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Little ears – Aboriginal programmes for hearing and EAR screening (LEAP – HEAR): a research protocol for co-design workshops to strengthen programmes

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ABSTRACT

Introduction Multiple well-considered but siloed initiatives and programmes exist in Australia to support ear and hearing screening and assessment for Indigenous children. However, the lack of coordination of these programmes leads to inefficiencies in resource allocation and disrupts opportunities to implement a cost-effective, efficient, and easily navigable system of care. Indigenous children experience high prevalence rates of middle ear disease, as well as earlier onset, increased severity and longer infections compared with non-Indigenous children. The aims of this study are to: (1) Understand current ear and hearing screening programmes in three New South Wales communities and evaluate their strengths and limitations, (2) Strengthen, implement and evaluate ear and hearing screening programmes and (3) Identify the barriers and facilitators for scaling strengthened ear and hearing screening programmes nationally and the importance and feasibility of each factor.

Methods and analysis A series of desktop searches and co-design workshops will be completed to achieve aim (1) and (2) and the results will be mapped into work-as-done and work-as-imagined using the Functional Resonance Analysis Method. Strengthened screening programmes will be implemented in communities using the criteria from national and international guidance documents and the Practical, Robust, Implementation and Sustainability Model and evaluated. Finally, workshops will be conducted with key stakeholders to identify the barriers and facilitators for scaling strengthened ear and hearing screening programmes nationally and the importance and feasibility of each factor.

Ethics and dissemination This project has received ethics approval from the Aboriginal Health and Medical Research Council Human Research Ethics Committee (Ref: 2350/24). Results will be disseminated to the community through the CEOs of the Aboriginal Community Controlled Health Organisations as well as published in peer-reviewed journals and presented at conferences. The findings from data collected will be used to inform the co-production of an enhanced system for ear and hearing care.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A strength of this study is the use of codesign methodology with researchers and Indigenous communities to understand and strengthen current ear and hearing screening programmes together.
⇒ A limitation of the study is that it will focus on screening programmes in a small number of Indigenous communities in New South Wales; however, these programmes will be workshopped to understand the barriers and facilitators to scale them nationally.
⇒ A limitation of this study is that it will focus on the screening component of the pathway of care, whereas follow-up care and management are essential (and are being investigated in parallel studies).
⇒ A limitation of this study is that it will focus on school-aged children rather than identifying the children in earlier critical years (though preschool screening programmes will also be included, acknowledging that preschool is not compulsory).

INTRODUCTION

Aboriginal and Torres Strait Islander peoples (hereafter respectfully referred to as Indigenous peoples) represent the oldest continuous living culture in the world. Indigenous peoples maintained a balanced and interconnected health ecology of land, people and place. Indigenous peoples have demonstrated strong resilience to colonisation; however, this disruption resulted in ongoing impacts on health outcomes and social-emotional well-being of Indigenous peoples. One example of this is otitis media, that is, middle ear disease. Otitis media and fluctuating hearing loss are often experienced by Indigenous children. In addition to increased prevalence rates, otitis media occurs earlier, with increased severity and lasts longer for Indigenous children compared with non-Indigenous children.[1] Otitis media can go on to adversely affect children's cognitive and educational outcomes.[2] Otitis media is strongly linked to social determinants of health, requiring a multifaceted public health approach to address this,[3] yet early detection

and effective treatment are key to reducing longer-term impacts on the child and family. The Otitis Media Guidelines for Aboriginal and Torres Strait Islander Children provide rigorous evidence-based recommendations for prevention, identification, treatment and referral, promoting surveillance by primary health or child health practitioners at every clinical interaction as a primary approach for the earliest detection of otitis media.[4] These guidelines were developed because Indigenous children require specific primary care management approaches due to experiencing greater severity and chronicity of otitis media. While surveillance by primary health or child health practitioners is important, this places an increased burden on an already stretched healthcare system, limiting uptake of the guidelines. Additionally, while prevention, early detection and management of otitis media is indeed a key goal, effective management of downstream effects of hearing loss and speech and language delays is also critical and, without this, reduces the effectiveness of ear check programmes. While this study will focus on the screening component of the care pathway, it is acknowledged that follow-up care and management are essential (and are being investigated in parallel studies).

Preschools and schools are essential access points to early diagnosis and management of childhood health concerns, particularly for priority populations where cultural barriers to mainstream primary healthcare may limit access.[5] School is regarded as the single best investment in human capability formation in individuals and populations; therefore, optimising access to learning opportunities is critical. In 2019, the national school attendance rate was 83.2% for Indigenous students, and while there is room to improve attendance rates, this provides an ideal opportunity to capture the majority of Indigenous children at critical points in their lifetime. The Australian Government's aim is that by 2025, 95% of Indigenous children will be enrolled in Year Before Full-time Schooling, which further supports the sustainability of this approach. It is acknowledged, however, that ear and hearing checks should still be conducted before school age,[6] but the focus of this study will be on preschool and school-aged children for the reasons outlined above.

Aboriginal Community Controlled Health Organisations (ACCHOs) are ideally positioned to deliver accessible, integrated, culturally safe healthcare services tailored to the needs of Indigenous peoples.[7] A recent systematic scoping review of Indigenous primary health programmes indicates the extent to which culture influences all aspects of the delivery of healthcare,[8] including services which are Indigenous led, governed and delivered. Strengthening ACCHOs to manage ear and hearing care recognises the importance of their role in delivering culturally appropriate care for the community.

Multiple well-considered but siloed initiatives and programmes exist in Australia to support ear and hearing screening and assessment for Indigenous children.[9] These include the Otitis media Ear and Hearing Assessment Equipment programme, Ear and Hearing Assessment Training for a blended delivery 'EarTrain' programme offered through New South Wales (NSW) Technical and Further Education, Ear Health Coordinator programme which supports ACCHOs to deliver comprehensive ear and hearing care services, and the new National Key Performance Indicator (nKPI) for primary healthcare—ear health that includes two proposed KPIs (# 1. Proportion of Indigenous regular clients aged 0–14 who received an ear health check and # 2. Proportion of Indigenous regular clients aged 0–14 with an ear condition).[10] In addition, surgical support and fly-in-fly-out programmes, such as through the Royal Flying Doctors Service and Hearing Australia, provide access to specialist services. Yet, coordination difficulties with these programmes lead to inefficiencies in resource allocation and disrupt opportunities to implement a cost-effective, efficient, and easily navigable system of care. Such fragmentation is not unique to ear and hearing care.[11]

Telehealth approaches improve outreach and cultural safety. Telehealth is now essential to healthcare and can help to lessen disparities. The COVID-19 pandemic has revealed significant gaps in healthcare, highlighting disparities in access to care for underserved rural and minority populations. Present for decades, telehealth solutions have assumed new critical significance. Telehealth can transform access for some underserved regional/remote and priority populations (dependent on internet quality) not only for clinical care, but also for prevention.[12] The convergence of digital and connectivity revolutions enables new ways of delivering decentralised ear and hearing care services along the entire healthcare journey using integrated eHealth solutions.[13] Critically missing, however, is a systems-thinking approach and an implementation and evaluation plan which demonstrates how people, processes and technologies must interact to deliver a unified and culturally-appropriate solution. Further, a robust evaluation of programmes is lacking in many initiatives focused on Indigenous health. Additionally, embedded quality assurance is needed for ongoing programme monitoring.

In 2008 there was a seminal NSW Health Report 'Evaluation of the Aboriginal Otitis Media Screening programme' which led to the significant change in policies and withdrawal of funding and infrastructure that supported ear and hearing screening programmes in NSW.[14] It reported that there was considerable uncertainty whether ear and hearing screening led to appropriate referral, treatment and support. As part of the evaluation, no systematic data on outcomes for Indigenous children was collected following ear and hearing screening. Therefore, the evaluation was not able to assess the effectiveness of screening in improving outcomes for Indigenous children. The report recommended a comprehensive public health approach to prevent and reduce the impacts of otitis media and hearing loss in young Indigenous children, including incorporating screening for otitis media and hearing loss into existing health programmes and

ceasing to continue to fund the Aboriginal Community Controlled Health sector to provide school and preschool screening for otitis media and hearing loss. Despite the lack of dedicated state funding, Aboriginal Community Controlled Health Services continue to fund and conduct ear and hearing screening for children from schools and preschools.

Our proposed project will specifically address key barriers identified in the seminal 2008 NSW Health Report.[14] Specifically, these were: (a) The extent to which resources and trained staff were available, (b) The ability to provide a coordinated response to increasing the number of children screened and (c) The extent to which Area Health Service management agreed with the focus on near universal screening.

Our proposed project directly aligns with Closing the Gap—a commitment from all Australian governments and Aboriginal and Torres Strait Islander representatives to a new way of working to close the gap between Indigenous and non-Indigenous people's outcomes.[15] Specifically, it aligns with target #5 that Indigenous students achieve their full learning potential.[15] The project will also explicitly address many of the desired outcomes in the Roadmap of Hearing Health, which sets out suggested actions to support short, medium and long-term improvements in hearing health for all people in Australia.[16] In particular: 'There is a sustained and trending reduction in the prevalence of otitis media and hearing loss among Aboriginal and Torres Strait Islander people, particularly children 0–7 years old' (pg. 9) and 'Community-led, strategically planned and coordinated research into effective strategies for promotion, prevention, identification, treatment, remediation and mitigation of the impacts of early onset, chronic ear disease and associated hearing loss in Aboriginal and Torres Strait Islander children is appropriately and consistently funded, managed and evaluated' (pg. 9).

Aims

With strong and established Indigenous leadership and discipline expertise in ear and hearing health, Indigenous research methodology, health policy, capacity-building and education, co-design, qualitative research approaches and established partnerships with three Indigenous communities (one urban, one regional and one rural/remote) in NSW as well as an Indigenous Community Governance Group, the LEAP HEAR research aims to:

1. Understand current preschool and school ear and hearing screening programmes in three Aboriginal communities (one urban, one regional and one rural/remote) in NSW and evaluate their strengths and limitations.
2. Strengthen, implement and evaluate ear and hearing screening programmes.
3. Identify the barriers and facilitators for scaling strengthened ear and hearing screening programmes nationally and the importance and feasibility of each factor.

The intended outcome of this research is to implement strengthened ear and hearing screening programmes that enable children with otitis media to be diagnosed and treated early, minimising the impact on their neurocognitive, literacy and language development.

METHODS AND ANALYSIS

Patient and public involvement

This project will be governed by an Indigenous Community Governance Group which will provide advice, expertise and cultural knowledge throughout the project.

Objectives

There are five objectives for this project:

1. Conduct participatory workshops to understand current ear and hearing screening programmes in urban, regional and rural/remote NSW communities and evaluate their strengths and limitations against the consolidated principles for screening from The Department of Health of Australia[17] and Dobrow *et al*[18] and identify the environmental context which could facilitate or hinder change.
2. Identify national and state policies and programmes that could be implemented to strengthen current ear and hearing screening programmes.
3. Conduct co-design workshops to strengthen ear and hearing screening programmes.
4. Implement strengthened ear and hearing screening programmes in the three NSW communities and evaluate them.
5. Conduct workshops to identify the barriers and facilitators to scaling strengthened ear and hearing screening programmes nationally and their importance and feasibility.

The study design is shown in figure 1. The following sections provide the methods and analysis for each objective of the project.

Participants for objectives 1, 3 and 4

Participatory workshops will be conducted with Aboriginal Health Workers, CEOs from ACCHOs, preschool and school staff and stakeholders in three partner communities in NSW (one urban, one regional and one rural/remote) to understand current ear and hearing screening programmes.

Inclusion and exclusion criteria

Workshop participants must be ACCHO staff or identified as a relevant community stakeholder by ACCHO staff. ACCHO staff may include administrative, medical, nursing and health promotion staff involved in the screening of otitis media and hearing loss, such as CEOs, general practitioners, audiologists, child and family nurses, Aboriginal Health Workers and paediatricians and ENT surgeons. Other relevant stakeholders identified by ACCHO staff may include non-ACCHO health staff, teachers, Aboriginal Liaison Officers, Aboriginal

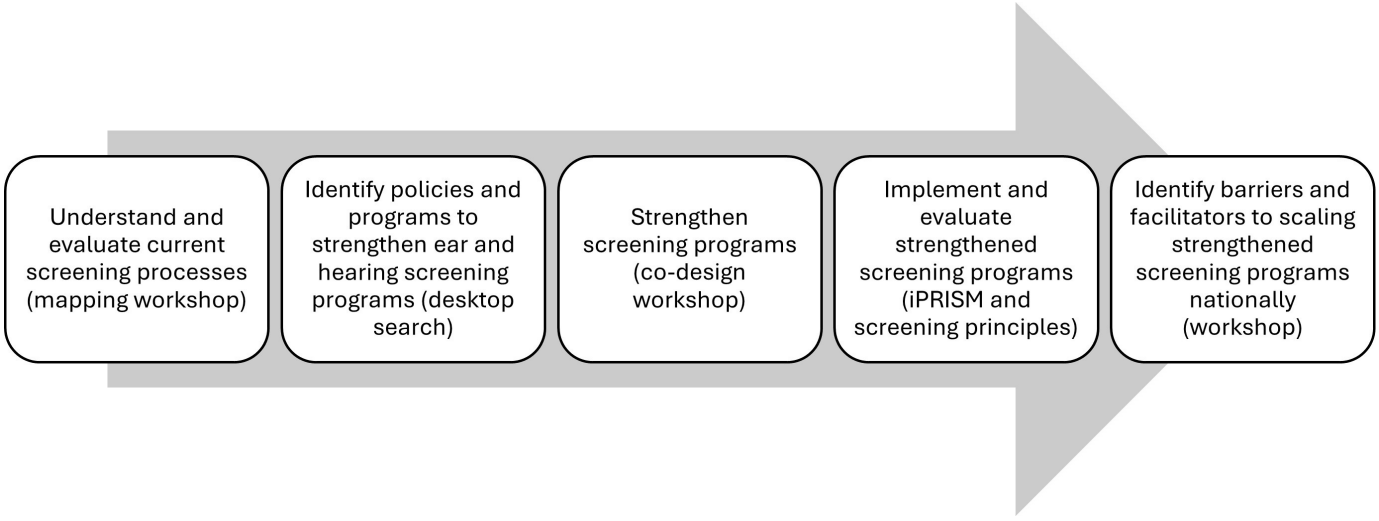

Figure 1 LEAP HEAR study design. iPRISM, Iterative, practical, robust implementation and sustainability model.

Education Officers, speech and language service staff and other preschool and school staff as well as other identified community members including education providers, NDIS service providers, families or Elders.

Sample size

We aim to recruit 40 stakeholder participants in total. This will include between 10–20 participants for each participating ACCHO. These sample sizes and categories of participant will allow for a diversity of experiences and understandings of screening programmes to be captured in the data collection.

Participant recruitment

The ACCHO investigators will lead the identification of potential stakeholder participants for the research, determine the optimal recruitment strategies and provide an environment where participants can be recruited by the researchers through an informed consent process.

Participants for objectives 5

Key stakeholders from the health and education sector and Indigenous organisations across Australia will be involved in two workshops to identify barriers and enablers to rolling out the strengthened ear and hearing screening programmes in other communities and jurisdictions.

Inclusion and exclusion criteria

Participants must be from the health or education sector or an Indigenous organisation.

Sample size and statistical or power issues

We aim to recruit 10–20 stakeholder participants in total. This sample size and categories of participants will allow for a diversity of experiences and understandings of scaling screening programmes to be captured in the data collection.

Participant recruitment

The ACCHO investigators will lead the identification of potential stakeholder participants for the research, determine the optimal recruitment strategies and provide an environment where participants can be recruited by the researchers. Potential participants will be encouraged to ask questions about the study and then will be able to accept or decline the invitation to participate in the evaluation.

Research activities and data analysis

Objective 1: conduct participatory workshops to understand current ear and hearing screening programmes in urban, regional and rural/remote NSW communities and evaluate their strengths and limitations

Participatory workshops (research activity)

The workshops will take place separately at each participating ACCHO, on-site at Macquarie University, or online. Prior to the workshop, the principles for screening programmes will be consolidated from The Department of Health of Australia[17] and Dobrow *et al*'s[18] consolidated principles for screening which were based on a systematic review and consensus process. At the workshop, the participants will be asked to complete a survey rating to what extent their current programme meets the screening principles (from 0=not at all to 5=completely). The workshop participants will then take part in a facilitated discussion on current ear and hearing screening programmes to understand (but not limited to) informed consent, current process and protocols, workforce and training needed, referral pathways, data capture and transfer, equipment used, barriers and enablers to follow-up, and alignment to the principles for screening programmes. The scope of the project is the pathway for school screening and data referrals into the ACCHO or local health district, and then the transfer of information back to the schools for educational supports. These workshops will take an iterative process until all the needed information is gathered, with each workshop taking approximately 2 hours. Workshops will be recorded to ensure we are able to refer to the discussion when preparing to report the

pathway. The workshop will be facilitated by lead Indigenous and non-Indigenous researchers from Macquarie University.

Data analysis

Current ear and hearing screening programmes will be mapped using the Functional Resonance Analysis Method (FRAM). The FRAMs are used to model complex socio-technical systems to identify and describe the functions that are being performed as well as their mutual dependencies.[19 20] This will achieve work-as-done models for the programmes in each of the communities. These programmes will also be evaluated against the principles of screening programmes to understand the limitations and areas to be strengthened.

Objective 2: identify national and state policies and programmes that could be implemented to strengthen current ear and hearing screening programmes

Research activity

A desktop search will be conducted to identify national and state policies and programmes that could be implemented to strengthen current ear and hearing screening programmes. Websites and documents searched will be limited to NSW Government policies, Australian Federal Government policies (Hearing Australia's Community Service Obligation, Medicare, NDIS), Indigenous Australians Health Programmes,[21] and Australian Institute of Health and Welfare (Ear and hearing health of Aboriginal and Torres Strait Islander people 2021.[22]

Data analysis

Relevant policies and programmes that can be implemented to strengthen current ear and hearing screening programmes will be incorporated into a work-as-imagined FRAM.

Objective 3: conduct co-design workshops to strengthen ear and hearing screening programmes

Co-design workshops (research activity)

The co-design workshops will take place separately at each participating ACCHO, on-site at Macquarie University, or online. The workshops will be a facilitated discussion to develop a strengthened ear and hearing screening programme taking into consideration available services, equipment, resources, local needs, policies and programmes and the consolidated screening principles. This will produce a framework for the strengthened screening programme that can be referred to by those implementing the screening programme. These workshops will take an iterative process until all the needed information is gathered, with each workshop taking approximately 2 hours. Workshops will be recorded to ensure we are able to refer to the discussion when preparing to report the new pathway. The workshop will be facilitated by lead Indigenous and non-Indigenous researchers from Macquarie University.

Data analysis

Proposed strengthened ear and hearing screening programmes will be mapped using the FRAM in each Aboriginal community using the information from Objective 2 and the principles of screening programmes to address the limitations consolidated in Objective 1. Each of the operational steps from Planning, operation and evaluation of screening programmes | Health Knowledge[23] will also be included. An implementation plan will be developed with the communities using the principles from The Department of Health of Australia, WHO and UK National Screening Committee.[17 24 25] This will achieve work-as-imagined FRAMs for the programme in each of the communities.

Objective 4: implement strengthened ear and hearing screening programmes in three NSW communities and evaluate them

Implementation

Research activity

The strengthened ear and hearing screening programmes will be implemented in the partner communities following the co-designed implementation plan using the principles from The Department of Health of Australia, WHO and UK National Screening Committee[17 24 25] and the Practical, Robust, Implementation and Sustainability Model (PRISM). The PRISM is the contextually expanded, updated version of the RE-AIM framework. The RE-AIM is a framework to guide the planning and evaluation of programmes according to the five key RE-AIM outcomes: Reach, Effectiveness, Adoption, Implementation and Maintenance. The PRISM adds the contextual factors including: programme characteristics from the perspective of the patient or community members; programme characteristics from the perspective of the organisational (setting) partners; recipient characteristics from the perspective of the patient or community members; recipient characteristics from the perspective of the organisational (setting) partners; implementation and sustainability infrastructure and the external environment.[26] Participants will be presented with the co-designed strengthened ear and hearing screening programmes and asked to complete the iPRISM tool (planning phase) and PRISM Contextual Survey Instrument to assess the context and fit of the strengthened programme (30 mins).

Data analysis

The iPRISM web tool will analyse the data to identify and prioritise strategies to improve the implementation success of the programme.

Evaluation: iPRISM and screening principles

Research activity

Six months after implementation, participants will be asked to complete the iPRISM tool (implementation phase) to assess to what extent the strengthened screening programme is achieving the PRISM outcomes. The participants will also be asked to fill out the survey

from Objective 1 rating to what extent their strengthened programme meets the screening principles identified in Objective 1 (from 0=not at all to 5=completely). The total time for completing both surveys will be up to 30 mins.

Data analysis

The iPRISM web tool will analyse the data to help assess progress, measure outcomes and context, and direct next steps in implementation. The results from the screening principles survey will be compared with the results from Objective 1 via a paired t-test to determine if the strengthened ear and hearing screening programmes now better achieve the screening principles.

Objective 5: conduct workshops to identify the barriers and facilitators to scaling strengthened ear and hearing screening programmes nationally and their importance and feasibility

Workshops (research activity)

Two workshops (up to 2 hours each) will be conducted with participants using concept mapping following Trochim and Kane methodology.[27] In the first workshop, the workshop leader will introduce the ear and hearing screening programme to the participants. Participants will brainstorm statements in response to the question 'What are the barriers and facilitators to scale ear and hearing screening programmes for Aboriginal and Torres Strait Islander children?' first individually, and then presented to the group for further brainstorming. After the workshop, the research team will remove duplicate statements, synthesise similar statements and edit the statements for clarity. In the second workshop, each of the refined statements will be presented to each participant and they will rate each statement in terms of its importance (1=not at all important to 5=extremely important) and feasibility (1=not at all feasible to 5=extremely feasible). Finally, participants will conduct a free sort of each of the refined statements where they will place similar statements into piles. Participants can use as few or as many piles as needed. Participants will also be asked to complete the iPRISM tool (sustainment phase) to assess the likelihood of the scaled screening programme in achieving the PRISM outcomes (30 mins).

Data analysis

Concept mapping[27] will be used to integrate input from multiple stakeholders as a mixed participatory method which collects qualitative and quantitative data for analysis. The sorted statements from the free sort will be analysed through multidimensional scaling,[28] which will be used to produce a visual representation of the ideas on the barriers and facilitators to scale ear and hearing screening programmes for Aboriginal and Torres Strait Islander children and their relationships to each other in the form of concepts. The rated statements will be plotted on a go-zone plot (importance on the x axis and feasibility on the y axis) to understand whether the statements were rated above or below the mean for importance and feasibility, that is, the plot will be cut into four segments representing low importance–low feasibility, low importance–high feasibility, high importance–low feasibility and high importance–high feasibility. The iPRISM web tool will analyse the data to identify and prioritise strategies to improve the sustainment success of the presented ear and hearing screening programme.

STUDY RESEARCH TEAM

The internal research team consists of two Indigenous researchers (LH and KN) and two non-Indigenous researchers (KM and CM). The external leadership team consists of two Indigenous leaders (DM and KW). LH and KN have experience in facilitating yarning circles, qualitative research and thematic analysis. KM has experience in quantitative and qualitative research. CM is a professor in linguistics/audiology and will provide supervision of the project. The project will be led and coordinated by KM.

ETHICS AND DISSEMINATION

This project has received ethics approval from the Aboriginal Health and Medical Research Council Human Research Ethics Committee (Ref: 2350/24) and State Education Research and Partnerships (SERAP 6500). Draft results of this research will be disseminated into the involved Aboriginal communities through community consultation forums and/or through printed research summaries. In line with Indigenous Data Sovereignty and Governance principles, any quotes that are used in publications will first be reviewed by the community participant to ensure that they are accurate and that the participant consents to their quote being used. Participants will be given opportunities to contribute to the finalisation of research findings. As well as the community dissemination of findings, results will be published in peer-reviewed journals and presentations will be made at appropriate conferences after the research is complete. The findings from data collected will be used to inform the co-production of an enhanced system for ear and hearing care.

Contributors All authors provided substantial contributions to the conception or design of the work. KM and CM were the primary authors of the manuscript. LH, KN, DM and KW edited and critically revised the manuscript for intellectual content, as well as providing cultural expertise. CM provided supervision. All authors provided final approval of the version to be published and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. KM is the guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

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