4	1-5

The number of participants who responded to the open-ended question ‘Do you have any comments regarding your project or participation?’ was very small (n=7). The responses are shown in full in Table 8.8 and are presented with the number of times and the activities in which participants reported being involved. These results, while limited by their number, show a complex picture of the interactions between the number of times young people had been involved, the ways they had been involved, and their experiences of being involved. They show that experiences of involvement vary considerably with some participants reporting a very positive experience, and others commenting that they would have preferred to be offered more opportunities than they were. For example, the two participants with the highest reported involvement had very different experiences, suggesting individual participant and researcher factors played a strong role.

Table 8.8 *Comments about experiences of involvement*

Comment text	Number of times involved	Involvement activities
I found follow-up to my involvement lacking. I have been involved in a number of projects where I have contributed to the planning, but then have not found out what happened with the plan (unless someone casually mentions it over dinner years down the track).	2	Survey, working group
I have never felt so supported in any project, of any kind, in all my life. Everywhere I've turned I've been met with feedback, affirmation, patience, kindness and trust.	21 or more	YBT, Survey, gave feedback, disseminated results
I wanted opportunities for more involvement but little opportunity was given.	1	Survey
It was difficult because the other young people were rude and mean, especially about my gender identity.	10	<i>No answer</i>
Results were poor due to too many stakeholders	2	Reviewed research proposal
Very good and I felt appreciated for my time and effort	4	Survey
Wish I could have been more involved	Several	Workshop, interview, survey

8.5 Discussion

The characteristics, motivations, and experiences of young people who are involved in youth mental health research have been described in a small number of studies to date. A reason for this limited quantity of data may be that documenting young people's involvement may be challenging or not always feasible, particularly for small-scale studies. This study contributes to the literature by examining a sample of young people who have been directly involved in various forms of youth involvement or have participated in their communities in other ways.

8.5.1 Young people's characteristics (Aim 1)

Aim 1 of the YIMHR project was to identify the characteristics of young people who are involved in youth mental health research and to compare this with other young peoples' characteristics and researchers' beliefs about these characteristics.

While the conclusions which can be drawn were limited by the small number of CRC participants compared to non-CRC participants, what can be understood is that on the majority of characteristics measured these young people are not significantly different to other young people who are involved or participate in their communities. The exception to this are those characteristics related to mental ill health. The following

section discusses these findings with reference to the extant literature and provides suggestions for how the findings can be used to improve the practice of youth involvement.

Significant differences were found between groups on the **hierarchy** on four mental health related measures: experience of mental ill health, help seeking for mental ill health, depression literacy and depression stigma. Specifically, the **CRC** subgroup reported lower stigma than the **none** subgroup, the **research** subgroup reported higher literacy scores than the **none** subgroup, the proportion of young people with an experience of mental ill health in the **mental health** subgroup was larger than other groups, and the proportion of all participants who had experienced mental ill health and had sought help for it was high across all groups. Because the area of interest in this study was how the subgroups differ from each other, the discussion in the following paragraphs follows the **hierarchy of participation** and groups the findings accordingly. The implications of these findings and suggested areas of further investigation follow.

The **research** subgroup reported significantly higher depression literacy than young people who had not participated at all (the **none** subgroup), and the **CRC** subgroup reported significantly lower depression stigma than young people who had not participated in their communities (the **none** subgroup). These measures were included in the study for two reasons. Firstly, due to the researcher's observation, while participating in mental health research herself, that her fellow young people displayed favourable attitudes toward mental ill health. Secondly, because mental health literacy has been identified as a major facilitator to help seeking, and stigma has been identified as a major barrier to help seeking (Gulliver et al., 2010; Rickwood et al., 2005). Hence, it was anticipated that young people who had been involved in the **CRC**, or in research related to mental health, youth or technology (the **research** subgroup), would have higher rates of literacy and lower rates of stigma. The findings from this study provide support for this. They suggest that young people who are involved bring particular understandings of mental health and may have a greater understanding of mental health information.

Further work should be undertaken to establish if young people with high rates of literacy, or low rates of stigma, provide different insights or input to young people who do not have these characteristics. Without this further work, it is difficult to draw conclusions about the impact of these . One way to establish the impact of these characteristics on involvement may be for researchers to measure and report the levels of literacy and stigma of the young people they involve and reflecting on how this

changed the outputs of their work. Examples of studies where researchers have reflected on how the input they received from young people affected their work exist, such as Monshat's (2012) description of changes which were recommended by young people involved in designing a mindfulness intervention. However, without an accompanying description of the characteristics of the young people who provided input, establishing if it was related to a specific aspect of their previous experience or personal characteristics is not possible. This absence of detail limits the conclusions, either positive or negative, which can be drawn about the impact of their input on work to date.

A larger proportion of young people who had taken part in a mental health organisation (the **mental health** subgroup) reported that they had experienced a mental health or behavioural problem than the other groups. In addition, a high proportion of all participants who had reported that they had experienced mental ill health had sought help for it. These findings suggest that young people take part in activities which are related to their personal experience. The broad criteria for selection into this participant group (the **mental health** subgroup) means it is unclear if the young people in this group took part in these activities to seek support for their experience of mental ill health, or because they are interested in the topic. These findings are similar to previous work in the youth involvement in mental health research literature which shows that the proportions of young people who are involved and have an experience of mental ill health are high. For example, in the cohort of youth consultants described by Howe et al., (2011), 37% of the young people were current or previous users of mental health services. From this, it could be surmised that there are likely to be higher than expected proportions of people with an experience of ill health in the groups of people who take part in this type of activity. This supposition was reflected in the researcher's own experience as a young person taking part in the CRC. She observed that a significant proportion of the young people involved with the CRC had prior experience of mental ill health and seeking help for it. The CRC research projects which participated in the survey chose to involve, or recruited, young people with a breadth of experiences of mental ill health and help seeking. When considered in light of the statistically significantly higher proportion of applicants to the YBT who had experienced mental ill health than their peers in the Australian population (Study 4 survey of advisory group applicants), this absence of a trend toward young people with an experience of mental ill health among the **CRC** subgroup may be attributable to the selection criteria which were used in individual studies, not an indication of the characteristics of young people who were interested in taking part. Further evidence for this is suggested by the finding

that the *Research* group reported significantly higher depression literacy than young people who had not participated in their communities at all. The **research** subgroup was similar to the **CRC** subgroup, with the exception that it cannot be conclusively ascertained that young people in this group were actively involved, only that they had participated in research in topics similar to those in the CRC.

Collectively, these findings provide an indication that, among young people who take part in mental health research and mental health groups, particular trends may exist. These trends are towards more favourable attitudes to mental ill health, and slightly higher rates of mental ill health, than young people who are engaged in their communities in other ways. When considered alongside the findings of the previous studies in this project, which have also suggested that young people who are involved in mental health research have higher rates of mental ill health, this finding shows the need for further work in the area. Specifically, future work should aim to ascertain the impact that any trends in these areas might have on the research that they are involved in.

Differences in the proportional representation of certain groups of the population were anticipated (e.g. women, students) based on previous literature (see Chapter 2, Sections 2.51 and 2.6.2). However, the only characteristic for which a significant difference was found between groups was young people living with a chronic illness or disability. The proportions of young people with this characteristic in all participant groups was still lower than the 41.4% found in the Australian Survey of Disability, Ageing and Carers (Australian Bureau of Statistics, 2009a). When the proportions of these characteristics in the sample in this study were compared to previous work, they have largely similar findings. For example, the proportion of females in the current study was similar to the 50% to 87% reported in previous examples of youth involvement in mental health research literature (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Monshat et al., 2012), and the results of Study 4 (survey of YBT applicants).

The absence of significant demographic differences between the groups, other than gender and main occupation, shows the importance of comparing the characteristics of groups of young people who are (or are not) participating in their communities in different ways. This will inform the ongoing discussion around whether there is sufficient diversity in the groups of young people who are involved in mental health research, and in involvement more broadly, as raised by a number of authors to date (Collin, Rahilly, et al., 2011; Hagen et al., 2012; Monshat et al., 2012; Simons, 2012).

Additionally, this absence of difference demonstrates that while some groups tend to be less engaged in volunteering and community participation activities—including culturally and linguistically diverse young people (Australian Bureau of Statistics, 2012b; K. Brown et al., 2013; Mission Australia, 2013; Muir et al., 2009)—this absence is not more pronounced in the specific case of involvement in youth mental health research.

Although the number of women and level of educational achievement is higher in this group than in the general population, it can be concluded that it is not significantly different to the other the participant groups examined in the current study. These findings warrant further exploration, as there may not be the strong bias towards young people with these characteristics engaging in research which has been suggested in previous studies. However, it remains important for researchers to make a particular effort to engage young men and those with a lower level of educational attainment. It would also be valuable to acknowledge any bias on in these categories when incorporating feedback from young people.

8.5.2 Young people's motivations (Aim 2)

Aim 2 of YIMHR was to compare the self-reported motivations of young people involved in mental health research to both researchers' perceptions of these motivations and the motivations that other groups of young people report for similar activities. In the present study this was achieved by comparing the groups on the **hierarchy of participation** in terms of their scores on the VFI (i.e. their self-reported motivations for volunteering and the organisations they were involved in); and by examining the self-reported reasons provided by young people who had not participated in their communities. The insights generated will help improve youth involvement in mental health research practice by suggesting ways that recruitment strategies and incentives for young people can be improved, identifying ways that activities can be best tailored to meet young people's expectations and desires, and by identifying ways these motivations can be used to improve young people's experiences of being involved.

The median scores reported by the **mental health** subgroup were significantly higher than the scores reported by the **youth** and **other** subgroups on the VFI enhancement and protective scales (see section 8.2.5, measures). On the Values scale the scores reported by the **CRC** and **mental health** groups were significantly higher than the scores reported by the **youth** and **other** groups. These differences show that the diversity in motivations between groups of young people who participate in their

communities may be related to specific domains. These may be attributable to the topic area of the activity as, if the differences were attributable to the type of activity, they would have also occurred between the groups which engaged in different types of activities (e.g. the **research** group).

A direct comparison of participants' scores to previous work which has used the VFI is limited due to the minimal extent to which the scale has been used in Australian and youth settings. Additionally, the psychometric properties of the short form of the scale used in the present study have not been published. These two factors make it difficult to ascertain if the findings of the current study are similar to previous work. For this reason, it is unclear as to whether the relative scores reported are comparable to young people in the general population, or whether there is a bias in the current sample regarding their motivations for being involved.

The differences in motivation between groups, as indicated by the VFI differences, adds detail to previous findings in this project and previous work in the non-youth involvement literature. Previous findings have suggested that people who choose to be involved in mental health research do so in response to a previous negative experience of either ill health or the health care system (Study 1: Focus groups; Study 2: interviews with researchers, Study 3: Analysis of applications; Study 4: Survey of YBT applicants; Tarpey, 2006). The use of face-to-face methods may have limited young people's willingness to discuss personal experiences in the presence of others. Alternatively, because the groups examined by previous work have been about mental ill health, participants may have believed that this motivation was implicit.

The higher median scores reported by the **CRC** and **mental health** subgroups, compared to the **youth** or **other** subgroups, on the values scale of the VFI is of note. These differences could be attributable to a number of factors. Firstly, groups higher up the hierarchy included young people who were involved in activities which are more specific to a particular topic or area of interest. Young people in these groups may have been able to link the specific values in their lives which motivated them to engage in those more specific activities. Alternatively, young people may have been involved in their communities in order to give back, a finding which has also been suggested by previous work in the area, such as Howe (2011). To reconcile this difference, future work should consider asking young people explicitly about the relationship of their experiences of mental ill health to their choice to be involved.

The majority of motivations identified here in the responses to the open-ended questions have previously been found in the youth involvement in mental health

research literature. Specifically, Mawn, Welsh, Kirkpatrick et al (2015) and Howe et al., (2011) have both noted that young people are motivated to ‘make a difference’ and ‘develop themselves’. In addition, young people in the Howe et al. (2011) study were also motivated by a desire to ‘connect with other people’ and to ‘give back to their communities’, and those in Mawn, Welsh, Kirkpatrick et al., (2015) were motivated to ‘develop themselves’. Other motivations recorded in the health and mental health service delivery involvement areas include, ‘gaining skills and experience’ (Coates & Howe, 2014; Coser et al., 2014; Fleming, 2010; Gyamfi et al., 2007; McDonagh & Bateman, 2012; National Children’s Bureau, 2010; Powers & Tiffany, 2006), the opportunity to achieve positive outcomes for other consumers or young people, e.g. *being interested or believing in the cause or topic* (Case et al., 2014; Coates & Howe, 2014; Ramey & Rose-Krasnor, 2015; Tarpey, 2006), or to *give back to the community* (Case et al., 2014).

The breadth of these findings, and in particular the absence of significant differences between the subgroups on the participant generated motivations, suggest that young people are motivated by a wide variety of factors, and that any homogeneity among groups may be limited to high level motivations, such as those captured by standardised scales. The existence of such variance, and the notion that is indicative of considerable heterogeneity amongst groups, has been identified in previous work examining people’s motivations for engaging in co-creation and innovation activities (Roberts, Hughes, & Kertbo, 2014), but not in work specifically pertaining to young people. The implication is that researchers should consider working with a group of the young people they want to involve, finding out how they want to be involved, and what that specific population group may be motivated by. The guidelines about incentives for youth involvement in health research created by INVOLVE UK, which were written with the assistance of a group of young people (National Institute for Health Research, 2016) are a good example of how this may be achieved. These guidelines include suggestions for researchers but acknowledge the variance in groups of young people and provide suggestions for how researchers can acknowledge this.

Participants were asked to list organisations they had volunteered with, or participated in, in an attempt to ascertain the breadth of differences between participants, and to discern if any patterns existed in the types of organisations different participant groups were involved in. The findings show that young people in all groups were involved in a wide variety of organisations, and that there were no significant differences between participant groups. This absence of significant differences between

groups suggests that recruitment of young people to organisations or research projects might be improved by identifying which organisations young people are already interested in and working with, and recruiting through them. Such efforts may assist in broadening the pool of young people involved to specific population groups which are currently under represented, such as culturally and linguistically diverse young people.

The reasons nominated by participants for not volunteering closely resemble the barriers to involvement and participation nominated by university students in the Study 1 focus groups. The most frequently mentioned barrier, that they ‘feel they don’t have time’, may suggest to researchers that making involvement activities easy to do, and less burdensome on participants, may facilitate participation and involvement. These findings also support the ideas from the interviews with researchers (Study 2) as to why young people do not partake in involvement in mental health research opportunities. This suggests that researchers have a good understanding of why young people choose not to take part. However, researchers may face limitations around the methods and practices through which they are able to involve young people. Some methods may, of necessity, require more time commitment on the part of young people, or are offered at inconvenient times. Researchers need to work collaboratively with both young people and other parties such as funding organisations, and to design processes which work for everyone; for example, finding ways to offer activities outside of work and study hours. These changes would also require input and cooperation from funding bodies and institutions in order to fund, facilitate and support the logistics of researchers working outside of business hours.

Alternatively, there may be differences between young people’s expectations of what involvement in research entails, and what is required of them in practice. This explanation is supported by the results of studies on young people’s experiences of involvement, which are discussed in the following section. It shows that there is a need for researchers and research organisations to involve young people not only at the point of recruitment into an activity, but in an ongoing way both prior to, and after, an experience of involvement. Given the high rates of internet use by this group, one way in which this could be achieved is through interactive social media pages which allow young people to gain familiarity with, and updates about, a project.

8.5.3 Young people’s experiences (Aim 3)

The third objective of the study was to describe the experiences of young people who were involved in the CRC, and to show how this differed from how they would

have liked to be involved. Within the youth involvement in mental health research area, very few (n=3) papers have previously focused on this. Of the papers which have, only Howe (2011) has described these experiences in detail. In the broader involvement area, a comparatively larger body of work has described young people's and consumers' experiences of involvement. However, in both areas, no attempt has been made to explicitly compare the experiences of young people who were involved with their desired experiences.

Understanding the experiences of young people from their perspective may allow researchers to better involve young people in their work. These improvements may be realised by considering the expectations and prior experiences of the young people they are involving, in addition to the needs and directions of the research they are undertaking. This understanding may lead to improvements in the practice of youth involvement by encouraging researchers to involve young people more regularly and actively than they do at present. This may also improve the experience of young people who are involved, by affording themselves and others more opportunities to be involved. This desire was expressed by young people in Study 1 (university student focus groups). In that study they also discussed that they would prefer activities to be as easy as possible for them to access.

The contrast found in this study between the stages of research at which young people wanted to be involved, and the stages at which they were involved, clearly show that young people's interests and desires regarding involvement are broader than the opportunities they are commonly offered. It was only the stage of 'doing research' where experience was commensurate with desire. Across all other stages, young people wanted more involvement than they experienced. The discrepancies which existed between two of the stages ('interpreting the findings' and 'writing a scientific report on the findings') may be attributable to when the survey was administered relative to the timespan of the CRC. It was conducted when most of the CRC projects still had two years of funding remaining. It is possible that the young people involved in the CRC may have been involved in these stages of research after completion of the current study.

These findings suggest that there are some young people who would be willing to be involved at each, or indeed all, of the stages of research. They provide encouragement and impetus to researchers who may be reluctant to involve young people because they believe that some do not want to be involved (Study 2, interviews with researchers). For example, researchers may believe that young people are less

likely to want to be involved at the ‘interpreting the findings’ and ‘writing a scientific report on the findings’ stages. One potential explanation for this belief might be around young people’s own perceptions of what these stages entail; the participants in Study 1 (focus groups with university students) commented that they wanted their involvement or participation to be easy and being involved in documenting a study may not be simple or easy, which may thus be a barrier.

The current study should be considered in light of the work of Hagen et al. (2012), who were commissioned by the CRC to write a guide to using participatory research to develop evidence-based online youth mental health promotion, intervention and treatment. This guide was provided to researchers in the CRC by the CRC head office as a potential stimulus and guide for their youth involvement strategies. In the guide, participatory design methods are described as follows:

... methods and tools from Participatory Design and related fields such as user-centred design, service design, market research and broader qualitative research methods. While used in isolation, these methods (such as focus groups and interviews) may not necessarily be participatory per se, but as part of a participatory framework they are considered Participatory Design methods’ (page 2; Hagen et al., 2012)

According to this description, researchers within the CRC may have viewed methods such as ‘interviews’ and ‘workshops’ as constituting active involvement. Alternatively, they may have used interviews in participatory ways. For example, interviews about setting the topic of the research may be participatory, whereas interviews as part of regular data collection may not be. In doing so, it highlights the subjective nature of the involvement process, and reinforces that above all, involvement processes should be fit for purpose for both the research being conducted, and the young people who choose to be involved. While this study has succeeded in documenting young people’s perceptions of the stages they were involved in, and their own perceptions of involvement, it has not linked these experiences to the specific studies they were involved in, and thus determining if these were fit for purpose cannot be easily established.

This study has examined young people’s experiences of involvement. It builds on the limited amount of work which has described young people’s experiences of involvement from their point of view (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Mawn, Welsh, Stain, et al., 2015), and the previous study in the project (Study 4 Survey of advisory group applicants). The high levels of endorsement on all of the

statements about their experiences of involvement show that young people who are involved have positive experiences, that they are comfortable asking for help, and that they feel as if they are members of the research team. These specific findings are encouraging and provide support for the previous broad conclusions that youth involvement has a positive effect on the young people who are engaged, in addition to the benefits that involvement processes bring to research (Chambers et al., 2012; S. Chen et al., 2007).

Future work could build on these findings by using the items from this survey or developing others more relevant to the specific project. One way to do this would be to measure young people's expectations before their research involvement, and then contrast these with their experiences collected post-involvement. Presenting these findings with direct reference to the researchers' account of their project could establish the impact of involvement at the specific stages. This body of work would lead to the development of a comprehensive understanding of the impact of youth involvement on young people. An example of an attempt to create such a measure was described by Scott and Wale (2017) in the area of consumer involvement in health services development. Their measure comprised a 16-question survey about consumer involvement in health services development which asked about the characteristics, stage, nature of involvement and what support the consumers who responded to it received from the organisations they were involved in. This measure could be used as a starting point for the creation of a measure specifically designed for youth involvement in mental health research.

The final area examined was young people's comments about their involvement. Once again, the low number of comments limits their generalisability. However, what can be understood is that young people's experiences were not clearly linked to the ways they were involved, or the number of times they were involved. This lack of relationship is interesting, as it further reinforces the above conclusions that research involvement should be fit for purpose, both for the project and for the young people who are involved. The most clearly negative experience reported was that other young people did not respect the participant's gender identity. This shows the importance of researchers working with young people to ensure that the experience is safe and positive for all involved. As suggested in Study 3 (analysis of applications), consideration should be given to promoting the use of self-care strategies among young people when they are involved and working collaboratively with mental health professionals, if required, to provide support. Where minority groups, such as gender diverse young

people are involved specifically, greater supports and communication may need to be considered with regard to interpersonal dynamics.

8.5.4 Limitations

The recruitment methods used led to lower-than-expected participant numbers in two of the targeted groups. The first of these groups was the young people who have not participated in research or their communities (the *None* group). Involving a group who is disengaged from their community is one of the key challenges in involvement practices. This challenge, which was also highlighted in Studies 1 and 2 (university student focus groups and researcher interviews), is an area that would benefit from further research. While the present study is able to contribute to an understanding of the characteristics of young people who participate in their community, and volunteering in some capacity, the small proportion of respondents who reported as not having participated means that any conclusions drawn from this group may lack generalisability.

The second participant group for which there were lower than anticipated numbers was the **CRC** subgroup. For participants to be recruited into the **CRC** subgroup, researchers had to choose to include the young people who had been involved in their study in the survey, and then the young people themselves had to choose to participate in this study. To ascertain if any biases could be related to which researchers decided to take part in the survey recruitment process, the topics, research methods and disciplines of the CRC projects who participated were analysed. No trends were identified that may have influenced the responses given to the survey by the young people who were involved. However, as described above, the extent to which information provided to the researcher reflected the actual processes of the investigators varied considerably across the CRC.

Related to this was the question that identified whether participants had previously volunteered with the CRC. The list of project names used in the question was provided by the CRC head office and reviewed against the CRC's website and the researcher's own knowledge. However, there were differences between these names and how the projects had identified themselves in their own recruitment strategies. These differences were not detected until recruitment had commenced, meaning that the question could not be altered. This may have resulted in young people not being able to identify a project that they may have been involved in, and thus may have contributed to the low number of CRC participants in the survey.

In addition, the recruitment of participants in this way meant that linking the young people to the specific research project they were involved in within the CRC was not possible. Hence, the findings are able to provide general insights into the practice of youth involvement, but not about the profile of the groups who are recruited for specific projects.

The distribution to the researcher's Facebook friends may have contributed to some of the biases present in the results. As a woman in her mid-twenties undertaking postgraduate education and living in a major city, it is reasonable to assume that a higher proportion of her friends share some or all of these characteristics than would be found in the general population. Given that these biases were evident in the sample, this recruitment strategy should be considered a limitation.

Finally, two limitations arose from the survey design: social desirability and the use of short-form measures. An important limitation when considering findings related to motivations for volunteering is the impact of social desirability. This bias may have impacted participants' responses in an attempt to make themselves appear more generous or charitable than they actually are.

The survey measured a wide variety of concepts, which meant that using long-form measures for all these concepts might have resulted in an unnecessarily high level of participant burden. To reduce this, the shortest available forms of measures were used. For example, the 13-item version of the Volunteer Functions Inventory (VFI) was used. This version, while theoretically understood to have many of the same properties as the standard 30-item version of the scale, has not been widely used. As a result, findings to which the results of the present study can be compared were limited.

8.6 Summary

Comparing the characteristics and motivations of young people who are involved in youth mental health research to those who are involved in their communities in other ways has shown that on the majority of measures they are not significantly different to this broader group. While this should provide confidence both to those who involve young people and in the results of the work, the significant differences on mental health related measures are of note. These have quantified existing assumptions in the field. Reflections on the processes used in this and other studies strongly suggest that avoiding these biases is a complex challenge that will require collaborative efforts, including from Human Research Ethics Committees.

Young people have shown that they would like to be involved in research more than they are currently given the opportunity to. In spite of the probable selection bias toward CRC projects which had more actively involved young people, this finding clearly suggests that researchers should consider more active and innovative ways to involve young people in their research projects. The implications of these findings, and how they compare and contrast with other YIMHR results, are discussed in the final chapter.

9 Discussion and conclusion

9.1 Summary of work and key findings

The Youth Involvement in Mental Health Research (YIMHR) project set out to improve the practice of youth involvement in mental health research by increasing the understanding of the characteristics, motivations and experiences of the young people who would either like to be, or are, involved in mental health research. This was achieved through an examination of youth involvement in mental health research in an overarching research organisation, the Young and Well CRC (the CRC), through the use of five studies. Specifically, three areas were examined: who these young people are (Aim 1), their motivations (Aim 2) and their experiences of being involved (Aim 3). Each of the five studies used a different research method and contributed to between one or more of the project aims, as illustrated in Figure 9.1.

Despite recognition of involvement in policy, there remains a lack of direct exploration about the practice of it and, in particular, descriptions of the people who choose to be involved. The YIMHR project made an initial step towards filling this gap in the literature by describing the characteristics, motivations and experiences of young people who are involved in youth mental health research from their point of view. By examining similar issues across five studies, this research has shown that there are some clear similarities between them. They have higher rates of mental ill health than the rest of the population and, coupled with a desire to further their relationships with other people, this motivates them to be involved. Their descriptions of being involved and how they would like to be involved show that there is a discrepancy between what they experience and what researchers think they experience. The increased understanding of these areas provided by this project will allow researchers to improve the processes they use to involve young people and will contribute to the wider adoption of consumer involvement in mental health research.

	Aim 1: Characteristics	Aim 2: Motivations	Aim 3: Experiences
Study 1: University student focus groups (Chapter 4)	✓	✓	✓
Study 2: Researcher interviews (Chapter 5)	✓	✓	✓
Study 3: Analysis of advisory group applications (Chapter 6)	✓	✓	✓
Study 4: Survey of advisory group applicants (Chapter 7)	✓		✓
Study 5: Survey of community members (Chapter 8)	✓	✓	✓

Figure 9.1 YIMHR project aims and studies

The CRC was an overarching research organisation that examined young people’s mental health, technology and wellbeing. All of the research projects funded by the CRC were required to actively involve young people throughout their work. While the degree to which this occurred varied between projects within the CRC it was, at the time of writing, one of the largest known instances of youth involvement in research. The large size of the CRC enabled the exploration of youth involvement on a much larger scale than has been previously reported in the small studies that dominate the literature in the area at present.

The preceding five chapters have detailed each of the studies independently. This final chapter compares these findings with the existing literature in the fields of: youth involvement in mental health research, consumer and youth involvement in research and mental health service delivery and youth civic participation (Section 9.2). How these findings can be applied and used in the above fields, and the implications for current and future research and organisational practice, are discussed. Suggestions are

made for a range of roles and organisational levels (Section 9.3). The strengths and limitations of the project are outlined focusing on those that may impact on the interpretation and use of the findings (Section 9.5). Finally, future directions for both research and practice are explored (Section 9.5).

9.1.1 Young people's characteristics (Aim 1)

The findings pertaining to Aim 1 show that the young people who are involved in youth mental health research experience high rates of mental ill health and help seeking, have positive attitudes toward mental ill health, and regularly participate in their communities. Researchers in Study 2 expressed divergent views regarding whether the groups who are involved are sufficiently diverse but did note that they thought the proportion of young people from culturally and linguistically diverse backgrounds was lower than ideal. These findings, which are drawn from all five YIMHR studies, have implications for the ongoing discussion about diversity and inclusiveness in involvement.

Young people who are interested in being involved, and who are involved, in youth mental health research have high rates both of mental ill health, and help seeking for these experiences. This finding emerged from all of the studies with young people interested, or involved in the CRC and was mentioned by the researchers interviewed in Study 2. The proportions of applicants to the Youth Brains Trust (the YBT; Study 3) who had experienced mental ill health were statistically significantly higher than has been found in the general population. In Study 5 (survey of community members), rates of mental ill health and help seeking were higher in groups who had participated in research but lower young people who chose to participate in non-research mental health organisations. High rates of mental ill health were also reflected in the self-descriptions of young people in the analysis of advisory group applications (Study 3).

From Studies 3, 4 and 5, which examined young people who were interested or involved in youth mental health research, it also emerged that these young people are comfortable seeking help for experiences of mental ill health and had likely done so previously.

Those involved are also knowledgeable about mental ill health. This is demonstrated by high levels of awareness of others' experiences of help-seeking for mental ill health (Studies 3, 4 and 5), high levels of mental health literacy (Studies 3, 4 and 5) and low levels of mental health stigma (Studies 4 and 5).

In Study 4, the proportion of applicants to the YBT who had obtained a bachelor's degree was found to be statistically significantly different to that of their peers in the Australian population. However, similarly high rates were not found in Study 5 (survey of community members). These higher rates may be able to be explained by the high proportion of university students who volunteer (Australian Bureau of Statistics, 2012a; McCabe et al., 2007).

Other than a bias toward young people who are more highly educated, none of the demographic characteristics measured in the quantitative studies (Studies 4 and 5) were found to be significantly different from the general population or from other groups of young people who had participated in their communities. However, it is important to note that this may have been limited by the small sample size in Study 4 and the low number of participants in particular population groups in Study 5.

9.1.2 Young people's motivations (Aim 2)

Investigating what motivates young people to be involved in youth mental health research, from their point of view, may have important implications for improving involvement practices. This was explored in four of the studies: university student focus groups (Study 1), researcher interviews (Study 2), survey of advisory group applicants (Study 3), and survey of community members (Study 5). The most frequently found motivation, mental ill health, was described by both researchers and young people.

One area of congruence found between young people's characteristics and motivations was that young people are motivated to engage in research by their previous, sometimes negative, experiences of mental ill health. This finding emerged across all studies that examined the area: university students suggested that a previous experience of mental ill health could be both a barrier and facilitator to being involved (Study 1), YBT applicants discussed previous negative experiences as a reason to try to change the health outcomes and experiences of others (Study 3), and young people involved in both mental health research and non-research mental health groups were motivated to take part because of their experiences of mental ill health (Study 5). This was also supported by researchers who proposed that it might be a reason young people chose to take part in involvement activities (Study 2).

Young people are also motivated to become involved in order to maintain and improve their relationships with both their peers and researchers. The prospect of interacting with other young people that they already know, or new people within their peer group as part of involvement activities, was identified as a motivating factor by

young people in Studies 1, 3, and 5 (university student focus groups, analysis of advisory group applications, survey of community members). Similarly, building on existing, or developing new, relationships with researchers and organisations emerged as a motivating factor in the same set of studies. However, this finding may be directly related to the research methods used in these studies. The majority of participants in the focus groups had a pre-existing relationship with the researcher, and many of the applicants to the YBT either had an existing knowledge of, or had researched, the organisation in order to boost the potential success of their applications.

Finally, young people take part in youth mental health research involvement to learn more about the research topic, and to gain skills in that area. These skills were both career-focused and more wide-ranging, including personal development. This emerged not just through the analysis of advisory group applications (Study 3), but also in the university student focus groups (Study 1) and the open-ended responses of young people involved in the CRC within the survey of community members (Study 5).

9.1.3 Young people's experiences (Aim 3)

The final project aim was to compare young people's actual and desired experiences of involvement in mental health research, and to contrast this with how researchers involve young people. The results show that young people would like to be involved to a greater degree than has been offered to them at present.

Two studies compared young people's actual experience of being involved with their desired experience of taking part in involvement activities (Studies 1 and 5). These studies indicated that young people wanted to be more regularly involved, and at more stages of the research process, than they currently are. They would like to be offered opportunities to be involved in all research stages and through a variety of mechanisms. The interviews with researchers provided a point of contrast to these experiences by exploring how they had involved young people in their work in the CRC (Study 2). Researchers believed they already involved young people across all research stages. This disparity suggests that either opportunities for young people to be involved at all research stages do exist. However, researchers may not be consistent in communicating this; or that the depth and frequency of involvement processes may not be consistent throughout the research stages of a project. As noted in the previous chapters, the project did not link specific CRC projects to the young people's accounts of being involved, and in the case of Study 1 (university student focus groups), this would not have been possible. This finding illustrates that perceptions of involvement can vary

between groups, even within the same broad research program. It emphasises that evaluations of involvement activities should include the perspectives of all parties, not just those who conduct them. Those in a position of greater power (the researchers) may have a more favourable evaluation of their work than those who are the beneficiaries of it (the young people).

Young people's experience of being involved was largely positive despite differences between their expectations and reality. Studies 1 and 5 showed that where young people had taken part in involvement activities they found this to be enjoyable and felt that they learned and developed as a result of the experience. Researchers also believed this to be the case, as described in Study 2. The findings of Study 4 indicate that any changes that young people experienced as a result of their involvement were not significantly different to those of the young people who were not involved.

These findings show that having a desire to be more involved than they currently are does not preclude young people from enjoying the activities they can take part in. It is encouraging that the efforts made by researchers to involve young people have positive outcomes, not only for their own research but for the young people who are involved. It suggests that, if and when researchers expand the extent to which they involve young people, they should continue to use some of the same techniques. However, they should also use these findings as an opportunity to learn from young people and using young people's contributions to build their practice.

9.2 Comparison with previous research

Consumer and community involvement in research is a growing field, but to date, there is limited data available about the practice of involvement. Despite mentions of involvement in high level policies and practices both within Australia and internationally, the translation of these broad directions into documented action remains limited. Where action has been documented, this has predominately been from the perspective of researchers and health practitioners. With some exceptions, this work has not described the consumers who are involved in shaping the work. Work which has done so notes that they are typically female, and educated or involved in education. The motivations of these groups, which have been more regularly described in the adult consumer involvement literature than the youth literature, include making improvements to the research process and to their own lives. When consumers and young people are involved, they have positive experiences and report increased skills, mental health and expansions of their networks. The YIMHR project represents an

advance in the research that has focused directly on these areas. The scope of this PhD project allowed young people's perspectives to be heard and compared in a way that may not have been feasible for the smaller scale research projects typical of the existing literature.

Examination of the characteristics of the young people involved in research shows that a substantial proportion of young people who are interested in being involved in research, or who are involved in research, have an experience of mental ill health. The incidence of young people who have an experience of mental ill health appears to vary depending on the topic or goal of the research project (Howe et al., 2011; Mawn, Welsh, Kirkpatrick, et al., 2015; Ross et al., 2012). For example, in the cohort of youth consultants described by Howe et al., (2011), 37% of the young people were current or previous users of mental health services. The phenomenon of people with an experience of a particular health condition taking part in research as a direct result of that experience, has also been reported in the adult involvement literature (Tarpey, 2006). These links suggest that, higher rates of health conditions related to the topic of investigation may be attributable to researchers actively targeting people with these characteristics. A novel finding from this project is the higher proportion of people with an experience of mental ill health found within groups of applicants to advisory groups, such as the YBT. This suggests that where studies need to involve young people without an experience of the health condition they are investigating, researchers will need to use specific selection criteria to include young people without these conditions or exclude those with them.

Other characteristics of note are that these young people are predominately students and have high rates of educational attainment. In the two papers which have reported on activities that young people were taking part in outside of the research project, there was a high level of student representation (Howe et al., 2011; Monshat et al., 2012). These rates are slightly higher, but broadly similar, to the rates of students in the general Australian population who regularly volunteer (Australian Bureau of Statistics, 2012a; McCabe et al., 2007). Similarly, there was a high rate of educational attainment among participants, with significantly higher rates of educational attainment found in Study 4 (survey of advisory group applicants) than in the general population. Within the youth involvement in mental health research literature, the rates of educational attainment of people who are involved has not been reported. However, in the adult involvement literature, two studies have suggested that consumers who choose to be involved are educated (Patterson et al., 2014; Tarpey, 2006). In particular,

Patterson, Trite and Weaver's 2014 survey of the activity and views of services users involved in mental health research found that the majority (63.9%) of consumers have completed tertiary education (Patterson et al., 2014).

The findings from the YIMHR project suggest that young people's motivations for being involved in mental health research are similar to their motivations for being involved in mental health service delivery, and consumers' motivations for being involved in research and service delivery. The new contributions of this study include the knowledge that young people's experience of mental ill health is a motivating factor and that young people are motivated by their relationships with other people. This highlights the importance of researchers and organisations actively investing time and effort into relationships with youth organisations and young people, and that consideration should be given to involvement processes which afford young people the opportunity to connect with others.

In this project, young people's experience of mental ill health was found to be a factor which motivates them. A similar motivation—a previous bad experience of health or the health care system—was reported by Tarpey (2006) in her exploration of motivations for being involved in health and social care research. Other than these limited findings, this motivation has not been previously reported. This absence may be because the issue has not been explored in the same level of detail as in this project. A wide range of more general motivations, such as the desire to make a difference, has been reported in both the mental health and broader involvement literature (Cargo & Mercer, 2008; Coates & Howe, 2014; Mawn, Welsh, Stain, et al., 2015; Ramey & Rose-Krasnor, 2015). This finding suggests that actions, such as choosing to be involved, can be driven by a previous negative experience related to the topic of the action. The idea that negative experiences can lead a person to engage in positive behaviour has been widely acknowledged by philosophers and psychologists from Frankl onwards (Frankl, 1946; Updegraff & Taylor, 2000). What has not been articulated in the youth mental health research field are the specific ways in which young people may engage as a result of a negative experience of youth mental health. The findings suggest that research may be considered by young people to be a positive and healing experience. Researchers should consider responding by using processes which allow young people time and space for discussion about their mental ill health, and creating spaces which are conducive to self-care.

Young people were motivated to take part to build and maintain quality relationships. This has been discussed in the youth involvement in mental health service

delivery literature, but not in the specific mental health literature (Coates & Howe, 2014; Collin, Metcalf, et al., 2011; Ramey & Rose-Krasnor, 2015). For example, studies with young people have shown that they are motivated to build and maintain quality relationships with themselves and researchers (Ramey & Rose-Krasnor, 2015) and each other (Coates & Howe, 2014). The young people in the current study may have been primarily motivated to maintain and further existing relationships, rather than to establish new relationships. This may be due to the existing relationships that many of the young people had with the primary researcher and/or the CRC.

The focus on young people's experiences of being involved has shown that they have a different experience from the researchers who involve them. For example, young people expressed that they would like to have the opportunity to be involved more regularly and in each stage of the process, rather than what they perceive to be the currently limited opportunities. A similar dissonance was found in Rutter et al.'s (2004) case studies of user involvement in health services in the UK. In this study, interviews with all stakeholders showed that the desires and expectations of service users and professionals differed from one another with regard to the extent that users were involved. As noted above, these findings demonstrate the need to evaluate and explore experiences of involvement from the point of view of all stakeholders, not only those who conduct the work.

The finding that young people want to be involved more regularly than they are, and at each stage of the process, shows that researchers need to strongly consider involving young people in more active ways. As explored in Section 2.4.1, a range of processes can be used to achieve the active involvement, participation and engagement of consumers and community members. The focus in the data collection on young people's perspectives precludes an analysis of the processes employed by the CRC. However, it can be surmised from what young people expressed that the processes used are likely to have focused on the lower stages of the IAP2 spectrum, or have been limited to involvement at only specific stages. When considered in light of the finding that the young people who are involved are more highly educated and that their motivations include improving relationships with researchers and gaining new skills, it suggests that there is scope for methods higher up the spectrum to be used. For example, the young people who want to be involved may have, or be willing, to develop skills to be co-researchers or to lead research themselves.

9.3 Practical implications of findings

The active involvement of consumers and community members in research, and in health and social care delivery, is at a stage of growth and development throughout the world. It is increasingly incorporated into national-level policy and rhetoric both within the mental health and broader health and social care sectors. In Australia, this can be seen in the mentions of involvement in national research and health policies over the last 20 years. Within mental health, the need to more actively involve consumers and community members has been in all national mental health strategies and plans to date, from the first mental health plan in 1993 to the fifth in 2017 (Australian Health Ministers, 1993, 2017). Within the broader Australian health sector its importance is demonstrated by the joint statements from the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (2002; 2016), and the strategic framework for the Medical Research Future Fund (Department of Health, 2016). It is also shown through the inclusion of consumer representatives in decision making bodies such as the Medical Services Advisory Committee and the Pharmaceutical Benefits Advisory Committee (Medical Services Advisory Committee, 2017).

Despite its visibility in high-level policy, the actual practice of involvement remains sporadic and varied. The differences between the 2002 and 2016 joint statements of the National Health and Medical Research Council and the Consumers Health Forum of Australia are a good example. The first iteration of the statement in 2002, was a bold and challenging call to action toward a more thorough involvement with communities and the funding of projects that genuinely and actively involved consumers and community members in research. The updated statement in 2016 is not as strongly worded, and arguably does not embody the same mandate as the 2002 statement. Also indicative of this backward trend is the omission of consumer and community members in the execution of the disbursements of the Medical Research Future Fund (the MRFF), despite recognition of the importance of consumer and community involvement throughout the strategy which informs it (Department of Health, 2016).

Consequently, the work of this thesis is timely and relevant to current policy debates. It is timely because it shows that young people are interested in being actively involved. It has provided suggestions for researchers of ways that they can capitalise on

these motivations, such as offering more opportunities to people to be involved and making these opportunities easier to access.

If consumer and community involvement is to be realised and fully utilised as the important and valuable process that it is, then work such as this needs to continue and be used to assist this translation from policy into ongoing practice. An important aspect of this will be increasing both researchers', and the research community's, understanding about the communities of people who they want to involve.

A barrier to achieving this is that current research practices appear to restrict how involvement is reported in the academic literature. To date, there has been minimal reporting about the young people who are involved, and many of the findings from this project have only been obtainable through comparisons between the studies. Other than a PhD project, one way to examine consumers on a larger scale in future work may be to collect descriptions of consumers who were involved in research in open data depositories. Specifically, researchers could make available in data repositories details about the consumers they have involved and how they have involved them. This would allow researchers to examine work across research projects and institutions, and to create larger, or more detailed, datasets about the people who choose to be involved and the practice of involvement. If this was to be attempted, people who were involved would need to be made aware of it, and such information may need to be added to human research ethics protocols to ensure that those who were involved were able to opt out of this data collection.

In addition to improving the retention of details about the consumers who are involved, there is also a need to improve the frequency and quality of how involvement is reported on and described in the academic literature. One attempt to do this was the creation of the reporting framework, Guidance for Reporting Involvement of Patients and the Public (GRIPP) and its successor, GRIPP2 (Staniszewska et al., 2017). These frameworks are an accessible way for researchers who are new to involving people to understand the essential elements of involvement and provide a guide for existing researchers to improve their practices. Section 4 of the long form of the GRIPP2 framework: methods of paper, and section 4b: people involved, are particular areas which should be reported on more frequently. As the authors of the framework note:

‘... more effective synthesis of the evidence base will help identify best practice, avoid poor practice, and contribute to research that is acceptable, relevant, appropriate and high quality and that has the potential to generate benefit for all’ (page 6; Staniszewska et al., 2017).

The difference in perspectives between how young people experience involvement and how researchers believe that young people do, as described in the results pertaining to Aim 3, shows the need for greater levels of communication between researchers and the consumer and community members who they are involving. The disparities in the way that research stages are discussed may be indicative of broader miscommunications between researchers and young people which will need to be rectified. This suggests a need for further investment in, and consideration given to, pre-involvement meetings in which expectations and terminology are discussed openly between groups, and agreement reached before involvement activities are commenced. Doing so may help ensure that all groups have a more satisfactory experience of involvement, and that the outputs are reliable and comprehensible to all parties.

While the proportion of people across the project who reported that they had experienced mental ill health was higher than the broader Australian population, the group was not representative of all those who exhibit mental ill health. Significantly higher proportions of groups known to have higher rates of mental ill health, such as Aboriginal and Torres Strait Islander populations and people who have a mental illness and may not be high functioning, were absent from the project. This is of note when considering the involvement of population groups who, due to their own or others' perceptions, may have less perceived agency within research involvement. It suggests that these groups either may not want to be involved at all, or that different recruitment and retention techniques will be required to include them. For example, people from Aboriginal or Torres Strait Islander backgrounds may have different conceptions of mental ill health to non-indigenous Australians. Also, people with lower levels of functioning may find it challenging to engage with typical forms of research involvement. The absence, or limited involvement, of both of these groups in the work shows the importance of tailoring research involvement to the needs of particular groups. With regards to culturally diverse groups it shows the importance of researchers speaking to people in their own languages and working within cultural and contextual understandings, rather than assuming that people who they want to involve have the same understandings and beliefs as themselves. When aiming to involve people with lower levels of functioning it shows the importance of researchers tailoring involvement to them, such as using offline methods or methods which do not assume a level of pre-existing knowledge or capability.

9.4 Implications for theory

While the project was based on practical experiences and lived experience, some implications have emerged for social identity theory and the theories which underpin consumer and community involvement.

The results of this project indicate that youth involvement and, involvement in general, should not necessarily adhere to particular theoretical frameworks. While involvement initially arose from theoretical positions, at present it is a highly pragmatic area which is best concerned with frameworks for particular types of involvement. This may encourage researchers with little formal training in the area to use involvement techniques by reducing the barriers to entry. It may also allow for greater innovation in the space, which as identified in this work, is an important next step.

The results from Study 1 (university student focus groups) suggested that one strategy to increase recruitment would be researchers demonstrating to young people that they have shared group memberships. This finding provides a practical example and application of social identity theory. While further work should be undertaken to establish this finding more clearly, the results from this project suggest that researchers demonstrating shared group memberships has a positive impact on research recruitment.

9.5 Strengths and limitations

An overarching strength and limitation of the project was that the approach taken was exploratory, data driven, and not situated in a specific involvement tradition. Instead, it was informed by the researcher's lived experience of being actively involved in mental health research and service delivery. This was the most appropriate approach available given the minimal work in the area to date, the way the CRC approached involvement, and the range of traditions that the field of consumer and community involvement draws on. It contributed to a number of strengths and limitations of the project.

The researcher (RR), and two of her supervisors (KG and LF), were funded by, and had relationships with, the CRC. RR had previously worked with members of the CRC head office and was involved in the CRC as a member of the YBT; and KG and LF were investigators on another CRC project. Without these relationships, RR may not have been able to access the data sources and participants for the studies nor have the insights into the topic that provided the basis for many of the areas of exploration. For example, RR had observed high rates of mental ill health in her peers who were

involved in the CRC. This specific experience informed the selection of the questions about mental ill health in Studies 1, 4 and 5 (university student focus groups, survey of advisory group applicants and survey of community members). In order to mitigate these relationships, RR continually reflected on this potential influence and worked with two supervisors (MB and AC) who were not affiliated with the CRC. In addition to this, participants in all studies were aware that the research was funded by the same organisation that was being investigated. This may have increased the likelihood that participants, particularly the researchers in Study 2, were more favourable in their reporting about aspects of youth involvement than they may have been if RR was independent of the CRC.

A limitation related to the above, which would have also strengthened the project, would have been the greater use of involvement mechanisms in the YIMHR project beyond the researcher being a consumer researcher. These could have included increased consultation with existing advisory structures like the YBT. For example, having a defined group of other young people and the use of their networks may have helped to expand the available range of young people who could be recruited from the community as participants in Study 5. Alternatively, young people could have provided feedback on the design of the project or the specific content of the surveys and research questions. As outlined in Section 3.9, these involvement mechanisms were not used for a range of reasons, but primarily because of the requirements of the PhD qualification around independent research.

A limitation of the project, that could have been overcome with more extensive use of involvement processes, was the significant recruitment challenges in Studies 4 and 5. As detailed in the respective chapters, the numbers of young people from the CRC who responded to survey invitations was low. This has meant that any conclusions drawn may not reflect the experiences of all participants in the CRC. Future work could consider using incentives to increase participation rates, as well as planning the studies into the overall research group design to ensure that other researchers are aware of the studies and their requirements from the outset of their work. Had Study 5 been pre-planned into the work of the CRC, investigators could have recruited young people in ways which allowed them to be recontacted. This would have enabled the experiences of a larger group of young people, who had been involved in shaping and designing the work of the CRC, to be examined. An alternative way to address this would be to include in consent procedures the opportunity to opt-in to being recontacted for future studies. This approach is consistent with current directions in research ethics which

value the re-use of research data and more flexible relationships between researchers and participants. It may also help fulfil the preference, expressed by participants in Study 1, for ongoing research involvement and for researchers to have ongoing relationships with communities.

As noted in Chapter 1, Section 1.2 (terminology), there is no universally agreed upon term to describe the active involvement of consumers in research. The terms used by the CRC head office included ‘youth participation’ and ‘end user engagement’ but how these terms were used varied within the CRC and across projects. This linguistic breadth is a challenge in the involvement space and was particularly challenging when the project was being devised and conducted. For example, what was meant by researchers in the CRC when they used terms such as ‘participatory,’ ‘involvement’ and ‘engagement’ may have varied to a greater extent than was captured in the qualitative analysis in Study 2 (researcher interviews) and Study 5 (survey of community members). As noted in the limitations sections of the relevant chapters, this could have been overcome by presenting a specific definition to participants prior to the interviews and the survey.

The qualitative description (QD) approach used in the three qualitative studies in the project was supported by evaluating the use of this approach against the strategies, or validity criteria, proposed by Milne and Oberle (2005) for QD: authenticity, credibility, criticality and integrity. Authenticity was supported in Study 1 through the use of participant driven data collection, where the focus groups were guided by participants, with additional probing questions being asked in some groups and not in others. In Study 2, it was supported by a strictly purposive sampling strategy, ensuring that a range of researcher voices from across the CRC were heard and in both studies 1 and 2 it was supported by thorough checking of the transcripts to ensure that the transcripts were accurate. In Study 3, it was supported through the method of data collection, archival data analysis, which meant that young people’s voices were not filtered through a researcher-imposed data collection framework.

Credibility, defined as capturing and portraying a truly insider-perspective, was supported in all studies through the design of the project, which emphasised participant’s voices and ideas rather than researcher posited ideas about youth involvement. Criticality was supported through the involvement of the supervisory team in all research design decisions, which ensured that there was as high level of transparency and accountability for the researcher, leading to a high degree of critical appraisal on each design decision. Similarly, integrity was supported through the

scrutiny of the supervisory team over the course of the project. It was also supported through the researcher continually reflecting on her own biases, as evidenced in the above paragraphs.

A strength of the study was the variety of methods used, which meant that those findings which emerged from more than one study could be more firmly established than if they had only been investigated through only one method, participant group or study. Given the limited existing work, this feature of the project allows the findings to be more confidently generalised and used in future. Where the findings contrast, the project shows that exploring these issues through different methods may produce different findings. Future work should examine the YIMHR project results through different research methods such as in-depth interviews with young people who have been engaged, and further surveys of both researchers and young people.

9.6 Future directions

The YIMHR project has examined youth involvement in mental health research within a specific research organisation, the CRC. While the similarities to previous work suggests that the findings are not necessarily isolated to the CRC context, future work is required to further validate confirm this. Specific aspects which could be varied in future work include investigating involvement in other countries, and expanding the types of research examined from only youth mental health research. In the current project, an attempt has been made to do this by comparing the findings to those of similar studies in the international literature. However, a direct investigation of involvement in a country other than Australia could demonstrate if there are aspects of the findings which are specific to the Australian context.

A standardised tool should be developed which facilitates the ongoing, systematic collection of the characteristics, motivations and experiences of the people who are involved in research. As noted above, some of this information is captured in the GRIPP framework (Staniszewska et al., 2017). However, one of its limitations is that it is designed to be reported prospectively. Prior to the start of a research project, researchers will not know the specific characteristics, motivations or experiences of those they involve. The creation of a tool which facilitates retrospective reporting about the people who were involved, rather than a more comprehensive evaluation of the process of involvement, would allow for this. It would also provide an incentive in the form of expectations and professional obligation for researchers to improve the

regularity with which they use involvement, and the specific details of the involvement they carry out.

Systematic collection of this data, using the proposed tool, could be hosted by research funding bodies or groups that promote consumer involvement in research. In the United Kingdom, this role could be undertaken by the National Institute of Health; and in Canada, the Canadian Institutes of Health. In Australia, no clear suitable body yet exists. The largest Australian health research funding body, the National Health and Medical Research Council, could be considered to have a questionable track record of requiring genuine consumer involvement in the research that it funds. At the time of writing, an alternative government research funding scheme, the Medical Research Future Fund (the MRFF), is being developed. Its future administrative system may be able to include this type of monitoring and reporting function.

In addition to these direct extensions of the research project, greater funding and resourcing of active involvement needs to be addressed. Funding was identified by researchers in Study 2 as a factor which impedes their current practice of involvement. One of the reasons for this may be that research which involves consumer and community members typically produces benefits that are longer term and thus potentially less visible to funding organisations. These benefits, such as greater uptake of the outputs of research by community members and policy makers, are less tangible than traditional outputs such as peer reviewed papers. Thus, if greater funding is to be achieved, a paradigm shift in how involvement is valued is required. With additional funding, involvement activities could be enriched through a range of mechanisms such as additional researchers to focus on involvement specifically, and direct investigations of ways that involvement can be made easier for consumers. Having additional researchers in a team would enable projects to focus on the process of involvement; for example making involvement opportunities easier for consumer and community members to access by hosting them at convenient locations and times.

This project has shown that there is not one homogeneous group of young people who are interested in being involved; rather, they have a broader range of characteristics and motivations than have been identified in previous work. One way in which these findings could be translated into action would be through the development of training for researchers. For example, the finding that young people are motivated by experiences of mental ill health could be incorporated into training to help researchers tailor their work in suitable ways to groups who may be more vulnerable than others. Examples of organisations who provide training and education to researchers and

community members do currently exist, but these groups do not presently focus on mental health research. These organisations include the Consumer and Community Health Research Network at the University of Western Australia and INVOLVE UK (Consumer and Community Health Research Network, 2018; National Institute for Health Research, 2018b). An area of future development for these, and similar organisations, could be the development of guidelines and training specifically for the mental health field. As noted by the university students in Study 1, young people with an experience of mental ill health may prefer to be involved in different ways to young people who do not. As recommended in Study 3 (analysis of applications), when people with an experience of mental ill health are involved, researchers may need to encourage them to engage in self-care activities, or to work with their chosen health providers if there is a possibility that the experience of being involved may cause distress. This shows that there is a need for mental health specific guidelines and procedures, beyond those for non-mental health involvement.

9.7 Conclusion

Consumer and community involvement is a widely supported, but not necessarily widely adopted, concept and range of practices. It is included in high-level policies both in Australia and internationally. While the quality and quantity of academic research in the area is developing rapidly, consumer and community involvement is yet to be used consistently in health research and health service delivery. The use of consumer and community involvement within youth mental health research is a critical tool to help reduce the gap between high rates of mental ill health and the low proportion of young people who seek help (Bhugra, 2010; Swanton et al., 2007). This gap may be due in part to researchers bringing presuppositions to their work, and they may have different objectives to the young people when designing treatments and interventions for young people. For example, products designed without the involvement of young people may be effective but may not have high relevance to, or uptake among, young people.

The YIMHR project represents a strong start to more comprehensive research in this field by describing the characteristics, motivations and experiences of young people who choose to be involved in mental health research. Further work is required to establish if, or to what extent, these findings can be generalised outside of youth mental health research, or in other countries. The project provides a basis from which this exploration can begin and suggestions for how this exploration could be achieved.

References

- Agresti, A. (2007). *An introduction to categorical data analysis*. Hoboken, NJ: Wiley.
- Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian and New Zealand Journal of Public Health*, 25(6), 494–7.
- Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*, 35(4), 216–224.
- Australian Bureau of Statistics. (2006a). *How Australians Use Their Time 2006*, cat. no. 4153.0. Canberra.
- Australian Bureau of Statistics. (2006b). *Voluntary Work, Australia*, cat. no. 4441.0. Canberra.
- Australian Bureau of Statistics. (2007). *National Survey of Mental Health and Wellbeing: Summary of Results*, cat. no. 4326.0. Canberra: ABS.
- Australian Bureau of Statistics. (2009a). *Disability, ageing and carers, Australia: summary of findings*, cat. no. 4430.0. Canberra.
- Australian Bureau of Statistics. (2009b). *Household Use of Information Technology Australia 2008-09*, cat. no. 8146.0. Canberra.
- Australian Bureau of Statistics. (2011). *Household use of information technology, Australia, 2010-11*, cat. no. 814. Canberra.
- Australian Bureau of Statistics. (2012a). *A Comparison of Volunteering Rates from the 2006 Census of Population and Housing and the 2006 General Social Survey, Jun 2012*, cat. no. 4441.0.55.002. Canberra.
- Australian Bureau of Statistics. (2012b). *Australian Social Trends: Using Statistics to Paint a Picture of Australian Society*, cat. no. 4102.0. Canberra.
- Australian Bureau of Statistics. (2013). *Australian Statistical Geography Standard (ASGS): Correspondences, July 2011*, cat. no. 1270.0.55.006. Canberra.
- Australian Bureau of Statistics. (2014a). *Aboriginal and Torres Strait Island health survey: first results, Australia 2012-13*, cat. no. 427.0.55.001. Canberra.
- Australian Bureau of Statistics. (2014b). *General Social Survey: Summary Results*, cat. no. 4159.0. Canberra.
- Australian Bureau of Statistics. (2014c). *Population by Age and Sex, Regions of Australia*, cat. no. 3235.0. Canberra.
- Australian Bureau of Statistics. (2016). *Census of population and housing (2016), TableBuilder. Findings based on use of ABS TableBuilder data.*
- Australian Government. (2011). *National Volunteering Strategy*. Canberra: Department of Prime Minister and Cabinet.
- Australian Government Department of Health. (2007). What is mental illness? Retrieved January 1, 2019, from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-w-whatmen-toc~mental-pubs-w-whatmen-what>
- Australian Health Ministers. (1991). *National Mental Health policy*. Canberra.
- Australian Health Ministers. (1993). *First National Mental Health Plan*. Canberra.
- Australian Health Ministers. (1998). *Second National Mental Health Plan*. Canberra.
- Australian Health Ministers. (2003). *National Mental Health Plan 2003-08*. Canberra.
- Australian Health Ministers. (2009). *Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009–14*. Canberra.
- Australian Health Ministers. (2017). *The Fifth National Mental Health and Suicide Prevention Plan*. Canberra.
- Australian Institute of Health and Welfare. (2015). *Australia's welfare 2015: Australia's welfare series no. 12*. cat. no. AUS 189. Canberra.
- Banfield, M. A., Barney, L. J., Griffiths, K. M., & Christensen, H. (2014). Australian

- mental health consumers' priorities for research: qualitative findings from the SCOPE for Research project. *Health Expectations*, 17(3), 365–375.
- Baum, F. E., Bush, R. A., Modra, C. C., Murray, C. J., Cox, E. M., Alexander, K. M., & Potter, R. C. (2000). Epidemiology of Participation: an Australian Community Study. *Journal of Epidemiology and Community Health*, 54(6), 414–423.
- Beresford, P. (2002). User Involvement in Research and Evaluation: Liberation or Regulation? *Social Policy and Society*, 1(2), 95–105.
<http://doi.org/10.1017/S1474746402000222>
- Beyea, S. C., & Nicoll, L. H. (2000). Collecting, analyzing, and interpreting focus group data. *Aorn J*, 71(6), 1278,1281-1283.
- Bhugra, D. (2010). *No Health without Public Mental Health: The Case for Action (Position statement PS4/2010)*. Royal College of Psychiatrists.
- Blanchard, M., Hosie, A., & Burns, J. (2013). *Embracing technologies to improve well-being for young people: An Australian view of evidence and policy implications*. Canberra.
- Boote, J. D., Telford, R., & Cooper, C. L. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy*, 61(2), 213–236.
- Brady, L.-M., & Preston, J. (2017). *Evaluating the extent and impact of young people's involvement in National Institute for Health Research (NIHR) studies: an assessment of feasibility*. <http://doi.org/10.13140/RG.2.2.36434.04804>
- Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for begginers*. (M. Carmichael, Ed.). SAGE Publications.
- Brown, K., Lipsig-Mumme, C., & Zajdow, G. (2013). *Active Citizenship and the Secondary School Experience: Community Participation Rates of Australian Youth. Longitudinal Surveys of Australian Youth*. Camberwell: ACER and Commonwealth Department of Education, Science and Training.
- Brown, P. (2012). *Mental Health statement of rights and responsibilities*. Canberra.
- Browne, G., & Hemsley, M. (2008). Consumer participation in mental health in Australia: what progress is being made? *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists*, 16(6), 446–449.
- Burdekin, B., Guilfoyle, M., & Hall, D. (1993). *Human rights and mental illness : report of the National Inquiry into the Human Rights of People with Mental Illness*. Canberra.
- Burns, J., Davenport, T., Ricci, C., Birrell, E., Blanchard, M., & Hickie, I. (2014). It's One "Smart" Solution: Using New and Emerging Technologies to Support the Mental Health and Wellbeing of Young Men. *Developing Practise*, Dec 40, 6–19.
- Calear, A. L., Christensen, H., MacKinnon, A. J., Griffiths, K. M., & O'Kearney, R. (2009). The YouthMood Project: a Cluster Randomized Controlled Trial of an Online Cognitive Behavioural Program with Adolescents. *Journal of Consulting and Clinical Psychology*, 77(6), 1021–1032.
- Calear, A. L., Griffiths, K. M., & Christensen, H. (2011). Personal and perceived depression stigma in Australian adolescents: Magnitude and predictors. *Journal of Affective Disorders*, 129(1), 104–108.
- Cargo, M., & Mercer, S. L. (2008). The Value and Challenges of Participatory Research: Stregnthening Its Practise. *Annual Review of Public Health*, 29, 325–350.
- Case, A. D., Byrd, R., Claggett, E., DeVaux, S., Perkins, R., Huang, C., ... Kaufman, J. S. (2014). Stakeholders' Perspectives on Community-Based Participatory Research to Enhance Mental Health Services. *American Journal of Community Psychology*, 54(3–4), 397–408.

- Chacón, F., Gutiérrez, G., Sauto, V., Vecina, M. L., & Pérez, A. (2017). Volunteer Functions Inventory : A systematic review. *Psicothema*, 29(3), 306–316.
- Chambers, D. A., Pringle, B., & Juliano-Bult, D. (2012). Connecting science and practice in child and adolescent mental health services research. *Administration and Policy in Mental Health and Mental Health Services Research*, 39(4), 321–326.
- Checkoway, B. (2011). What is youth participation? *Children and Youth Services Review*, 33(2), 340–345.
- Chen, J., Kingston, N., Tiemann, G., & Gu, F. (2010). Hypothesis. In N. J. Salkind (Ed.), *Encyclopedia of Research Design* (pp. 1499–1503). Thousand Oaks, United States: SAGE Publications.
- Chen, S., Poland, B., & Skinner, H. A. (2007). Youth Voices: Evaluation of Participatory Action Research. *The Canadian Journal of Program Evaluation*, 22(1), 125–150.
- Clary, E. G., Snyder, M., Ridge, R. D., Copeland, J., Stukas, A. A., Haugen, J., & Miene, P. (1999). Understanding and Assessing the Motivations of Volunteers: A Functional Approach. *Personality Processes and Individual Differences*, 74(6), 1516–1530.
- Coates, D., & Howe, D. (2014). The importance and benefits of youth participation in mental health settings from the perspective of the headspace Gosford Youth Alliance in Australia. *Children and Youth Services Review*, 46, 294–299.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Academic Press.
- Collin, P., Metcalf, A., Stephens-Reicher, J., Blanchard, M., Herrman, H., Rahilly, K., & Burns, J. (2011). ReachOut.com: The Role of an Online Service for Promoting Help-Seeking in Young People. *Advances in Mental Health*, 10(1), 39–51.
- Collin, P., Rahilly, K., Stephens-Reicher, J., Blanchard, M., Herrman, H., & Burns, J. (2011). *Meaningful participation for promoting mental health and wellbeing of young Australians*. Sydney.
- Consumer and Community Health Research Network. (2018). Consumer and Community Involvement in Health Research. Retrieved January 15, 2018, from <http://www.involvingpeopleinresearch.org.au>
- Cortina, J. M. (1993). What is coefficient alpha? An examination of theory and applications. *Journal of Applied Psychology*, 78(1), 98–104.
- Coser, L. R., Tozer, K., Van Borek, N., Tzemis, D., Taylor, D., Saewyc, E., & Buxton, J. A. (2014). Finding a Voice: Participatory Research With Street-Involved Youth in the Youth Injection Prevention Project. *Health Promotion Practice*, 15(5), 732–738.
- Crawford, M. J., & Rutter, D. (2004). Are the views of members of mental health user groups representative of those of “ordinary” patients? A cross-sectional survey of service users and providers. *Journal of Mental Health*, 13(6), 561–568. <http://doi.org/10.1080/09638230400017111>
- Crowe, K. M. (2007). Using Youth Expertise at all Levels: the Essential Resource for Effective Child Welfare Practice. *New Directions for Youth Development*, (113), 113–139.
- Dao, T. K., Kerbs, J. J., Rollin, S. A., Potts, I., Gutierrez, R., Choi, K., ... Prevatt, F. (2006). The Association between Bullying Dynamics and Psychological Distress. *Journal of Adolescent Health*, 39(2), 277–282.
- Department of Health. (2016). *Australian Medical Research and Innovation Strategy 2016-2021*. Canberra.
- deVaus, D. A. (2002). *Surveys in social research*. North Sydney: Allen & Unwin.
- Dold, C. J., & Chapman, R. A. (2011). Hearing a Voice: Results of a Participatory

- Action Research Study. *Journal of Child and Family Studies*, 20(21(3)), 512–519.
- Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research*, 14(1), 89. <http://doi.org/10.1186/1472-6963-14-89>
- Donald, M., Dower, J., Lucke, J., & Raphael, B. (2000). *The Queensland Young Peoples' Mental Health Survey Report*. Brisbane.
- Dunn, O. J. (1964). Multiple comparisons using rank sums. *Technometrics*, 6, 241–252.
- Edwards, A., Elwyn, G., Smith, C., Williams, S., & Thornton, H. (2001). Consumers' Views of Quality in the Consultation and Their Relevance to "Shared Decision Making" Approaches. *Health Expectations*, 4, 151–161.
- Elf, M., Rystedt, H., Lundin, J., & Krevers, B. (2012). Young Carers as Co-Designers of a Web-Based Support System: the Views of Two Publics. *Informatics for Health and Social Care*, 37(4), 203–216.
- Epstein, M. (2013). *The Consumer Movement in Australia: A memoir of an old campaigner*. Melbourne.
- Etherington, K. (2004). Connecting Doctoral Research Topics to Ourselves. In J. Kingsley (Ed.), *Becoming a Reflexive Researcher - Using Our Selves in Research*. London: J Kingsley Publishers.
- Ferrier, F., Roos, I., & Long, M. (2004). *Passions, People and Appreciation: Making Volunteering Work for Young People*. Canberra: National Youth Affairs Research Scheme.
- Fleming, J. (2010). Young People's Involvement in Research: Still a Long Way to go? *Qualitative Social Work*, 10(2), 207–223.
- Frankl, V. (1946). *Man's Search for Meaning*.
- Gee, A., McGarty, C., & Banfield, M. A. (2015). What Drives Systemic Mental Health Advocates? Goals, Strategies, and Values of Australian Consumer and Carer Advocacy Organisation. *SAGE Open*, 1–8.
- Graham, T., Rose, D., Murray, J., Ashworth, M., & Tylee, A. (2014). User-generated quality standards for youth mental health in primary care: a participatory research design using mixed methods. *BMJ Quality & Safety*, *Published*.
- Griffiths, K. M., Christensen, H., & Jorm, A. F. (2008). Predictors of depression stigma. *BMC Psychiatry*, 8(25).
- Griffiths, K. M., Christensen, H., & Jorm, A. F. (2009). Mental Health Literacy as a Function of Remoteness of Residence: an Australian National Study. *BMC Public Health*, 9, 92.
- Griffiths, K. M., Christensen, H., Jorm, A. F., Evans, K., & Groves, C. (2004). Effect of web-based depression literacy and cognitive behavioural therapy interventions on stigmatising attitudes to depression. *British Journal of Psychiatry*, 185, 342–349.
- Griffiths, K. M., Crisp, D., Christensen, H., MacKinnon, A. J., & Bennett, K. (2010). The ANU WellBeing study: a protocol for a quasi-factorial randomised controlled trial of the effectiveness of an Internet support group and an automated Internet intervention for depression. *BMC Psychiatry*, 10(20).
- Griffiths, K. M., Jorm, A. F., & Christensen, H. (2004). Academic consumer researchers: a bridge between consumers and researchers. *Australian and New Zealand Journal of Psychiatry*, 38(4), 191–196.
- Gueorguieva, R., & Krystal, J. H. (2004). Move over ANOVA. *Arch Gen Psychiatry*, 61(3), 310–317. <http://doi.org/10.1001/archpsyc.61.3.310>
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review. *BMC Psychiatry*, 10(113).
- Gulliver, A., Griffiths, K. M., Christensen, H., MacKinnon, A. J., Caley, A. L., Parsons, A., ... Stanimirovic, R. (2012). Internet-Based Interventions to Promote

- Mental Health Help-Seeking in Elite Athletes: An Exploratory Randomized Controlled Trial. *Journal of Medical Internet Research*, 14(69).
- Gyamfi, P., Keens-Douglas, A., & Medin, E. (2007). Youth and Youth Coordinators' Perspectives on Youth Involvement in Systems of Care. *Journal of Behavioral Health Services & Research*, 34(4), 382–394.
- Hagen, P., Collin, P., Metcalf, A., Nichols, M., Rahilly, K., Swainston, N., & Nicholas, M. (2012). *Participatory Design of Evidence-Based Online Youth Mental Health Promotion, Intervention and Treatment*. Melbourne, Australia.
- Hart, R. A. (1991). *Children's participation: from tokenism to citizenship*. Florence, Italy.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology, 58(1), 1–23.
- Haslam, S. A., & McGarty, C. (2003). *Research methods and statistics in psychology*. (S. A. Haslam & C. McGarty, Eds.), *Sage Foundations of Psychology Series*. London: Sage Publications Ltd.
- Hickie, I., Groom, G., McGorry, P., Davenport, T., & Luscombe, G. M. (2005). Australian Mental Health Reform: Time for Real Outcomes. *Medical Journal of Australia*, 182(8), 401–406.
- Hill, M., Russell, J., & Brewis, G. (2009). *Young People, Volunteering and Youth Projects: A Rapid Review of Recent Evidence*. London: Institute of Volunteering Research.
- Howe, D., Batchelor, S., & Bochynska, K. (2011). Finding Our Way: Youth Participation in the Development and Promotion of Youth Mental Health Services on the NSW Central Coast. *Advances in Mental Health*, 10(1), 20–28.
- Howell, D. C. (2010). *Statistical Methods for Psychology* (Seventh). Wadsworth Cengage Learning.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277–1288. <http://doi.org/10.1177/1049732305276687>
- Hyde, M. K., & Knowles, S. R. (2013). What predicts Australian university students' intentions to volunteer their time for community service? *Australian Journal of Psychology*, 65(3), 135–145.
- IMB Corp. (2015). Released 2015 SPSS for Macintosh, Version 23.0. Armonk, NY: IBM Corp.
- International Association for Public Participation. (2014). *IAP2's Public Participation Spectrum*.
- Iwasaki, Y., Springett, J., Dashora, P., McLaughlin, A.-M., & McHugh, T.-L. (2014). Youth-guided youth engagement: Participatory Action Research (PAR) with high-risk, marginalized youth. *Child & Youth Services*, 35(4), 316–342.
- James, A. M. (2007). Principles of Youth Participation in Mental Health Services. *Medical Journal of Australia*, 187(7), S57–S60.
- Jorm, A. F. (2011). Mental Health Literacy Empowering the Community to Take Action for Better Mental Health. *American Psychologist*, 67(3), 231–243.
- Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). "Mental Health Literacy": a Survey of the Public's Ability to Recognise Mental Disorders and Their Beliefs about the Effectiveness of Treatment. *Medical Journal of Australia*, 166, 182–186.
- Jorm, A. F., & Reavely, N. J. (2012). Public Confusion Caused by Differing Understandings of the Term "Mental Illness." *Australian and New Zealand Journal of Psychiatry*, 46(5), 397–399. <http://doi.org/10.1177/0004867412444109>
- Kauer, S. D., Mangan, C., & Sanci, L. A. (2014). Do Online Mental Health Services Improve Help-Seeking for Young People? A Systematic Review. *Journal of*

Medical Internet Research, 16(3), e66.

- Kaufman, C. L. (1999). An introduction to the mental health consumer movement. In A. V. Horwitz & T. L. Scheid (Eds.), *A handbook for the study of mental health: social contexts, theories, and systems* (pp. 493–507). New York, New York, USA: Cambridge University Press.
- Kessler, R. C., Amminger, P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Ustun, T. B. (2007). Age of Onset of Mental Disorders: A Review of Recent Literature. *Current Opinion in Psychiatry*, 20(4), 359–364.
- Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S. L. T., ... Zaslavsky, A. M. (2002). Short Screening Scales to Monitor Population Prevalences and Trends in Non-Specific Psychological Distress. *Psychological Medicine*, 32(6), 959–976.
- Kirby, P. (2004). *A Guide to Actively Involving Young People in Research: For researchers, research commissioners, and managers*. INVOLVE support unit. Eastleigh.
- Kwan, B., & Rickwood, D. (2015). A systematic review of mental health outcome measures for young people aged 12 to 25 years. *BMC Psychiatry*, 14(15).
- Laerd Statistics. (2015). Kruskal-Wallis H test using SPSS Statistics. Retrieved December 16, 2017, from <https://statistics.laerd.com/>
- Laerd Statistics. (2018). Binomial Logistic Regression.
- Lakens, D. (2013). Calculating and reporting effect sizes to facilitate cumulative science: A practical primer for t-tests and ANOVAs. *Frontiers in Psychology*, 4(NOV), 1–12. <http://doi.org/10.3389/fpsyg.2013.00863>
- Lamers, S. M., Westerhof, G. J., Bohlmeijer, E. T., ten Klooster, P. M., & Keyes, C. L. (2011). Evaluating the psychometric properties of the Mental Health Continuum-Short Form (MHC-SF). *Journal of Clinical Psychology*, 67(1), 99–110.
- Lance, C. E., Butts, M. M., & Michels, L. C. (2006). The Sources of Four Commonly Reported Cutoff Criteria: What Did They Really Say? *Organizational Research Methods*, 9(2), 202–220.
- Lea, T., de Wit, J., & Reynolds, R. (2014). Minority Stress in Lesbian, Gay, and Bisexual Young Adults in Australia: Associations with Psychological Distress, Suicidality and Substance Use. *Archives of Sexual Behaviour*, 43, 1571–1578.
- Liabo, K., Boddy, K., Burchmore, H., Cockcroft, E., & Britten, N. (2018). Clarifying the roles of patients in research. *Bmj*, 361(April), k1463. <http://doi.org/10.1136/bmj.k1463>
- Lloyd, C., & King, R. (2003). Consumer and carer participation in mental health services. *Australasian Psychiatry*, 11(2), 180–185.
- Lolacano Merves, M., Rodgerds, C. R. R., Johnson Silver, E., Sclafane, J. H., & Bauman, L. J. (2015). Engaging and sustaining adolescents in Community-Based Participatory Research: Structuring a youth-friendly CBPR environment. *Family & Community Health*, 81(1), 22–32.
- Mawn, L., Welsh, P., Kirkpatrick, L., Webster, L. A. D., & Stain, H. J. (2015). Getting it right! Enhancing youth involvement in mental health research. *Health Expectations*, 19(4), 1369–7625.
- Mawn, L., Welsh, P., Stain, H. J., & Windebank, P. (2015). Youth Speak: increasing engagement of young people in mental health research. *Journal of Mental Health*, 24(5), 271–275.
- McCabe, T. L., White, K. M., & Obst, Patricia, L. (2007). The importance of volunteering functions to university students. *Australian Journal of Vounteering*, 12(2), 585–608.
- McDonagh, J. E., & Bateman, B. (2012). “Nothing about us without us”: considerations for research involving young people. *Arch Dis Child Educ Pract Ed*, 97, 55–60.

- McGorry, P., Bates, T., & Birchwood, M. (2013). Designing Youth Mental Health Services for the 21st Century: Examples From Australia, Ireland and the UK. *The British Journal of Psychiatry*, 202, s30–s35.
- McLaughlin, H. (2011). *Service-user research in health and social care*. Sage Publications.
- McLeod, J. (2001). Critical Issues in the Use of Qualitative Inquiry. In J. McLeod (Ed.), *Qualitative Research in Counselling and Psychotherapy* (pp. 182–210). London: SAGE Publications Ltd.
- Medical Services Advisory Committee. (2017). *Health Technology Assessment Consumer Consultative Committee (CCC) Terms of Reference*. Canberra.
- Miller, C. L., Mott, K., Cousins, M., Miller, S., Johnson, A., Lawson, T., & Wesselingh, S. (2017). Integrating consumer engagement in health and medical research - an Australian framework. *Health Research Policy and Systems*, 15(9).
- Milne, J., & Oberle, K. (2005). Enhancing Rigor in Qualitative Description: a case study. *Journal of Wound Ostomy Continence Nursing*, 32(6), 413–20.
- Mission Australia. (2013). *Mission Australia's 2013 Youth Survey Report*. Sydney.
- Moffat, L. (2011). *Engaging Young People in Volunteering: What Works in Tasmania? Full Report*. Hobart: Volunteering Tasmania.
- Monshat, K., Vella-Brodrick, D., Burns, J., & Herrman, H. (2012). Mental Health Promotion in the Internet Age: a Consultation with Australian Young People to Inform the Design of an Online Mindfulness Training Programme. *Health Promotion International*, 27(2), 177–186.
- Monson, K., & Thurley, M. (2011). Consumer participation in a youth mental health service. *Early Intervention in Psychiatry*, 5(4), 381–388.
- Morley, R. F., Norman, G., Golder, S., & Griffith, P. (2016). A systematic scoping review of the evidence for consumer involvement in organisations undertaking systematic reviews : focus on Cochrane. *Research Involvement and Engagement*, 2(36), 1–20.
- Muir, K., Mullan, K., Powell, A., Flaxman, S., Thompson, D., & Griffiths, K. M. (2009). *State of Australia's Young People: A Report on the Social, Economic, Health and Family Lives of Young People*. (Australian Government Office for Youth, Ed.), Australian Government Department of Education, Employment and Workplace Relations.
- National Children's Bureau. (2010). *Young People in Research: How to Involve Us*.
- National Health & Medical Research Council. (2007). *Australian Code for the Responsible Conduct of Research AUSTRALIAN CODE FOR THE RESPONSIBLE CONDUCT*.
- National Health & Medical Research Council (NHMRC) and the Consumers Health Forum of Australia. (2002). *Summary Statement on Consumer and Community Participation in Health and Medical Research*. Canberra: NHMRC.
- National Health & Medical Research Council & Australian Research Council Australian Vice Chancellors Committee. (2007). *National Statement on Ethical Conduct in Human Research*. Canberra.
- National Health & Medical Research Council and the Consumers Health Forum of Australia. (2005). *A Model Framework for Consumer and Community Participation in Health and Medical Research. Medical history* (Vol. 9). Canberra.
- National Health & Medical Research Council and the Consumers Health Forum of Australia. (2016). *Statement on Consumer and Community involvement in Health and Medical Research*. Canberra.
- National Institute for Health Research. (2016). Reward and recognition for children and young people involved in research – things to consider. Retrieved January 18, 2018, from <http://www.invo.org.uk/wp-content/uploads/2016/05/CYP-reward-and->

recognition-Final-April2016.pdf

- National Institute for Health Research. (2018a). Briefing note two: What is public involvement in research? Retrieved March 27, 2018, from <http://www.invo.org.uk/posttypesresource/what-is-public-involvement-in-research/>
- National Institute for Health Research. (2018b). INVOLVE. Retrieved January 15, 2018, from <http://www.invo.org.uk/about-involve/>
- National LGBTI Health Alliance, & Rosenstreich, G. (2013). *LGBTI People, mental health and suicide* (Revised 2n). Sydney: National LGBTI Health Alliance.
- National Mental Health Commission. (2014). *The National Review of Mental Health Programmes and Services*. Sydney: NHMC.
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description-the poor cousin of health research? *BMC Medical Research Methodology*, 9(1). <http://doi.org/10.1186/1471-2288-9-52>
- Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement. *BMJ Quality and Safety*, 25(8), 626–632. <http://doi.org/10.1136/bmjqs-2015-004839>
- OECD. (2010). OECD.Stat. Retrieved March 12, 2018, from <http://stats.oecd.org/index.aspx?DatasetCode=RPOP#>
- OECD. (2014). *Making Mental Health Count: The Social and Economic Costs of Neglecting Mental Health Care*. *OECD Health Policy Studies*. OECD Publishing.
- Oliver, K. G., Collin, P., Burns, J., & Nicholas, J. (2006). Building resilience in young people through meaningful participation. *Australian E-Journal for the Advancement of Mental Health*, 5(1).
- Orlowski, S. K., Lawn, S., Venning, A., Winsall, M., Jones, G. M., Wyld, K., ... Bidargaddi, N. (2015). Participatory Research as One Piece of the Puzzle: A Systematic Review of Consumer Involvement in Design of Technology-Based Youth Mental health and Well-Being Interventions. *JMIR Human Factors*, 2(2).
- Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E., & Aitken, P. (2010). Involving Service Users in Intervention Design: a Participatory Approach to Developing a Text-Messaging Intervention to Reduce Repetition of Self-Harm. *Health Expectations*, 14(3), 285–295.
- Patel, V., Araya, R., Chatterjee, S., Chisholm, D., Cohen, A., De Silva, M., ... van Ommeren, M. (2007). Global Mental Health 3: Treatment and prevention of mental disorders in low-income and middle-income countries. *The Lancet*, 370(9591), 991–1005.
- Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental Health of Young People: a Global Public Health Challenge. *The Lancet*, 369(9569), 1302–1313.
- Patterson, S., Trite, J., & Weaver, T. (2014). Activity and views of service users involved in mental health research : UK survey, 68–75. <http://doi.org/10.1192/bjp.bp.113.128637>
- Powers, J. L., & Tiffany, J. S. (2006). Engaging Youth in Participatory Research and Evaluation. *Journal of Public Health Management and Practice, Suppl*, S79–S87.
- Ramey, H. L., & Rose-Krasnor, L. (2015). The new mentality: Youth–adult partnerships in community mental health promotion. *Children and Youth Services Review*, 50, 28–37.
- Rammstedt, B. (2007). The 10 Item Big Five Inventory: Norm Values and Investigation of Sociodemographic Effects Based on a German Population Representative Sample. *European Journal of Psychological Assessment*, 23(3), 193–201.
- Rammstedt, B., & John, O. P. (2007). Measuring personality in one minute or less: A 10-item short version of the Big Five Inventory in English and German. *Journal of Research in Personality*, 41(1), 203–212.
- Raphael, B. (1991). *Mental Health statement of rights and responsibilities*. Canberra.

- Reavley, N. J., & Jorm, A. F. (2011a). Stigmatizing attitudes towards people with mental disorders: findings from an Australian National Survey of Mental Health Literacy and Stigma. *Australian and New Zealand Journal of Psychiatry*, 45(12), 1086–1093. <http://doi.org/10.3109/00048674.2011.621061>
- Reavley, N. J., & Jorm, A. F. (2011b). Young people's stigmatizing attitudes towards people with mental disorders: Findings from an Australian national survey. *Australian and New Zealand Journal of Psychiatry*, 45(12), 1033–1039. <http://doi.org/10.3109/00048674.2011.614216>
- Rickwood, D., Deane, F. P., Wilson, C. J., & Ciarrochi, J. (2005). Young People's Help-Seeking for Mental Health Problems. *Australian eJournal for the Advancement of Mental Health*, 4(3 (Supplement)).
- Roberts, D., Hughes, M., & Kertbo, K. (2014). Exploring consumers' motivations to engage in innovation through co-creation activities. *European Journal of Marketing*, 48(1/2), 147–169.
- Robinson, K. H., Bansel, P., Denson, N., Ovenden, G., & Davies, C. (2014). *Growing Up Queer: Issues Facing Young Australians Who Are Gender and Sexuality Diverse*. Melbourne.
- Robson, B. (2008). From mental hygiene to community mental health. *Provenance: The Journal of Public Record Office Victoria*, 7.
- Ross, A. M., Hart, L. M., Jorm, A. F., Kelly, C. M., & Kitchener, B. A. (2012). Development of key messages for adolescents on providing basic mental health first aid to peers: a Delphi consensus study. *Early Intervention in Psychiatry*, 6(3), 229–238.
- Roy Morgan. (2015). *Is Australia getting gayer - and how gay will we get? Roy Morgan Single Source, January 2006 - December 2014*.
- Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 58(10), 1973–1984.
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334–340. [http://doi.org/10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](http://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33(1), 77–84. <http://doi.org/10.1002/nur.20362>
- Scott, A. M., & Wale, J. L. (2017). Patient advocate perspectives on involvement in HTA: an international snapshot. *Research Involvement and Engagement*, 3(1), 2.
- Sethi, S., Campbell, A. J., & Ellis, L. A. (2010). The Use of Computerised Self-Help Packages to Treat Adolescent Depression and Anxiety. *Journal of Technology in Human Services*, 28(3), 144–160.
- Sharpe, D. (2015). Your Chi-Square Test is Statistically Significant: Now What? *Practical Assessment, Research & Evaluation*, 20(8).
- Shaw, C., Brady, L.-M., & Davey, C. (2011). *Guidelines for research with children and young people. ... : National Children's Bureau Research ...*. <http://doi.org/10.1111/jcpp.12457>
- Simons, L. (2012). *Diversity and inclusion: What's it about and why is it important for public involvement in research? Report*.
- Skinner, A., & Fleming, J. (2007). *Influence through participation: A critical review of structures for youth engagement*.
- Slade, T., Johnson, A., Oakley Browne, M. A., Andrews, G., & Whiteford, H. A. (2009). 2007 National Survey of mental health and wellbeing: methods and key findings. *Australian and New Zealand Journal of Psychiatry*, 43, 594–605.
- Smith, E., Jones, T., Ward, R., Dixon, J., Mitchell, A., Hillier, L., & The Australian

- Research Centre in Sex, H. and S. (2014). *From Blues to Rainbows; Mental Health and Wellbeing of Gender Diverse and Transgender Young People in Australia*. Melbourne.
- Snyder, M., & Omoto, A. M. (2008). Volunteerism: Social Issues Perspectives and Social Policy Implications. *Social Issues and Policy Review*, 2, 1–36.
- Spence, S. H., Donovan, C. L., March, S., Gamble, A., Anderson, R. E., Prosser, S., & Kenardy, J. (2011). A Randomised Controlled Trial of Online Versus Clinic-Based CBT for Adolescent Anxiety. *Journal of Consulting and Clinical Psychology*, 79(5), 629–642.
- Spinuzzi, C. (2005). The Methodology of Participatory Design. *Technical Communication*, 52(2), 163–174.
- Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., ... Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *BMJ (Online)*, 358.
- Starkman, M. (2013). The movement. In B. A. LeFrancois, R. Menzies, & G. Reasume (Eds.), *Mad matters: A critical reader in Canadian mad studies*. Toronto, Canada: Canadian Scholars' Press.
- Swanton, R., Collin, P., Burns, J., & Sorensen, I. (2007). Engaging, Understanding and Including Young People in the Provision of Mental Health Services. *International Journal of Adolescent Medicine and Health*, 19(3), 325–332.
- Sweeney, A., Greenwood, K. E., Williams, S., Wykes, T., & Rose, D. (2013). Hearing the voices of service user researchers in collaborative qualitative data analysis: The case for multiple coding. *Health Expectations*, 16(4), 89–99.
- Szebeko, D., & Tan, L. (2010). Co-designing for Society. *Australasian Medical Journal*, 3(9), 580–590.
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed.). Boston: Pearson.
- Tarpey, M. (2006). *Why people get involved in health and social care research: a working paper*. Eastleigh.
- University Admissions Centre. (2016). Frequently Asked Questions About the ATAR.
- Updegraff, J. A., & Taylor, S. E. (2000). From Vulnerability to Growth: Positive and Negative Effects of Stressful Life Events. In J. Harvey & E. Miller (Eds.), *General perspectives on loss, trauma, coping and the positive impacts of loss*. Philadelphia, United States, Philadelphia: Brunner-Routledge.
- Vromen, A. (2003). "People Try to Put Us Down ...": Participatory Citizenship of "Generation X." *Australian Journal of Political Science*, 38(1), 79–99. <http://doi.org/10.1080/1036114032000056260>
- Wadley, G., Lederman, R., Gleeson, J., & Alvarez-Jimenez, M. (2013). Participatory Design of an Online Therapy for Youth Mental Health. *25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration*. Adelaide, Australia: ACM.
- Walsh, L., & Black, R. (2015). *Youth Volunteering in Australia: An Evidence Review*. . Report prepared for the Australian Research Alliance for Children and Youth. Canberra: ARACY.
- Willig, C. (2013). *Introducing qualitative research in psychology*. Milton Keynes, United Kingdom: McGraw-Hill International.
- Wilson, C. J., Deane, F. P., Ciarrochi, J., & Rickwood, D. (2005). Measuring Help-Seeking Intentions: Properties of the General Help-Seeking Questionnaire. *Canadian Journal of Counselling*, 39(1), 15–28.
- Wright, A., Harris, M. G., Wiggers, J. H., Jorm, A. F., Cotton, S. M., Harrigan, S. M., ... McGorry, P. D. (2005). Recognition of depression and psychosis by young Australians and their beliefs about treatment. *MJA*, 183(1).

- Wright, A., Jorm, A. F., & MacKinnon, A. J. (2011). Labeling of Mental Disorders and Stigma in Young People. *Social Science & Medicine*, 73, 498–506.
- Yap, M. B., Reavely, N. J., & Jorm, A. F. (2013). Where Would Young People Seek Help for Mental Disorders and What Stops Them? Findings from an Australian National Survey. *Journal of Affective Disorders*, 147, 255–261.
- Young and Well Cooperative Research Centre. (2013). *Young and Well CRC Standard Measures*. Melbourne: Young and Well CRC.
- Young and Well Cooperative Research Centre. (2014). *Youth Involvement Guidelines*. Melbourne.
- Young and Well Cooperative Research Centre. (2016a). Our Collective. Retrieved June 30, 2016, from archived webpage
- Young and Well Cooperative Research Centre. (2016b). Our Vision. Retrieved June 30, 2016, from archived webpage

Appendix 3.1 List of CRC Supporting partners

- The Alana and Madeline Foundation
- Australian Communications and Media Authority
- Australian Federal Police
- Basic Needs, Basic Rights
- Berry Street
- BoysTown
- Canteen
- City of Melbourne
- Connectica
- Curtin University
- Victoria State Government Justice and Regulation
- Facebook
- Flinders University
- Foundation for Young Australians
- Freedom Centre
- Google
- Government of South Australia – SA Health
- Hello Sunday Morning
- Hitnet
- Hunter Institute of Mental Health
- Inspire Foundation
- John Hopkins Bloomberg School of Public Health
- Ladder – tackling youth homelessness
- Lifeline
- Mind
- Movember Foundation
- National Association for Prevention of Child Abuse and Neglect (NAPCAN)
- National Cannabis Prevention and Information Centre
- National Children’s and Youth Law Centre (NCYLC)
- National LGBTI Health Alliance
- Nationwide Children’s Hospital

- Novita Children's Services
- NSW Kids and Families
- Government of South Australia Office for Youth
- Commission for Children and Young People
- Ohio State University College of Social Work
- Principals Institute Australia
- Queensland Institute of Medical Research
- The Reach Foundation
- Royal Melbourne Institute to Technology (RMIT) University
- Spark Strategy
- Starlight Children's Foundation
- STREAT
- Student Edge
- Suicide Prevention Australia
- SYN
- Telstra
- Turning Point Alcohol and Drug Centre
- Twenty Ten
- Twitter
- University of California San Francisco
- University of Canberra
- University of Newcastle
- University of the Sunshine Coast
- Victoria University
- Yahoo
- ycentral
- Youth Focus
- Zuni

Appendix 4.1 Study 1 Human Research Ethics approval letter

Protocol: 2013/214

Understanding university students' preferences for research involvement in the Virtual Clinic

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science & Medical DERC on 23 October 2013.

Appendix 4.2 Study 1 Consent form



Investigating the views of students regarding the methods used to engage students in creating a virtual clinic for mental health.

CONSENT FORM FOR PARTICIPANTS

The Centre for Mental Health Research (CMHR), ANU College of Medicine, Biology & Environment, The Australian National University (ANU) are currently conducting a study to develop an online tool to improve the mental health of university students.

As part of this process we are inviting ANU students to participate in focus groups to discuss attitudes towards being engaged in mental health research, how we should engage students in this research and how we should evaluate these methods. **No screening for mental health will take place.**

The study involves attending one short focus group held **at the Centre for Mental Health Research** with 6-10 participants, which will take approximately **one hour**. A moderator will guide the discussion. Participants will be encouraged to contribute but can choose their own level of involvement and on which topics they would like to comment. All participants are requested to keep information disclosed by other participants in the focus group confidential, yet whilst this is requested, confidentiality cannot be guaranteed.

Your participation in this project is voluntary, and if you wish, you can withdraw from the study at any time without consequence. It is anticipated that risk will be minimal; however, if you feel distressed as a result of these groups, please contact the following: Lifeline T: 13 11 14, ANU Counselling Service T: 6125 2442

This research is carried out in accordance with the ethical guidelines set out by the National Health and Medical Research Council. An ethics protocol for this study has been approved by The Australian National University Human Research Ethics Committee. Any person with concerns or complaints about the conduct of a research study can contact the Ethics Manager, The ANU Human Research Ethics Committee, The Australian National University, T: 6125 3427, E: Human.Ethics.Officer@anu.edu.au.

Only first names will be used on audiotapes and the only persons with access to these audiotapes will be Lou Farrer and the project staff employed by CMHR to undertake data analysis. The audiotapes will be typed up without names or other identifying information. **The researchers will not disclose or use any information provided to us that could identify participants** unless we are required to do so by law. Names will be stored separately from audiotapes of the interview and transcripts and kept under strict security. All identifying data will be destroyed after a period of five years. Findings will be published without reference to names to protect the identity of individuals.

If you have any questions about any aspect of this study, please contact **Rebecca Randall** E: Rebecca.randall@anu.edu.au, PhD Candidate Centre for Mental Health Research, ANU College of Medicine, Biology & Environment T: 02 612 50674, **Dr Lou Farrer** E: louise.farrer@anu.edu.au; T: 02 6125 8859, Postdoctoral Research Fellow, Centre for Mental Health Research, ANU College of Medicine, Biology & Environment or **Professor Kathy Griffiths** E: kathy.griffiths@anu.edu.au; T: 02 6125 9723, Director, Centre for Mental Health Research, ANU College of Medicine, Biology and Environment.

I, _____ (PLEASE PRINT NAME CLEARLY)

agree to take part in this focus group in which I will be asked to discuss my views on seeking help for mental health problems online and an online mental health support tool for university students. I understand that my participation is voluntary and that I can withdraw at any time. I understand the purpose of the project and methods to be used. Any contribution I make will be confidential, and my name will be withheld from any part of it that is published.

Signed: _____

Date: _____

Appendix 4.3 Study 1 Recruitment email and participant information sheet

Recruitment email

Dear <insert name>,

Hi, my name is Rebecca Randall and I'm a researcher from the Centre for Mental Health Research at the ANU.

You've previously provided your name and e-mail address to the Centre indicating your interest in the work we are doing researching mental health and online programs.

I'm contacting you to ask if you would be interested in participating in a focus group with other students designed to obtain your opinions and ideas of students regarding the methods used to engage students in creating a virtual clinic for mental health, specifically for university students.

The focus group will be held on campus at the Centre for Mental Health Research, at a time that is convenient for you and other students to attend. The group should take approximately 1 hour, and will be composed of approximately 6-10 students. If you would like to attend with friends, that would be great. Just let us know so we can accommodate them.

During the focus group we would like to discuss your opinions and ideas regarding the methods used to engage students in creating a virtual clinic for mental health. Your privacy and confidentiality will be protected, and you are free to stop participating in the group at any time if you wish.

As a thank you for your time and input, you will receive a movie pass for participating in the group.

If you would like any further information about the group before making a decision, please feel free to contact me.

If you're interested in being involved, just reply to this e-mail. Hope you can take part!

Cheers,

Rebecca

Participant information sheet



Investigating the views of students regarding the methods used to engage students in creating a virtual clinic for mental health.

INFORMATION SHEET FOR PARTICIPANTS

The Centre for Mental Health Research (CMHR), ANU College of Medicine, Biology & Environment, The Australian National University (ANU) are currently conducting a study to develop an online tool to improve the mental health of university students.

As part of this process we are inviting ANU students to participate in focus groups to discuss attitudes towards being engaged in mental health research, how we should engage students in this research and how we should evaluate these methods. No screening for mental health will take place.

The study involves attending one short focus group held at the Centre for Mental Health Research with 6-8 participants, which will take approximately one hour. A moderator will guide the discussion. Participants will be encouraged to contribute but can choose their own level of involvement and on which topics they would like to comment. All participants are requested to keep information disclosed by other participants in the focus group confidential, yet whilst this is requested, confidentiality cannot be guaranteed.

Your participation in this project is voluntary, and if you wish, you can withdraw from the study at any time without consequence. It is anticipated that risk will be minimal; however, if you feel distressed as a result of these groups, please contact the following: Lifeline T: 13 11 14, ANU Counselling Service T: (02) 6125 2442

This research is carried out in accordance with the ethical guidelines set out by the National Health and Medical Research Council. An ethics protocol for this study has been approved by The Australian National University Human Research Ethics Committee. Any person with concerns or complaints about the conduct of a research study can contact the Ethics Manager, The ANU Human Research Ethics Committee, The Australian National University, T: 6125 3427, E: Human.Ethics.Officer@anu.edu.au.

Only first names will be used on audiotapes and the only persons with access to these audiotapes will be Rebecca Randall and the project staff employed by CMHR to undertake data analysis. The audiotapes will be typed up without names or other identifying information. **The researchers will not disclose or use any information provided to us that could identify participants** unless we are required to do so by law. Names will be stored separately from audiotapes of the interview and transcripts and kept under strict security. All identifying data will be destroyed after a period of five years. Findings will be published without reference to names to protect the identity of individuals.

If you have any questions about any aspect of this study, please contact **Rebecca Randall** E: Rebecca.randall@anu.edu.au, PhD Candidate Centre for Mental Health Research, ANU College of Medicine, Biology & Environment T: 02 612 50674, **Dr Lou Farrer** E: louise.farrer@anu.edu.au; T: 02 6125 8859, Postdoctoral Research Fellow, Centre for Mental Health Research, ANU College of Medicine, Biology & Environment or **Professor Kathy Griffiths** E: kathy.griffiths@anu.edu.au; T: 02 6125 9723, Director, Centre for Mental Health Research, ANU College of Medicine, Biology and Environment.

If you agree to participate in this project, please fill in and sign the attached Consent Form for participants and return it to the moderator before the start of the focus group.

Yours sincerely,

Ms Rebecca Randall, PhD Candidate

Dr Lou Farrer, Postdoctoral Research Fellow

Professor Kathy Griffiths, Director

Centre for Mental Health Research, ANU College of Medicine, Biology & Environment, The Australian National University

Appendix 4.4 Study 1 Focus group protocol

Question area	Key question/information
Introduction to the clinic and what the purpose of the focus group is	N/A
1. Previous research participation	Have you participated in research before? (show of hands)
	What sort of research have you participated in?
	Would you participate in other research? (show of hands)
2. Motivations	Were (or would) your motivations for participating in research other than research like this be similar to participating in this sort of research?
	Why are you here participating in research today?
	How did you find out about the focus groups?
	What motivated you to click on the advertisement and information sheet?
	Was there anything about the wording of the advertisement, or how you found out about it that made you particularly interested?
	Do you think the fact that it was advertised as a mental health focus group affects your participation, or who might participate?
	These focus groups were advertised quite widely, and only a small group of the students who saw that advertisement have followed up and participated in these groups. I'd like you to brainstorm with me some ideas of what might have stopped you, or them, from participating today?
	What might impede you from participating?
	What barriers can you see that might stop people from participating?
3. Experience of, and ideas about, recruitment to research studies	If we want to attract a group of students to participate in research – what are the best ways we could do that?
	How would you prefer to hear from researchers?
	Should we identify ourselves as being from the university – does who is conducting the focus groups make a difference to you?
	What forms of media would you prefer to hear from researchers through?
4. Methods of involving young people in research	Thinking a bit more broadly now, I'm interested in getting your perspectives on how young people can be involved in the research process:
	What ways do you think that young people can be involved in the research process?
	Which ones of these have you participated in?
	Looking at the list we've just generated, some of these are 'active' and some of them are 'passive' participation.
	Are there reasons why you might be attracted more to passive or active participation?
	Do you think certain people or groups might be more attracted to active or passive participation?

Looking at the list we've generated, I'd like you to list your preferences for these methods with regards to:

- Which ones you would participate in again
- Which ones you found most engaging
- Which ones do you think would allow you to give the best information
- Which ones you think might be positive for your mental health

Appendix 4.5 Study 1 Initial theme tables

Major theme	Theme
Participant's prior research participation	Found out through – [ways that participants found out about the focus groups]
	Had participated before
	Were happy to sign up without reading all the material about the study that was provided to them
	Minimal attention was paid to the information sheet
	Would participate in other research
Barriers	Cultural and linguistic barriers
	Group or unfamiliar situations challenging
	If research went against personal values
	Unfamiliar location
	Not being aware that it was happening
	Not being interested
	Not feeling as if their personal contribution matters
	Time costs
Concerns that arise due to the topic of mental health	Too hard to organise
	Could be polarising
	Mental health term didn't influence participation
	Mental health term may make other young people less likely to take part
	Mental health term made them more likely to participate
	Mental health will attract a particular sample
	Specific mental health term used may influence participation rates
Facilitators	Being comfortable with ethical aspects of the research
	Ease of initiating participation
	Friends invited or were attending
	Interested in, or related to, the topic
	Make the topic of the research personal
	Like doing research projects
	Participation perceived to be easy or have little cost to the participant
	Seeing the impact of their involvement
Incentives	Have choice of incentives
	Instant gratification important
	Money and movie tickets not an incentive
	Needs to be something convenient to redeem
	Participation built into university courses (research credit)
	Types of incentives
Recruitment	Make the topic or participation personal

	Methods through which students don't want to be contacted
	Things that researchers can do to better facilitate recruitment
	Tools or techniques that can be used for recruitment
Phases of the research that young people could be involved in	At every point
	Range of intensity levels
Ways that young people could be involved in research	Face to face methods
	Game
	Journals for people to reflect on their experience of mental ill health
	Online consultative methods
	Private ways because people don't like talking about mental health
	Surveys
	At the design phase
	Creating the website directly
	Data analysis
Ways to keep people engaged through the research process	Involve students at every point
	Need a range of active and passive involvement activities to cater to levels of interest
	Regular invites to participate in small activities
	Start with passive then increase to active levels of involvement
	Updates about project desired

Appendix 5.1 Study 2 Human Research Ethics approval letter



Protocol: 2014/634

Professionals' views on involving young people in research

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science and Medical DERC on 5 November 2014.

Appendix 5.2 Study 2 Consent form



WRITTEN CONSENT for Participants

Professionals' views on involving young people in research

I have read and understood the Information Sheet you have given me about the research project, and I have had any questions and concerns about the project addressed to my satisfaction. I agree to participate in the project.

YES ☐ NO ☐ I agree to this interview being audio-recorded

Signature:.....

Appendix 5.3 Study 2 Recruitment emails and participant information sheet

Recruitment email

Dear *insert name*,

My name is Rebecca and I'm a PhD student with the Young and Well Cooperative Research Centre, based at the National Institute for Mental Health Research at the Australian National University. I'm supervised by Professor Kathy Griffiths and have been working in conjunction with Associate Professor Jane Burns.

My PhD is looking at end user involvement with Young and Well CRC and I'm writing to ask if you would be willing to participate in a 90-minute interview study of researchers perceptions of and attitudes towards involving young people in your work.

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee.

I would be conducting the interview over the phone or via skype at a time that is convenient to you. Informed consent will be obtained through my sending an information sheet and a consent form for you to sign and your scanning or photographing it to send it back to me prior to the interview.

In published work, conference proceedings and my PhD thesis you will only be identified by a code and the only people who will know the names of those who participate in the interview are myself and my supervisory team (Professor Kathy Griffiths, Dr Lou Farrer, Dr Michelle Banfield and Dr Alison Caelear). Due to the qualitative nature of the research, quotes may be published, which means that you should be aware that there is a possibility that you will be identifiable from this research. An information sheet is attached detailing the data storage procedures that will be used.

If you are interested in participating please reply to this email (Rebecca.randall@anu.edu.au) or call me (0432083702) so we can arrange a time to conduct the interview.

Thankyou for your time,

Rebecca Randall

Participant information sheet



Participant Information Sheet

Researcher: Rebecca Randall is a PhD student at the National Institute for Mental Health Research (NIMHR) in the Research School of Population Health, College of Medicine Biology and the Environment at the Australian National University. The research project is supervised by Professor Kathy Griffiths, the Director of NIMHR.

Project Title: Professionals' views on involving young people in research

General Outline of the Project:

1. **Description and Methodology:** This study forms the final stage of a Young and Well CRC PhD project aiming to examine end user involvement in mental health research. It seeks to examine your experiences of engaging young people in your Young and Well research project. The study involves a 90 minute phone or Skype interview undertaken at a time of your choosing. The interviews will ask about your research background, details of the project you have conducted with Young and Well CRC, the benefits and challenges of involving young people in your work and your views on involving young people in your research. The interviews will be recorded for later transcription and written consent for this will be obtained before the interviews commence. You will be able to withdraw from the study and if you do your data will be destroyed.
2. **Participants:** Eight researchers from the Young and Well Cooperative Research Centre.
3. **Use of Data and Feedback:** The data will be included in Rebecca's PhD thesis, in publications and in conference presentations. No individually identifiable data will be presented or published.
4. **Project Funding:** This project is resourced by the Young and Well CRC (youngandwellcrc.org.au). The Young and Well CRC is established under the Australian Government's Cooperative Research Centres Program.

Participant Involvement:

5. Your involvement or choice not to be involved will have no impact on your relationship with the Young and Well CRC or any member of the research team.

Inclusion criteria:

6. Researchers who are part of the Young and Well Cooperative Research Centre will be invited to participate. Potential participants have been selected based on their level of experience, type of organisation they are employed by and their area of research within the Young and Well Cooperative Research Centre.

Confidentiality:

7. Only Rebecca Randall will have access to the audio files for transcription purposes. All individually identifiable data will be kept separate from audiotapes and transcripts. To protect the identity of individuals, findings will be published without reference to names and will only use participant codes. The researchers will not disclose, publish or use any information provided to us that could identify individuals unless we are required to do so by law. Participants should be aware that it is possible that you could be identified from wording in quotes in the published work. If a participant chooses to withdraw their data will be destroyed.

Data Storage:

8. **Where:** Interviews will be audio-recorded and subsequently transcribed. Participant's names and other identifying details will be stored separately from the recordings and notes/transcriptions of the interviews. Participant information and data will be stored under strict security. Paper records associated with this study will be stored in a locked filing cabinet at NIMHR. Data converted to digital format will be securely stored on ANU servers. Deidentified data will be stored on the primary investigators' encrypted and password protected computers during analysis. Data will be stored for a minimum of 5 years after the date of publication and securely deleted or shredded after this time. Routine access to data will be restricted to members of the research team (i.e. those listed on the application). This restriction will be achieved by directory level controls. It is also necessary that any ANU IT support staff from IT and MHS IT with administrator level access to file servers and backup systems will also technically be able to access data files. This is normal practice for such services.
9. **How long:** Paper and electronic records will be retained for a minimum of five years from publication.
10. **Destruction of Data:** Paper and electronic records will be deleted a minimum of five years after publication.

Queries and Concerns:

Contact Details for More Information:

Rebecca Randall, primary investigator, Rebecca.randall@anu.edu.au, 6125 0674

Dr Lou Farrer, Louise.farrer@anu.edu.au, 6125 8859

Professor Kathy Griffiths, Kathy.griffiths@anu.edu.au, 6125 9723

Ethics Committee Clearance:

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee. If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager

The ANU Human Research Ethics Committee

The Australian National University

Telephone: +61 2 6125 3427

Email: Human.Ethics.Officer@anu.edu.au

Appendix 5.3 Study 2 Interview protocol

Topic Area	Key question/information
Introduction text	Hi, thanks for agreeing to participate in an interview today, I really appreciate the time you've been willing to spare. As you know, my name is Rebecca Randall and I'm a PhD student based at the National Institute for Mental Health Research at the Australian National University. I'm funded by the Young and Well Cooperative Research Centre, of which you are also a part, and my work will be reported back to them. At no stage will members of the Young and Well Cooperative Research Centre outside of the immediate research team, comprised of myself, Prof Kathy Griffiths, Dr Lou Farrer, Dr Michelle Banfield and Dr Alison Callear, know who has participated in these interviews. Participants will only be identified by a code in any publications, conference presentations or the PhD thesis that will arise from this work. All recordings, transcription and analysis will be kept under strict security at the ANU. Thank you for returning your signed consent form. I'd just like to remind you that you're welcome to withdraw at any time by telling me that you wish to withdraw and that if you do I will destroy the recording of our conversation and it will not be analysed. Are you happy to proceed with the interview now? Great, let's get started then. I'll start the recording now.
Participant experience	First question – please tell me a bit about your professional background: For how long have you been involved in the mental health sector or mental health research? For how long have you been involved in the youth mental health sector or youth mental health research? For how long have you been involving end users in your research or work? For how long have you been involving young people in your research and/or work?
Experience with the CRC	Thinking about your research and work with the Young and Well CRC specifically now: Why have you chosen to involve young people in your CRC work? How do you involve young people in your CRC work?

	What media do you use to involve young people in your work? Face to face? Online? On the phone? Through other methods? <i>If yes to this – which?</i>
	Thinking about the ways you engage young people, what do they do when they are engaged?
	Do you involve them when you are? Deciding what to do? Deciding how to do it? Doing it? Letting people know the results?
	Do you approach your work with Young and Well, particularly the work involving young people, from a theoretical model or background? If so, which one?
Approach to involving young people Perceptions of, and ideas around, youth involvement	How do you feel this affects your practice?
	Thinking more broadly now, so including your involvement with Young and Well and other experience you may have had outside of Young and Well for these next questions:
	What challenges do you see arising from involving young people in your research and/or work?
	What benefits do you see arising from involving young people in your research and/or work?
	Do you think engaging young people in research involves different challenges or benefits or issues compared to engaging those over 25 years?
	Acknowledging that there are many different ways and approaches to involving young people, and that this is a very developing and dynamic space, I've got a couple of questions about your possible future practice and how your experience with Young and Well may impact on that future practice.
	In future projects or work, what would you do differently with respect to involving young people as a result of your CRC experience? Have specific challenges arisen during the project that mean you would do things differently?

	How do you think involving young people changes a project? Does involvement make the project better? More challenging? Easier?
Perception of why young people choose to become involved	Final question – why do you think young people choose to participate in the work we do?
Finishing text	That's it for the questions – do you have anything else you would like to add, about any of the questions or a comment on the research?
	Thank you again for your participation. The information sheet has my contact details, that of my supervisors and that of the ANU Human Research Ethics Committee who has approved this study. Please feel free to contact us at any point if you have any concerns.

Appendix 5.4 Study 2 Initial theme tables

Major theme	Theme
Differences	When considering involving young people or older people there are a lot of the same principles
	By there are some differences
	Young people have... (characteristics)
	Young people are (characteristics)
	All of which causes researchers to (actions)
Recognition of the diversity of young people	-
Future work	Expressed plans to continue youth involvement in much the same way
	Participants also had specific ideas about or ways they could improve youth involvement
How youth involvement is done - process	-
Interaction with literature	-
Involvement methods	Deciding how
	General comments
	Mediums used for youth involvement
	Research planning
	Roles that young people take
	Specific research activities
Organisational attitudes towards and experience of youth involvement	The influence of <i>reachout</i> was mentioned
	How 'other' researchers work with young people
	Challenges about the ways organisations work
	Attempts that have been made
Practical or concrete challenges of working with young people	-
Resources and how they can influence (or not) youth involvement	-
Sample	Sometimes it can be hard to reach certain groups
	Reasons it is hard to reach certain groups
	Participants acknowledged importance of trying to reach certain groups
Theory	No specific approach
	Specific ideas or labels
Why do youth involvement	Overarching reasons
	Benefits to the researchers or organisations
	Importance or goodness of the method
	Respect and human rights and ethical reasons
	Youth involvement helps the products' relevance or young people's priorities (better product)
	Youth involvement makes the product or research better on a number of levels
	Youth involvement keeps the focus on young people
Young people get involved because	Of the benefits they get
	Because the topic is (reasons)
	Other reasons that young people might want to get involved include (list)

Appendix 6.1 Study 3 Human Research Ethics approval letter



Protocol: 2013/576

Investigating the characteristics of young people who apply to be part of the Youth Brains Trust of the Young and well CRC through analysing previously written applications

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science & Medical DERC on 23 October 2013.

Appendix 6.2 Study 3 Recruitment emails and participant information sheet

Recruitment email

Dear <<FirstName>>,

In (insert year of application) you applied to be a member of the Youth Brains Trust of the Young and Well Cooperative Research Centre. I'm writing to see if you would be happy for the application you wrote when you were applying to be part of the Youth Brains Trust (YBT) to be sent to one of our researchers who as part of her PhD is exploring how and why young people are involved in the CRC. The YBT applications will contain valuable information for her study.

If you agree to participate, your application will have identifying information removed from it before I forward it on to her. However, it's important that you know that that there is a small chance that she may be able to identify you from what you wrote.

The researcher is Rebecca Randall, a member of the 2013 Youth Brains Trust and a PhD student at the Centre for Mental Health Research. This research, and the way she will handle the applications, have been approved by the Australian National University's ethics committee and we've included their details on the below information sheet if you wish to contact them.

We'd like to emphasise that your participation in this study will have no impact on your relationship or further involvement with the Young and Well CRC.

If you wish to participate:

Read the below information sheet

Reply to this email with the below paragraph filled in

I (insert name) consent to my application to the Youth Brains Trust being sent to Rebecca Randall for the purpose of it being analysed and included in her PhD research.

I understand that replying with this wording indicates that I have read and understood the information contained in the email and information sheet.

If you have any questions about her research, Rebecca can be contacted by emailing Rebecca.randall@anu.edu.au or you can contact me directly on 03 9937 1320.

Rebecca's PhD supervisors at the ANU are Professor Kathy Griffiths and Dr Lou Farrer.

Kris Gesling

Participant information sheet



The Youth Brains Trust Analysis of Applications Study: 1

INFORMATION SHEET FOR PARTICIPANTS

The Centre for Mental Health Research (CMHR) at The Australian National University (ANU) is currently conducting a study designed to learn about youth participation in Australia.

As part of this process we are inviting young people who have previously applied to be part of the Youth Brains Trust of the Young and Well Cooperative Research Centre and are over 18 to consent to a researcher analysing the application you wrote when applying to be part of the Youth Brains Trust. The application sent to the researchers will have had any identifying information removed before they receive it. This study aims to understand why young people apply to be part of the Youth Brains Trust. By analysing your applications Rebecca (the researcher) is represent your views and wishes in a more complete way than other, quantitative, research may do.

If you agree to participate, your application will have identifying information removed from it by Kris Gesling before it is sent to the researchers. However, it's important that you know that that there is a small chance that the primary researcher (Rebecca) may be able to identify you from what you wrote.

The researcher is Rebecca Randall, a member of the 2013 Youth Brains Trust and a PhD student at the Centre for Mental Health Research. This research, and the way she will handle the applications, have been approved by the Australian National University's ethics committee and we've included their details on the attached information sheet if you wish to contact them.

Your participation in this study and its surveys will have no impact on your relationship with the Young and Well Cooperative Research Centre.

Participating in this study involves replying to this email that this sheet was attached to indicating that you consent for your application to be de-identified and sent to the research team.

Your participation in this project is voluntary.

This research is carried out in accordance with the ethical guidelines set out by the National Health and Medical Research Council. An ethics protocol for this study has been approved by The Australian National University Human Research Ethics Committee. If you have any concerns or complaints about the conduct of the research study please can contact the Ethics Manager, The ANU Human Research Ethics Committee, The Australian National University, T: 6125 3427, E: Human.Ethics.Officer@anu.edu.au.

The only persons to have access to de-identified data will be Ms Rebecca Randall, and her PhD supervisors Professor Kathy Griffiths and Dr Lou Farrer. **The researchers will not disclose or use any information provided to us that could identify participants** unless we are required to do so by law. All information provided will be kept confidential and stored under strict security. Findings will be published without reference to names to protect the identity of individuals.

**If you have questions about any aspect of this study, please contact:
Ms Rebecca Randall**

PhD Candidate, Centre for Mental Health Research, ANU College of Medicine,
Biology & Environment E: Rebecca.randall@anu.edu.au, T: 61250674

Dr Lou Farrer

Postdoctoral Research Fellow, Centre for Mental Health Research, ANU College of
Medicine, Biology & Environment E: louise.farrer@anu.edu.au
T: 02 6125 8859, or

Professor Kathy Griffiths

Director, Centre for Mental Health Research, ANU College of Medicine, Biology and
Environment

E: kathy.griffiths@anu.edu.au

T: 02 6125 9723

Appendix 6.3 Study 3 Initial theme tables

Theme
Activity
Aspirations
Attributes
Interests
Volunteering
Work experience

Theme
CRC will do a range of positive things
Engaged with research
Feel they are part of the CRC
Has ability to make change
Have experienced mental ill health
Have views about research
Interested in mental ill health
Interested in technology
Involving young people in their research
They feel that the YBT would be a positive experience
Want to be part of the YBT to do

Appendix 7.1 Study 4 Human Research Ethics approval letter

Protocol: 2013/502^[1]_[SEP] Investigating the characteristics, civic engagement and technology use of applicants to the 2013-14 Youth Brains Trust of the Young and Well Cooperative Research Centre.

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science and Medical DERC on 5 September 2013.

Appendix 7.2 Study 4 Survey text

Question area	Survey	Question text	Answer options
Acceptance	6-month	Were you accepted to be a member of the 2014 Youth Brains Trust?	No Yes
Participant characteristics	Pre acceptance	What is your gender?	Male Female Other (please specify)
	Pre-acceptance	How old are you?	Open-ended
	Pre-acceptance	Do you feel you are a member of any of the following groups? Select as many as apply	I'm from a culturally and linguistically diverse background I'm a newly arrived migrants or refugee I live with a chronic illness or disability I identify as lesbian, gay, bisexual, transgender, intersex or queer I'm a carer I have an experience of homelessness

Question area	Survey	Question text	Answer options
	Pre-acceptance	Which of the following best describes your main activities? (please choose one)	Full-time work greater than or equal to 30 hours paid employment per week Part-time work less than 30 hours paid employment per week Unemployed/looking for work Home duties Have a job but not at work due to illness, vacation etc Not working and currently receiving sickness allowance/disability support pension Volunteer work Student attending school Student attending university Student attending TAFE or other training institution
	Pre acceptance	Have you previously applied to be a member of the Young and Well CRC's Youth Brains Trust?	No Yes, once Yes, twice
	Pre-acceptance	What is the highest level of primary or secondary schooling you have completed?	Some primary All of primary Some secondary Four years of secondary Six years of secondary
	Pre-acceptance	What is the highest level of post-secondary or tertiary schooling you have completed?	Trade/apprenticeship Other certificate Associate or undergraduate diploma Bachelors degree Higher degree

Question area	Survey	Question text	Answer options
	Pre-acceptance	What UAI or ATAR score did you achieve?	Below 30 30-40 41-50 51-60 61-70 71-80 81-90 91-100 I did not receive an ATAR/UA1
Personality factors	Pre-acceptance	How well do the following statements describe your personality? I see myself as someone who... 1. Is reserved 2. Is generally trusting 3. Tends to be lazy 4. Is relaxed, and handles stress well 5. Has few artistic interests 6. Is outgoing, sociable 7. Tends to find fault with others 8. Does a thorough job 9. Gets nervous easily 10. Has an active imagination 11. Is considerate and kind to almost everyone	Likert scale – 1 (Disagree strongly) – Agree strongly (5)
Technology use	Pre-acceptance	How often do you use the internet or spend time online?	Every day or almost every day Once or twice a week Once or twice a month Less than once a month

Question area	Survey	Question text	Answer options
	Pre-acceptance	Approximately how much time would you spend using the internet on a normal school/work day	Open-ended
	Pre-acceptance	Approximately how much time would you spend using the internet on a non-school/work day?	Open-ended
	Pre-acceptance	How many days a week do you go online after 11pm at night?	1 – 7 days per week
	Pre-acceptance	Which of the following technologies do you use on a more or less daily basis (please choose as many as apply to you)	A smart phone A mobile phone that can't access the internet A tablet (e.g. iPad) A laptop A desktop computer A games console or portable gaming device Other handheld portable devices A television A landline telephone
	Pre-acceptance	Where do you most commonly access the Internet/go online? (Select one only?)	Anywhere via my smart phone or tablet At a friend's home At a relative's home In living room (or other public room) at home In own bedroom (or other private room) at home School, TAFE or University Work Other public place (e.g. library, shopping centre, café, internet café)
Activities undertaken online	Pre-acceptance 6-month 12-month	Please select from the following list all the things you have done <u>online</u> in the past month? Select as many as apply	Accessed chat rooms Accessed health information online Accessed online virtual worlds (e.g. Second Life) Accessed social network websites (e.g. Facebook)

Question area	Survey	Question text	Answer options
			Checked email Gambled Listened to, downloaded or uploaded music (e.g. iTunes, Spotify, Sngle) Made or received Voice Over Internet Protocol (VOIP) phone calls (e.g. Skype) Used online or email counselling Played games alone Played games with others over the internet Posted or viewed photos (e.g. Flickr, dropshots, Pinterest, Instagram) Read a blog entry Read or watched the news Searched for new friends Used a webcam Used an instant messenger (e.g. MSN or Gmail messenger) Used eBay, auction sites, Internet shopping facilities Used forums, bulletin boards, or discussion groups Used the Internet for school, study or work Used Twitter Watched, downloaded or uploaded video clips, cartoons, movies, etc, e.g. YouTube Written a blog or online diary Accessed pornography Sexted (sent or received nude or semi-nude photos of yourself or others)

Question area	Survey	Question text	Answer options
Experience of mental ill health	Pre-acceptance	Have you ever had mental health or behavioural issues?	Something else (specify _____) No Yes
	6-month 12-month	In the last six months have you experienced a mental health or behavioural problem?	No Yes
	Pre-acceptance 6-month 12-month	In the last four weeks, about how often ... • Did you feel tired out for no good reason? • Did you feel nervous? • Did you feel so nervous that nothing could calm you down? • Did you feel hopeless? • Did you feel restless or fidgety? • Did you feel so restless that you could not sit still? • Did you feel depressed? • Did you feel that everything was an effort? • Did you feel so sad that nothing could cheer you up? • Did you feel worthless?	Likert scale 1 (none of the time) – 5 (all of the time)

Question area	Survey	Question text	Answer options
	Pre- acceptance 6-month 12-month	Please answer the following questions about how you have been feeling during the past month. During the past month, how often did you feel... 1. Happy 2. Interested in life 3. Satisfied with life 4. That you had something important to contribute to society 5. That you belonged to a community (like a social group, or your neighbourhood) 6. That our society is becoming a better place for people like you 7. That people are basically good 8. That the way our society works made sense to you 9. That you liked most parts of your personality 10. Good at managing the responsibilities of your daily life 11. That you had warm and trusting relationships with others 12. That you had experiences that challenged you to grow and become a better person 13. Confident to think or express your own ideas and opinions 14. That your life has a sense of direction or meaning to it	6 point scale – Never – Every day
Help seeking for mental ill health	Pre-acceptance	Have you ever sought treatment for a mental health or behavioral problem?	No Yes, I used self-help Yes, I sought professional help
	6-month 12-month	In the last six months have you sought treatment for a mental health or behavioural problem?	No Yes, I used self-help Yes, I sought professional help

Question area	Survey	Question text	Answer options
	Pre- acceptance 6-month 12-month	Below is a list of people who you might seek help or advice from if you were experiencing a personal or emotional problem – Please choose the option that shows how likely is it that you would seek help from each of these people for a personal or emotional problem? 1. Partner (e.g. significant boyfriend or girlfriend) 2. Friend (not related to you) 3. Parent 4. Other relative/family member 5. Mental health professional (e.g. school counsellor, psychologist, psychiatrist) 6. Phone help line (e.g. Lifeline, Kids Help Line) 7. Family doctor/ GP 8. Teacher (year advisor, classroom teacher, university lecturer) 9. The internet 10. Someone else not listed above (please describe who this was) 11. I would not seek help from anyone	Likert scale: 1 (extremely unlikely) – 7 (extremely likely)
	6-month 12-month	In the last six months have any of your close friends or close family members experienced a mental health problem?	No Yes

Question area	Survey	Question text	Answer options
Depression literacy	Pre- acceptance 6-month 12-month	The following questions are about your understanding of the symptoms of depression and the way it can be treated. Please indicate whether the statements below are true or false 1. Reckless and foolhardy behaviour is a common sign of depression. 2. Having several distinct personalities may be a sign of depression. 3. Clinical psychologists can prescribe antidepressants. 4. Moderate depression disrupts a person's life as much as multiple sclerosis or deafness. 5. Many treatments for depression are more effective than antidepressants. 6. Counselling is as effective as cognitive behavioural therapy for depression. 7. Cognitive behavioural therapy is as effective as antidepressants for mild to moderate depression. 8. Of all the alternative and lifestyle treatments for depression, vitamins are likely to be the most helpful. 9. People with depression should stop taking antidepressants as soon as they feel better. 10. Antidepressants are addictive. 11. Antidepressant medications usually work straight away	True False Don't know

Question area	Survey	Question text	Answer options
Depression stigma	Pre- acceptance 6-month 12-month	Below are statements about depression. Please indicate how strongly you personally agree or disagree with each statement. 1. People with depression could snap out of it if they wanted. 2. Depression is a sign of personal weakness. 3. Depression is not a real medical illness. 4. People with depression are dangerous. 5. It is best to avoid people with depression so you don't become depressed yourself. 6. People with depression are unpredictable. 7. If I had depression I would not tell anyone.	True False Don't know
Civic participation	Pre-acceptance 6-month 12-month	Have you been involved in any of the following groups or activities? Select all that apply	An online community group (e.g. eBay, Myspace or Facebook, TakingITGlobal, VibeWire.net) A support group Mental health organisation (eg. beyondblue, Create Foundation) A local library A human rights, development or aid organisation A group or club based at your school, TAFE or university A local sporting or recreational group A band, artistic collective or other creative network Some other political or activist organisation A youth club An environmental organisation Organisations or groups concerned with women's or gender issues

Question area	Survey	Question text	Answer options
			Any type of group related to a specific ethnic group in the community A citizen's association A church group A conservation or heritage organisation (e.g. National Trust, or National Parks and Wildlife) Made a donation Volunteered time Signed a petition 'Boycotted' or boycotted a product Written a letter to the editor or contributed to talk back radio discussion or commented on an online article None of these Other (please specify)

Appendix 7.3 Study 4 Text of recruitment emails

Email from Rebecca to participants

Dear <insert name>,

Hi, my name is Rebecca Randall and I'm a PhD student from the Centre for Mental Health Research at the ANU. I'm also a member of the 2013 Youth Brains Trust.

I'm emailing to ask you to participate in a short survey which will ask a few things about you, your mental health history and your technology use. If you participate, you'll also be asked to complete follow up surveys in February and September 2014.

I'm asking you to do this because I'm interested in the factors that lead people to participate in the activities of the Young and Well CRC, and what factors lead young people to be selected into the Youth Brains Trust.

Your participation in this survey will have no impact on your selection into the Youth Brains Trust. No one who makes decisions about the selection of the Youth Brains Trust will have access to your results.

To participate, please go to this link:
<insert link to survey>

If you have any concerns or further questions, please reply to this email.

Cheers,

Rebecca

Email from Kris Gesling (CRC Youth Participation Officer) to participants

Dear <<FirstName>>,

Thank you for nominating for the 2014 Youth Brains Trust, applications are now closed and we hope to let you know who will be a part of the group by Friday the 13th of September.

To review the applications we bring together a special selection panel made up of two staff members from our centre office, two staff members from our partner organisations, and one member of the previous Youth Brains Trust. The selection panel only receives the answers you provided and do not know your name, email address birth date or home address.

This year Rebecca Randall has started a PhD at the ANU and a member of the 2013 Youth Brains Trust is conducting a research project looking at how young people are involved in the Young and Well CRC. If you indicated in your application that you were happy to be contacted, Rebecca will soon be emailing you to ask you to participate in a series of short web based surveys about your personal characteristics, civic engagement and technology use. This survey will be the first of a few studies she'll be doing over the next two years.

The email will be coming from webmaster@mentalhealth.anu.edu.au as it's important that Rebecca doesn't have access to your email addresses or names for confidentiality reasons. To do this an independent researcher at ANU named Anthony Bennett will assign your nomination a unique ID so that Rebecca won't have access to your name or email address.

We'd like to emphasise that your participation in this survey will have no impact on your selection into the Youth Brains Trust. No one who makes decisions about the selection of the Youth Brains Trust will have access to the survey you complete for Rebecca's research. They will not know how you responded to the survey, or even whether you responded at all.

If you have any questions about her research, Rebecca can be contacted by emailing Rebecca.randall@anu.edu.au or you can contact me directly on 03 9937 1320. Rebecca's PhD supervisors at the ANU are Dr Lou Farrer and Professor Kathy Griffiths.

Appendix 7.4 Study 4 Information sheet and consent form



The Youth Brains Trust 2013 Participation Research Study: 1

INFORMATION SHEET FOR PARTICIPANTS

The Centre for Mental Health Research (CMHR) at The Australian National University (ANU) is currently conducting a study designed to learn about youth participation in Australia.

As part of this process we are inviting young people who have applied to be part of the 2013-14 Youth Brains Trust of the Young and Well Cooperative research Centre and are over 18 to participate in a series of short web based surveys about their characteristics, civic engagement and technology use. We would like to invite you to participate in this research study which involves completing three surveys over the next year.

Your participation in this study and its surveys will have no impact on your selection into the Youth Brains Trust. No one who makes decisions about the selection of the Youth Brains Trust will have access to your results.

The study involves completing an anonymous online survey now, the next in February 2014 and a third in September 2014. You can choose the time and place that is convenient to participants. Each survey will take **approximately 15-20 minutes** to complete.

Your participation in this project is voluntary, and if you wish, you can withdraw from the study at any time without any consequences.

It is anticipated that risk will be minimal; however, if you feel distressed as a result of this survey, please contact Lifeline (Telephone: 13 11 14; www.lifeline.org.au)

This research is carried out in accordance with the ethical guidelines set out by the National Health and Medical Research Council. An ethics protocol for this study has been approved by The Australian National University Human Research Ethics Committee. If you have any concerns or complaints about the conduct of the research study please can contact the Ethics Manager, The ANU Human Research Ethics Committee, The Australian National University, T: 6125 3427, E: Human.Ethics.Officer@anu.edu.au.

The only persons to have access to de-identified data will be Ms Rebecca Randall, Dr Lou Farrer and Professor Kathy Griffiths. **The researchers will not disclose or use any information provided to us that could identify participants** unless we are required to do so by law. All information provided will be kept confidential and stored under strict security. Findings will be published without reference to names to protect the identity of individuals.

If you have questions about any aspect of this study, please contact:

Ms Rebecca Randall

PhD Candidate, Centre for Mental Health Research, ANU College of Medicine,
Biology & Environment E: Rebecca.randall@anu.edu.au, T: 61250674

Dr Lou Farrer

Postdoctoral Research Fellow, Centre for Mental Health Research, ANU College of
Medicine, Biology & Environment E: louise.farrer@anu.edu.au
T: 02 6125 8859, or

Professor Kathy Griffiths

Director, Centre for Mental Health Research, ANU College of Medicine, Biology and
Environment

E: kathy.griffiths@anu.edu.au

T: 02 6125 9723

Appendix 8.1 Study 5 Human Research Ethics approval letter



Protocol: 2014/569

Young Australian's involvement in their communities

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science and Medical DERC on 2 October 2014.

Appendix 8.2 Study 5 Emails sent to CRC researchers

Dear Young and Well CRC Project Managers

Earlier this year you would have heard from Rebecca Randall, one of our PhD students, who was asking about youth participation in your projects. Thank you to those who responded to her initial request.

She has developed a survey which asks young people who have been involved in the CRC about their experiences of being involved. In order to access the young people that have been involved in your project she is hoping to work with you, where you have ethics approval, to obtain variations to those approvals for her survey to be sent out.

She will be emailing you individually about this in the next few days.

While we understand she is asking additional work of you, we hope you will respond and help her.

Kind regards,

Tom

Appendix 8.3 Study 5 Facebook message text

How are you? Hope things are well. *insert brief personal comment*

I'm in the middle of my PhD and I've just launched the biggest study I'll be doing as part of it. I'm looking at young people's background, their mental health history, views about mental health issues, their experiences of being involved in research and how they are involved in their communities in Australia through an anonymous online survey.

To do this, I've got 15 minute survey for 18-25 year olds and I'm hoping to get 1000 respondents.

I really need your help to do this though. I know it's a big ask, but I'm hoping you will help me out by doing one (or more) of the following 3 things:

1. Complete the survey yourself!
2. Share my project's Facebook page on your Facebook page to encourage your friends to complete it. (link)
3. Share it around any Facebook groups you belong to or networks you have. I'm happy to help with this by providing wording, or anything else I can do.

I really, really appreciate any time you can give me. Getting respondents to this survey is essential to my PhD's success, so this is really important to me.

Thanks so much

Appendix 8.4 Study 5 Participant information sheet



Participant Information Sheet

Researcher:

Rebecca Randall is a PhD student at the National Institute for Mental Health Research in the Research School of Population Health, College of Medicine Biology and the Environment at the Australian National University.

Project Title: Young Australians' involvement in their communities

General Outline of the Project:

- Description and Methodology: This project aims to obtain information about young people's background, their experiences of being involved in research and how they are involved in their communities in Australia through an anonymous online survey.
- Participants: Approximately 1000 Australian young people will be involved.
- Use of Data and Feedback: The data will be included in Rebecca's PhD thesis, in publications and in conference presentations. A plain language summary will be available through youth organisations and online. Data may also be used in future research
- Project Funding: This PhD project is funded by the Young and Well Cooperative Research Centre

Participant Involvement:

- Voluntary Participation & Withdrawal: Your participation in this study is voluntary and you may, without any penalty, withdraw at any time during completing the survey by closing the browser window. If you haven't clicked the 'submit' button at the end of the survey, your responses will not be used. Due to the anonymous nature of the survey once you have submitted the survey you will not be able to withdraw as there will be no way to identify your information.
- What will participants have to do? You will complete a 15 minute online survey.
- Location and Duration: You will be involved once at a time and place of your choosing.
- Risks: There are no foreseeable risks or discomforts as a result of your participation.
- Implications of Participation: Your involvement or choice not to be involved will have no impact on your relationship with the Young and Well CRC or any other organisation you are involved in.

Inclusion criteria:

Young people who reside in Australia and are aged 18-25 are eligible to participate.

Confidentiality:

Confidentiality: The only persons to have access to survey data will be the research team at the National Institute for Mental Health Research who are involved with the project. All information provided will be kept confidential as far as the law allows and stored under strict security. Findings will be published without reference identifying any identifying information to protect the identity of individuals.

Data Storage:

Where: The survey software (Limesurvey) runs on servers at the ANU, to which access is controlled. Access to data will be restricted to authorised personnel on ANU managed computers and will be kept for 5 years after publication.

How long: Data will be kept for five years from publication.

Destruction of Data: De-identified data will be placed in the ANU Data Repository.

Queries and Concerns:

Contact Details for More Information:

Rebecca Randall, primary investigator, Rebecca.randall@anu.edu.au, 6125 0674

Dr Lou Farrer, louise.farrer@anu.edu.au, 6125 9723

Professor Kathy Griffiths, Kathy.griffiths@anu.edu.au, 6125 8859

Ethics Committee Clearance:

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee. If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager

The ANU Human Research Ethics Committee

The Australian National University

Telephone: +61 2 6125 3427

Email: Human.Ethics.Officer@anu.edu.au

Appendix 8.5 Study 5 Survey text

Question area	Question text	Answer options
Participant characteristics	How old are you?	Open-ended numerical
	What is your gender?	Male Female Other (please specify)
	What is your postcode?	Open-ended numerical
	Is English the only language you speak?	No Yes No answer
	Which other languages do you speak?	Open-ended
	Are you of Aboriginal or Torres Strait Islander Origin?	No Yes, Aboriginal Yes, Torres Strait Islander Both Aboriginal and Torres Strait Islander
	Do you feel you are a member of any of the following groups? Select as many as apply	I'm from a culturally and linguistically diverse background I'm a newly arrived migrants or refugee I live with a chronic illness or disability I identify as lesbian, gay, bisexual, transgender, intersex or queer I'm a carer I have an experience of homelessness No answer

Question area	Question text	Answer options
Educational attainment	What is your highest level of education?	No formal education Completed or partially completed primary school Completed or partially completed junior high school (years 7-10) Completed or partially completed senior high school (year 11 and 12) Certificate or diploma Degree Post graduate Diploma, Masters or PhD
	Which of the following best describes your main activities? (please choose one)	Full-time work greater than or equal to 30 hours paid employment per week Part-time work less than 30 hours paid employment per week Unemployed/looking for work Home duties Have a job but not at work due to illness, vacation etc Not working and currently receiving sickness allowance/disability support pension Volunteer work Student attending school Student attending university Student attending TAFE or other training institution
Technology use	How often do you use the internet or spend time online?	Every day or almost every day Once or twice a week Once or twice a month Less than once a month

Question area	Question text	Answer options
	Which of the following technologies do you use on a more or less daily basis (please choose as many as apply to you)	A smart phone A mobile phone that can't access the internet A tablet (e.g. iPad) A laptop A desktop computer A games console or portable gaming device Other handheld portable devices A television A landline telephone
Activities undertaken online	Please select from the following list all the things you have done <u>online</u> in the past month? Select as many as apply	Accessed chat rooms Accessed health information online Accessed online virtual worlds (e.g. Second Life) Accessed social network websites (e.g. Facebook) Checked email Gambled Listened to, downloaded or uploaded music (e.g. iTunes, Spotify, Songle) Made or received Voice Over Internet Protocol (VOIP) phone calls (e.g. Skype) Used online or email counselling Played games alone Played games with others over the internet Posted or viewed photos (e.g. Flickr, dropshots, Pinterest, Instagram) Read a blog entry Read or watched the news Searched for new friends

Question area	Question text	Answer options
		Used a webcam Used an instant messenger (e.g. MSN or Gmail messenger) Used eBay, auction sites, Internet shopping facilities Used forums, bulletin boards, or discussion groups Used the Internet for school, study or work Used Twitter Watched, downloaded or uploaded video clips, cartoons, movies, etc, e.g. YouTube Written a blog or online diary Accessed pornography Sexted (sent or received nude or semi-nude photos of yourself or others) Something else (specify) No Yes
Experience of mental ill health, help seeking and knowledge of others' mental ill health	Have you ever had mental health or behavioural issues?	No
	Have you ever sought treatment for a mental health or behavioural problem?	Yes
Depression Literacy	Have any of your close friends or close family members ever sought help for a mental health or behavioural problem?	No
	The following questions are about your understanding of the symptoms of depression and the way it can be treated. Please indicate whether the statements below are true or false	Yes
	The following questions are about your understanding of the symptoms of depression and the way it can be treated. Please indicate whether the statements below are true or false 1. Reckless and foolhardy behaviour is a common sign of depression. 2. Having several distinct personalities may be a sign of depression. 3. Clinical psychologists can prescribe antidepressants.	True False Don't know

Question area	Question text	Answer options
	4. Moderate depression disrupts a person's life as much as multiple sclerosis or deafness. 5. Many treatments for depression are more effective than antidepressants. 6. Counselling is as effective as cognitive behavioural therapy for depression. 7. Cognitive behavioural therapy is as effective as antidepressants for mild to moderate depression. 8. Of all the alternative and lifestyle treatments for depression, vitamins are likely to be the most helpful. 9. People with depression should stop taking antidepressants as soon as they feel better. 10. Antidepressants are addictive. 11. Antidepressant medications usually work straight away	
Depression Stigma	Below are statements about depression. Please indicate how strongly you personally agree or disagree with each statement. 1. People with depression could snap out of it if they wanted. 2. Depression is a sign of personal weakness. 3. Depression is not a real medical illness. 4. People with depression are dangerous. 5. It is best to avoid people with depression so you don't become depressed yourself. 6. People with depression are unpredictable. 7. If I had depression I would not tell anyone.	True False Don't know

Question area	Question text	Answer options
Involvement with other groups	Have you participated in research other than with the Young and Well Cooperative Research Centre in the past three years?	Yes No
Civic participation	Please provide any details you remember about your participation Have you been involved in any of the following groups or activities? Select all that apply	Open-ended An online community group (e.g. eBay, Myspace or Facebook, TakingITGlobal, VibeWire.net) A support group Mental health organisation (eg. beyondblue, Create Foundation) A local library A human rights, development or aid organisation A group or club based at your school, TAFE or university A local sporting or recreational group A band, artistic collective or other creative network Some other political or activist organisation A youth club An environmental organisation Organisations or groups concerned with women's or gender issues Any type of group related to a specific ethnic group in the community A citizen's association A church group A conservation or heritage organisation (e.g. National Trust, or National Parks and Wildlife) Made a donation Volunteered time Signed a petition 'Boycotted' or boycotted a product Written a letter to the editor or contributed to talk back radio discussion or commented on an online article

Question area	Question text	Answer options
Volunteering motivations and experience	Please indicate how important each of the following statements were for you in doing volunteer work. • I feel it is important to help others • I can do something for a cause that is important to me • Volunteering can help me get my foot in the door at a place where I would like to work • I can explore my own strengths • Volunteering is an important activity to the people I respect • Volunteering helps me deal with some of my own problems • Volunteering makes me feel needed • I can make new contacts that might help my business or career • I can learn new skills through direct hands-on experience • I feel compassion toward people in need • Volunteer experience will look good on my resume • Volunteering allows me to gain a new perspective on things • Volunteering helps me to explore different career options.	None of these Other (please specify) 5 point likert scale: 1 (not at all important) to 5 (very important)

Question area	Question text	Answer options
CRC involvement	What are your main reasons for volunteering?	Open-ended
	What are your main reasons for not volunteering?	Open-ended
	Which organisations have you been involved with?	Open-ended
	Have you ever volunteered with the Young and Well Cooperative Research Centre (Young and Well CRC) or any of the below projects: - eTools for Wellbeing - Online Centre for Wellbeing - Safe and Well Online - Young and Well National Surveys - Young and Well Towns - Gaming Research Group - Mapping Digital Inclusion and Exclusion - How do you feel? - Digital collaborative storytelling for wellbeing - Engaging creativity through technology - Growing up Queer - Messages of Hope - Technologies for supportive communities - Young people and game developers working together - The Lab evaluation - Livewire Chat - Online Communities - Transforming Communities and Institutions - Link - Uni-Virtual Clinic (ANU)	Yes No Unsure No answer

Question area	Question text	Answer options
	- e-mental health clinic - Interactive Online E-Tool for Assessment - Young Men's intervention - Better Practise guide - Bridging the digital disconnect - Counting the cost: Young Men's Mental Health - Evidence Review	
	In what stage or stages in the research process did you feel you were involved? (select as many as apply) When the researchers were:	Deciding what to do Deciding how to do it Doing it Interpreting the findings Writing a scientific report on the findings Letting the community know the results
	In what stage or stages in the research process would you have liked to be involved? (Select as many as apply)	Deciding what to do Deciding how to do it Doing it Interpreting the findings Writing a scientific report on the findings Letting the community know the results
	In what ways were you involved? (select as many as apply)	Face to face Online On the phone Other (please specify)
	How many times were you involved in the research? (E.g. participating in a survey – one time, attending a meeting or workshop – one time)	Open-ended

Question area	Question text	Answer options
	What did your involvement entail? e.g. 'I did my honours research' or 'I did a survey'	Open-ended
	Support for my participation was given in an approachable and available manner.	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	I had a clear understanding of my project and my role	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	I was able to access the people and resources I needed to complete my participation activities	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	I knew who to ask for assistance when I needed it.	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	There was enough flexibility in my participation to allow for unexpected changes in my personal or work life.	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	Overall I had a positive experience during my participation	Likert scale 0 (strongly disagree) to 4 (strongly agree)
	Do you have any comments regarding your project or participation?	Open-ended
	Was technology used to help you participate?	Yes No
	How was technology used to help you participate?	Open-ended
	Did the use of technology in the project you were involved in help you participate?	Yes No
	Do you think technology could have been used differently to improve your experience?	Yes No
	If yes – how?	Open-ended