Qualitative Study

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Feasibility of a goal sharing digital platform designed to empower children with disability and their families: A qualitative, pre-implementation study

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Abstract

Background: Family-centred goal setting is central to optimal care and outcomes for children with a disability. Digital innovations show promise for increased engagement and empowerment of families. While digital products have the potential to improve collaboration, there are barriers which may prevent service providers and families from using these resources.

Objective: This study aimed to: (a) understand goal sharing experiences of service providers and caregivers, and (b) identify views on a digital platform designed to share the goals of children with a disability between service providers and families.

Methods: Semi-structured interviews ($n = 12$) were conducted with paediatric service providers and caregivers in Australia. Transcripts were analysed using a qualitative content analysis approach.

Findings: Experiences of sharing goals were reflected in sub-categories: *conversations and listening to families' needs*; *collaboration and building relationships*; *adopting a family-driven approach*; *big picture and specific goals*; *communicating and documenting goals*; *goals need to be meaningful; using a structured approach; National Disability Insurance Scheme (NDIS) goals* and *challenges and barriers*. Views on using a digital platform were captured by sub-categories: *potential to empower families*; *collaboration and shared understanding; communication in your own time*; *everything in the same place*; *accessible and user friendly*; *functionality and preferred features*; *workload; some families might not engage with it* and *using new technology*.

Conclusion: We developed an understanding of how the goals of children are shared and perspectives on a digital platform. These findings have implications for the development and implementation of digital health products designed to improve care for children with a disability.

Keywords

Family-centred practice, children with disabilities, digital health, goal setting, collaboration, qualitative research

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A family-centred approach to care is based on a set of underlying values, including an understanding that every family is unique and that a child's family are experts on their needs and abilities.[1] This approach emphasises partnership between service providers and families, acknowledging the important role that families have in planning and implementing care.[2] While recognised as best practice, there are barriers experienced in implementing integrated family-centred services for children living with disability in Australia.[2] Families often experience considerable burdens associated with coordinating care across multiple service providers.[3,4]

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Fragmented care may result in duplication of services, higher costs, and negative experiences.

Collaborative goal setting is central to effective family-centred service for children with disability.[5,6] Goal setting can be helpful for families and service providers in conceptualising what is planned, increasing engagement, and guiding care.[2,7] Extant research has identified that although service providers often intend to use family-centred practices, there remain logistical problems when sharing and collaborating on goals.[2,3,8] Goal setting occurs across multiple care providers, and there can be problems with sharing information (i.e. both with families and between organisations).

Integrated care is particularly important for people with chronic conditions and complex needs. It refers to an efficient and easy to navigate service system that is coordinated across sectors (e.g. health, social, and education) to optimally meet needs of the people using it.[9] In Australia, the 'key worker model' is one example of a service model for children with a disability that is designed to increase coordination of care. This model involves the delegation of a worker who is a single point of contact for a family. The model is designed to empower families, assist them in navigating services and increase the integration of care across different services.[10,11]

Despite the understanding that comprehensive and coordinated care leads to optimal outcomes for children with disability, there are barriers to achieving integrated care. Current health information systems may not optimally support or enable families to experience integrated information sharing across services. For example, goals are typically stored within health information technology systems that have been developed under the auspices of individual organisations (e.g. hospital records). Furthermore, families may not easily be able to contribute to their goals in a manner that is truly collaborative. Consequently, children with disability often have multiple sets of goals, which may lead to competing plans, increased fragmentation of care, and additional child and family burden.

Digital platforms and applications are emerging innovations to address the need for integrated health care.[12–14] Globally, the COVID-19 pandemic contributed to a necessary and accelerated adoption of digital technologies in healthcare, leading to increased interest in its potential advantages.[9,15,16] In the US, a recent set of guiding principles[9] for service provision for children with special health care needs described integration of information technology across sectors as a promising solution for improving care and reducing health disparity in access to services.

In paediatric disability care, digital platforms have the potential to allow families to set, store, share, and track goals with their child's care teams. Use of these products has potential to create a more collaborative, integrated way to share the goals of children and young people with a disability. Improved collaboration may have meaningful effects on family engagement, empowerment, quality of care, and outcomes. While digital products are promising, there are a range of potential barriers to sustainable uptake, including privacy concerns and data sensitivity, costs, training needs, complexity and usability of the product. It is clear that a wide range of considerations need to be understood and addressed for successful design and implementation of digital products in health care.[12,13,17]

Extant research has focused on the use of digital platforms in adult populations. For example, Babbage et al. (2024) trialled a tablet app intended to communicate goals for brain injury rehabilitation, through instructional videos. While the tablet app was found to improve collaboration in goal planning, there were challenges reported, including maintaining client engagement and integration of the tool with existing practices.[18] While the use of digital platforms to support family-centred goal sharing for children does not yet have a large research base, there is growing interest in the utility of technology in this context. A scoping review[19] on parent-led digital platforms for parents of children with disability found that the available literature has predominantly focused on the use of platforms with social interaction options (e.g. social media), search engines, medical websites, and health-related apps. Another recent study[14] reported on an implementation trial of a care-planning tool (Participation and Environment Measure-Plus; PEM+) for children with disability and found that overall it was a feasible and acceptable tool (from the caregivers perspective) to improve caregiver confidence and promote child participation.

Implementation science methodologies incorporating participatory co-design are crucial to ensuring the successful uptake of interventions to improve health care outcomes.[12,20] A pre-implementation study is an important step to identifying possible barriers and facilitators for organisations, service providers, and families involved in goal setting for children with a disability. It is important to invest time in understanding the current processes and challenges, to avoid arriving at a solution prematurely.[12] Relevant end users should be engaged in the early stages of the conception of a digital innovation.[12] In the context of the current project, it was important to engage end users of the proposed digital platform, including caregivers raising a child with disability and health professionals.

The current study utilised qualitative methods to explore service provider and caregiver experiences of sharing goals and views on the use of a goal sharing digital platform. The aim of the current research was to better understand how the goals of children with disabilities are shared and to identify factors influencing use of a digital platform across health and community care systems. The following research questions guided the study:

(a) How do service providers and caregivers describe their experiences of sharing and collaborating on the goals of children with disability?

(b) What are the views of service providers and caregivers on using a digital platform for sharing the goals of children with a disability and what factors do they perceive would influence implementation?

Method

Design

A qualitative approach was adopted to capture an in-depth understanding of caregiver and service provider perspectives. A steering committee was convened to oversee the project. The committee included experts from a range of disciplines (rehabilitation medicine, occupational therapy, psychology, physiotherapy, and digital health innovation), as well as two parents of children with disabilities. Parent members brought to the steering committee expertise from their own lived experiences of navigating health and disability services for their children. The steering committee met monthly throughout the course of the project (January 2023–March 2024). Members provided input on the study design, interview guide, recruitment, interpretation of findings, and the development of key recommendations. The design of the study is presented in Figure 1.

Ethical approval to conduct this study was granted by the Royal Children's Hospital, Melbourne, Human Research Ethics Committee (HREC94833). As per the approved protocol, all participants provided verbal informed consent prior to their participation in the research. This process involved emailing participants a study flyer and written information letter prior to the interview, confirming receipt of the letter and obtaining consent prior to commencement of the interview. A script was used to support this process, and verbal consent was documented on a standardised form. The design, procedure, and reporting of the study were informed and guided by the Standards for Reporting Qualitative Research.[21]

Interview participants

Participants were recruited via convenience sampling, that is, a research flyer was distributed through networks of the steering committee and relevant organisations. As recruitment progressed, a purposive approach was employed to ensure that a range of disciplines and work settings were represented in the service provider sample. For the caregivers, purposive sampling ensured inclusion of parents of older and younger children.

The sample included nine service providers: medical rehabilitation specialists ($n = 2$); physiotherapists ($n = 2$); occupational therapists ($n = 2$); a speech pathologist ($n = 1$); a paediatrician ($n = 1$); and a social worker ($n = 1$) and three caregivers. At the time of interview, seven of the service providers worked in hospital (inpatient or outpatient) paediatric rehabilitation settings and two clinicians worked in paediatric private practices. These settings provided services for children with a range of disabilities, including cerebral palsy, spinal cord injury, acquired brain injury, and neurodevelopmental disorders.

All service providers identified as female and described their cultural background as Caucasian, Anglo-Saxon, and/or Australian. Service providers were in Australia: Victoria ($n = 6$); New South Wales ($n = 2$); and Western Australia ($n = 1$). Service providers reported an average of 20 years (range = 4–40 years) of experience in their discipline.

The three caregivers interviewed were all mothers of children with a disability. All caregivers had more than one child but focused their interview primarily around their experience with one of their children. Caregivers reported accessing a wide range of medical and disability services for their children (currently and historically). All caregiver participants lived in Victoria, Australia.

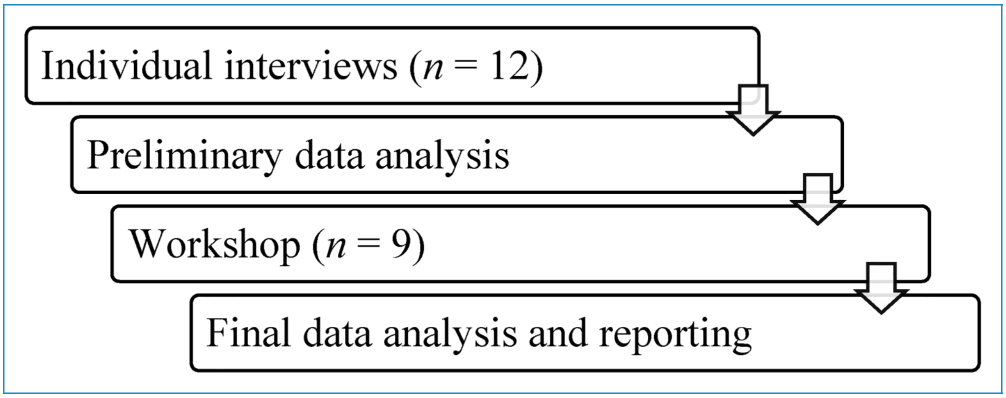


Figure 1. Qualitative data collection and analysis.

Caregivers described their cultural background as Caucasian, Anglo-Saxon, and/or Australian.

Caregiver One was mother to a 17-year-old daughter attending a specialist school, with multiple diagnoses (intellectual disability, communication difficulties, delayed motor skills, oppositional defiant disorder, and autism) in the context of a genetic condition. Caregiver Two was mother to an 18-year-old daughter in a post-school program, with multiple diagnoses including autism, intellectual disability, cerebral palsy, and epilepsy. Caregiver 3 was mother to a 6-year-old son in his first year at a specialist school with multiple diagnoses (intellectual disability, physical disability, and epilepsy) related to a genetic condition.

Workshop participants

All interview participants were invited to attend a workshop. The workshop was attended by eight of the interviewed participants including: services providers from paediatric rehabilitation settings ($n = 4$), a private clinician ($n = 1$), and caregivers of young people with a disability ($n = 3$). A representative from a hospital health data analytics team ($n = 1$) attended the workshop to provide a digital health perspective.

Procedure

Interviews. Semi-structured interview guides were developed for service providers and caregivers (see supplementary material). The interview guides were informed by an implementation science framework, the Consolidated Framework for Implementation Research.[22] Questions and prompts were refined in consultation with the project steering committee.

Questions were focused on two main areas related to the research questions: (a) participants' experiences of sharing and collaborating on children's goals, and (b) views on using a purpose-built digital platform to collaborate on goals. To set the scene, participants were informed that the digital platform would be designed specifically to share goals, be family-centred, and meet security requirements. A semi-structured interview approach allowed scope for participants to focus on details most pertinent to their own experience, and flexibility for the interviewer to probe for further details.

Interviews occurred between August and November 2023. Most interviews ($n = 11$) were conducted via a video conferencing platform. One interview was conducted over the phone due to technical difficulties. The majority of interviews were conducted by the first author (MW), with one completed by the second author (BO). The length of interviews ranged between 24 and 55 min. Caregiver participants received a $25 gift card to recognise the contribution of time from those in caregiver roles. Audio from the interviews was transcribed by a professional service. Transcripts were checked for accuracy and de-identified for analysis by MW.

Workshop. To verify and assist in the interpretation of the interview findings, a 2-h online workshop was facilitated by MW and project steering committee members (BO & RB) in February 2024. The workshop facilitators included two clinician-researchers and a parent of a child with disability. The aims of the workshop were to (a) obtain feedback on findings and (b) assist in the interpretation of findings. The structure of the workshop involved a presentation of the proposed categories and sub-categories from the interview analysis. The presentation was followed by a discussion guided by the following questions:

- Which findings resonate with you?
- Are there any ideas that stand out as most important?
- Have we missed anything? Are there ideas that you thought might be identified that are not presented here?
- What do you think a digital platform would need to do to improve collaboration on goals?
- What do you think are the important considerations for implementing a goal sharing digital platform?

Caregiver workshop participants received an $80 gift card for their contribution. The workshop was recorded and professionally transcribed. The transcript was checked for accuracy and de-identified for analysis. Analysis involved one round of coding the transcript for main ideas (completed by MW), resulting in a categorisation of key discussion points. The discussion points were then mapped on to the categories that were identified through the interviews with the aim of confirming findings and providing an opportunity to extend on these ideas through reflection on the workshop discussion. The project steering committee de-briefed and finalised recommendations, informed by the interviews and workshop.

Analysis

Theoretical and analytic approach. This study used qualitative methods to explore the perspectives of key stakeholders in the context of paediatric disability settings. A critical realist position was taken, allowing an understanding of participants' interpretations of their personal experiences. An inductive content analysis (ICA) was adopted for the analysis of interview transcripts, following the steps outlined by Vears and Gillam, 2022. This method has been described as a useful approach for data that is intended to inform practice or policy in health research.[23] The purpose of ICA is not to verify a pre-existing framework, but to derive a comprehensive understanding on the topic by identifying categories, supported by evidence in the dataset.[23] In ICA, there is not a focus on calculating frequencies of ideas in the data set; instead, the views of participants are coded, organised into categories, and described. In qualitative research, there is not an agreed method for determining adequate sample size.[24] In a practical sense, sufficient data is needed to address the research question. For this study, it was determined that enough interviews had been completed when transcripts were coded without the need to create new codes. Data saturation was determined to have been reached by discussion and agreement within the research team and members of the steering committee.

Data coding and organisation of categories. The following steps were followed: (a) carefully reading the transcripts, (b) organising the content into broad categories related to the research questions, (c) identifying sub-categories and refining, and (d) synthesising the categories and producing the final report.[23] Transcripts in the dataset were analysed in multiple rounds of coding (i.e. an iterative process) to refine the categories. Through this process, sub-categories were collapsed to avoid overlap or divided into separate codes when warranted. The codes prioritised semantic content (provided explicitly by participants) over interpreted latent ideas. Each sub-category was intended to convey a coherent meaning or idea, distinct from the other sub-categories in the overall framework. Coding was completed using NVivo Version 14 by the first author (MW). To enhance trustworthiness, reflexivity, credibility, transferability, and transparency were embedded in the planning and methodology of the study.[25]

Reflexivity. The research team acknowledged that their own knowledge, experiences, characteristics, and biases were important to consider when undertaking qualitative research. The team considered and declared perceived, potential, and actual conflicts of interests at the beginning and throughout the research process. The project steering committee met monthly to discuss the progress of the research. These meetings allowed for reflection on the interpretation of findings and the incorporation of a range of perspectives. Additionally, the interviewer wrote a journal entry following each interview to consolidate the main ideas raised and observations that might be relevant to interpretation of the data.

Credibility. To aid credibility, three interview transcripts were randomly selected and coded by the third author (MD), a researcher with experience in qualitative methods external to the project steering committee. The double-coding was used to reflect on the understanding of the meaning of codes, consistency of coding, and refinement of the analysis. Further credibility measures were embedded in the research design where (a) the research steering committee brought diverse perspectives to early versions of the interview data analysis, and (b) workshop participants were provided an opportunity to learn about the findings of the study, provide feedback, and share additional ideas. Perspectives from these sources were considered in the final analysis and development of recommendations.

Transparency. Care was taken throughout the research process by reflective journaling, documenting minutes for steering committee meetings, maintaining an audit trail file of the coding rounds, saving versions of the NVivo file at different stages of the analysis, and sharing preliminary results for feedback during the workshop.

Transferability. The recruitment process and sample were described in detail to allow readers to make a determination about the relevance of the findings to other settings.

Results

Category 1: experiences of sharing and collaborating on goals

Nine sub-categories captured experiences of sharing and collaborating on goals. Table 1 provides a description of the Category 1 sub-categories and supporting quotes from interview participants. While a number of sub-categories revealed aspects of goal sharing that currently work well, challenges and barriers were also raised.

The importance of the interactions and relationships between those involved in setting and sharing goals was highlighted by participants. *Conversations and listening to the needs of families* related to the conversations between service providers and families. Ongoing conversations are essential for identifying goals that meet the needs of young people and their families. *Collaboration and building relationships* captured experiences related to working in partnerships, both between service providers and between service providers and families. A *Family-driven approach* was described by participants, indicating that families of young people often come to service providers with goals, advocate for their child, and connect their care team. Participants expressed the importance of involving young people and their families in goals when possible.

Other sub-categories related to the processes involved in setting and management of goals. Participants explained that *Goals need to be meaningful* to the young person and relevant for their daily life. Goal setting often involves consideration of *Big picture and specific goals,* where broad goal areas are broken down into smaller, achievable steps. Goal setting is often supported by a framework and tools to measure progress (*Using a structured approach).* Experiences related to *Communicating and documenting goals* were described as well as the impact of the *National Disability Insurance Scheme (NDIS)* on goal setting, management, and sharing.

Table 1. Category 1: experiences of sharing and collaborating on goals: sub-categories, descriptions and supporting quotes.

Sub-category	Description	**Supporting quotes**
Big picture goals & specific goals	Big picture goals are broken down into smaller specific goals. These goals are sometimes discipline specific.	‘The family will often come up with big goals about “I want to be normal again” or “I want to be like the other kids” and so really having to tease out, well, what does that mean for you, what does that look like for you?’ (occupational therapist, paediatric rehabilitation). ‘We bought a key lock for outside the front door so when she comes back with her support worker, she can let herself into the house with support. I guess, within that independence goal are lots of little mini goals that we’re trying to address’ (caregiver of a 17-year-old).
Challenges & barriers	Challenges and barriers experienced when collaborating on goals. Including: -limited communication -barriers communicating across settings -limitations of existing platforms -difficulty collaborating with families -lack of funding or resources	‘I think the challenge is in when they don’t communicate well, like the psychiatrist, so when we first started seeing him, I asked him to send me a copy of the notes and he didn’t’. And then I was talking to the paediatrician, I said, ‘Look, I’ve heard nothing from him’, and she goes, ‘Oh, yeah, but I’ve got a six-page letter sitting on the portal. I can print it off for you, I can forward it to you’ (caregiver of a 17-year-old). ‘I feel like we still tend to be fairly discipline restricted in our goal setting [for inpatients], and I think we aren’t as collaborative as I would ideally like to be, but I think there’s a lot of concern from team members that families are very fragile or they might not understand what to think about in terms of a goal, what to try and aim for, what to expect, and I think they sense that we are very heavily relied upon to know what goals to be setting and therefore that part doesn’t necessarily get included’ (paediatrician, paediatric rehabilitation). ‘Unless I’m emailing them [service providers in other organisations] or I’m calling them after every session, which is not practical, there’s not that much communication on where we are with our goals and how our goals are affecting other therapy goals in different scopes’ (occupational therapist, private practice). ‘I would love to have a regular team meeting over zoom with all of my providers. The only thing that stops us doing that is the amount of funding that it will require’ (caregiver of an 18-year-old). ‘I don’t like that [our existing platform] is not super family friendly probably in the way that it prints out. It looks really clinical and medical and is a bit clunky’ (occupational therapist, paediatric rehabilitation).
Collaboration & building relationships	Working together and building relationships with others is important when collaborating on the goals of young people with a disability.	‘Because we’ve had the same service providers for quite a long time now, they understand where [my child] is at and what they think [my child] should aim for or what we should aim for to get [my child] doing. A lot of the time I have a similar view but it’s nice to see what they want to do with him and what they think we should focus on. Something that I probably haven’t thought of’ (caregiver of a 6-year-old). ‘The first thing in my experience, it’s a relationship. To me, that’s first and foremost and that takes time. So, it’s really important to me to set the foundation for a really equal collaborative relationship and not using jargon, not trying to fit families into a process that is not meaningful to them and to also, actually just meeting as two people in a room’ (physiotherapist, private practice). ‘When we see children at an initial visit there’s always myself plus some of the other team and so they’re always present. I would, it’s very rare, I don’t think I ever can remember where I’ve set goals with a family and a client where I’m the only one, it doesn’t work like that because they always have something to add to the conversation’ (physiotherapist, paediatric rehabilitation). ‘Within the team, we have our care team meetings once a week where we discuss a client, discuss their goals, and then that’s a forum for other therapists to jump in and say I could do this to help achieve that goal. Certainly, that in-house shared communication about a client, that’s the crux of the multidisciplinary team setting anyway’ (social worker, paediatric rehabilitation).
Communicating and documenting goals	Goals are communicated (e.g. emails, letters, phone calls, sharing reports)	‘It goes into the medical record and a copy always goes to the parent’s GP, any other specific people caring for the child, I don’t generally send it out to all the therapists because I don’t always have their contact details. But by providing the letter to the family,

(continued)

Table 1. Continued.

Sub-category	Description	**Supporting quotes**
	and documented. Communication can work well, but in some cases is limited or not successful.	I hope, and expect that they will share that with their NDIS funded therapy team. Sometimes it will go directly to the therapist. If we have a direct kind of collaboration with them. Talking, email. They send us reports, I will send them a copy of the report. But if I haven't had communication with them, I don't really know them, I don't send copies out to everybody' (medical specialist, paediatric rehabilitation). 'Some therapists, we're really, we know their emails, they contact us, we contact them, it's a very open communication. And then other therapists don't seem interested to have our input at all and want to just do their own thing' (paediatrician, paediatric rehabilitation). 'Then we enter the goals into a database that we've got. We often ask families if they'd like a copy of the goals, more often than not, they're happy to not take a copy with them, but we print a copy of their goals and pop it in the client's medical record, and that forms the basis of our rehab intervention with that child' (social worker, paediatric rehabilitation). 'Because we are a rehab service, we are required under public health guidelines to have documented goals. Typically, in our service we try to establish that within our first meeting with a client' (speech pathologist, paediatric rehabilitation).
Conversations & listening to the needs of families	Goals are set through conversations and listening to the needs of families.	'They [the families] need to know that you are listening and that while you may not necessarily agree with the things that they want to work on, their voice is very important and you value what they've got to say, that's absolutely vital' (physiotherapist, paediatric rehabilitation). 'Those informal conversations that are important and I'll say, particularly for some of the newer therapists in the team, that they don't want to get too bogged down in setting smart goals and measuring things and actually maybe starting with two questions, which is what's important to you and what do you want to work towards? And the second question being, what do you need from me to support that? So, start with that and then funnel into the goals, rather than, alright, start with the opposite, which is, okay, what are your goals and let's get these written down and how we're going to measure them' (physiotherapist, private practice).
Family-driven approach	Moving towards an approach where families drive goals, including involvement from young people. Caregivers often advocate for their child & connect the team.	'I think, to me, the ideal scenario is that families, they come with some ideas, and I don't necessarily mean set goals necessarily, but the starting point is that families are leading the process' (physiotherapist, private practice). 'A lot of the time, the parents are coming to me with goals in their head. They're coming to me with a purpose of this is what I want to work on' (occupational therapist, private practice). 'In inpatients there's often quite a bit of direction by the inpatient team, but that's in acute trauma situations that the families are going through. But there's always an opportunity to work on what they want, so what's important to them as a family for the child as an individual, and how do we get back to doing that, rather than what the clinician wants' (medical specialist, paediatric rehabilitation). 'Most of the goals have been set from a point of view, like I said before, from my point of view about what I would like to see' (caregiver of an 18-year-old). 'Depending on the age of the child we will try and get them involved in setting their own goals with us, whether that's about getting back to school or often getting back to basketball or something that they're interested in' (occupational therapist, paediatric rehabilitation). 'Then in clinics, I usually just ask the children, the young people, what their goals are, and then the parents, and we'd usually document that in the clinic letter' (medical specialist, paediatric rehabilitation).

(continued)

Table 1. Continued.

Sub-category	Description	**Supporting quotes**
Goals need to be meaningful	Goals need to be relevant to daily life. Goals form the basis of intervention/therapy.	'[My child] doesn't need to know his colours. It would be great, but it's not really going to make a positive impact in his life if he knows colours. If he knows what food he wants to eat or whether he can say yes or no to food, that's going to impact his quality of life' (caregiver of a 6-year-old). 'They need to be meaningful and achievable for that young person, even though there may be quite a lot of steps to actually getting to that point' (medical specialist, paediatric rehabilitation). 'From my point of view is, the first question is, why? And this is something that I feel is really important and often missed. So, physios, you might hear them working on core stability, those things that are still that impairment focus and they match with the parents' expectations, but it's not really working on anything that's meaningful or anything that's going to go anywhere. There's no end point' (physiotherapist, private practice).
NDIS goals	The NDIS can impact goal setting, communication, documentation & available resources.	'Mostly I think what happens is they use the goals that are set out in her NDIS plan. They might have the initial discussion about what they think might help her or ask me what my goals would be for her, then they'll use her NDIS plan for the overall' (caregiver of an 18-year-old). 'I don't specifically set goals for the NDIS, but I may actually talk to the families about what kind of goals they might want to be thinking about to include in the NDIS plan that they're putting together, and we generally record those in the clinic letter for reference' (medical specialist, paediatric rehabilitation). 'There's also been times that I've had this full discussion with the family and then I've got their NDIS plan, and the goals are completely different for what we set, and I can't work on goals that aren't in the NDIS plan. To use their NDIS funding, my goals have to relate directly to their plan goals' (occupational therapist, private practice).
Using a structured approach	Frameworks and assessments are used to inform goal setting, measure progress, and demonstrate outcomes.	'Essentially, they need to be tangible and measurable goals. On top of that, they are Canadian Occupational Performance Measure (COPM), they've got a COPM score attached to them which is an occupational therapy tool which essentially looks at getting the satisfaction and participation scale pre at the time of the goal setting, and then revisiting those scores post to see if there's been a shift in their satisfaction and participation of those goals' (social worker, paediatric rehabilitation). 'I definitely find it easier that there is an outcome measure and kind of a real structure to the conversation and that we do get a score, like a baseline, and we can have that score as well with subsequent ratings to then always refer back to' (speech pathologist, paediatric rehabilitation). 'In my first session with the child, kind of use a visual goal setting picture, graph type thing that has lots of pictures they can choose from. We go through it, and we look at the different pictures, and we say "Is this hard, is this easy? Do you think you can do this with a little bit of help? Would you like to do this easier?" It really depends on the client. Once I set the goal, we have COPM style scoring system on performance and how they're going at the moment' (occupational therapist, private practice).

NDIS: National Disability Insurance Scheme.

Participants shared *Challenges and barriers* that they have experienced when sharing and collaborating on goals including: difficulty with communication (particularly across organisational settings); limitations of existing platforms; difficulty collaborating with families; and limited funding or resources.

Category 2: views on using a digital platform for goal sharing

Participants shared their views on using a digital platform for collaborating on goals. The nine sub-categories related to Category 2 and supporting quotes from interview participants are shown in Table 2. Some ideas related to the specific features of the digital platform including *Functionality and preferred features* and *Accessible and user friendly* formats. These sub-categories contained views about what would make a platform useful (e.g. links to resources, capacity to upload videos), and the idea that the platform would need to be easy to navigate and accessible to all end users, including young people.

Other sub-categories related to potential advantages of a goal sharing digital platform, including: the *Potential to empower families*, *Collaboration and shared understanding*, *Everything in the same place,* and *Communication in your own time*. Participants expressed views that demonstrated understanding that a digital platform may be able to help families by giving them more control over their own goals, offering a system for keeping all goal-related information together, and increasing collaboration.

Factors that might impact uptake and implementation were covered in the sub-categories of *Workload, Some families might not engage with it,* and *Using new technology*. Participants acknowledged that a digital platform could either reduce or increase workload for service providers and families, depending on how well it fits with existing systems and responsibilities. Participants expressed the view that some families might not engage with a digital platform for a range of reasons including feeling overwhelmed by existing responsibilities, level of engagement, or socio-economic disadvantage. Some participants felt that the introduction of new technology could be met with resistance (e.g. concerns about privacy and security) whereas others felt adopting a new platform would be relatively straightforward.

The categories outlined in Table 1 include features of goal setting and sharing that need to be supported by the introduction of a digital platform. These involve features that participants expressed were important or necessary for the provision of optimal care and elements that facilitated collaboration (e.g. listening to families and building relationships). There were also barriers and challenges currently experienced by services (e.g. limited communication across settings) that present opportunities that a digital platform could be designed to address. In Table 2, views on the feasibility of a digital platform highlighted specific advantages (e.g. flexibility and individualised care) relative to goal sharing within the confines of standard face-to-face appointments. While the potential advantages of a digital platform were prominent in the findings, it was clear that there would also barriers to overcome with the introduction of new technology, including uptake, privacy concerns, and the burden of additional work.

Workshop

The workshop participants reflected on the aggregated interview participants' views on a goal sharing digital platform. Reflections that aligned with sub-categories were evident throughout the workshop discussion. Additional considerations, ideas, and explanations related to the design and implementation of a goal sharing digital platform were raised by workshop participants, including:

1. A goal sharing digital platform needs to support collaboration in a way that is easy to navigate, presents defined advantages, and has potential to improve the current process.
2. The introduction and implementation of a new platform needs to be carefully planned to ensure uptake and sustainability, particularly considering the needs of those who may be disadvantaged.
3. The platform needs to be individualised and tailorable. It is important to understand that families have different needs. A flexible approach is required for families to have autonomy in what information they would like to share, how they would like to share it, and who they would like to share it with.
4. Innovative features of a digital platform (such as the capacity to share photos and videos securely) could support families in being able to share their story and service providers to be able to see the 'whole picture'. These features may help to keep goals active, by embedding them into everyday life.
5. Supporting families through a transition from paediatric to adult disability and health services is important to consider in the introduction of a new process. This has been identified as an area where continuity of care is compromised.
6. A digital platform for sharing goals would need to meet the needs of all proposed stakeholders (e.g. families, young people, clinicians, and organisations).

Discussion

This study aimed to better understand how the goals of children with a disability are shared and to identify factors influencing the use of a digital platform across health and community care systems. Results of an inductive qualitative

Table 2. Category 2: using a digital platform for sharing goals of young people with a disability: sub-categories, descriptions and supporting quotes.

Sub-category	Description	**Supporting quotes**
Accessible & user friendly	A digital platform needs to be accessible, easy to navigate, and child friendly.	'I think if it's user friendly and helps and is really straight forward to use, then it would be really well received' (social worker, paediatric rehabilitation). 'The challenges are probably making sure that it meets so many needs in terms of whether that's from a basis of understanding technology or being able to visually break things down in a way that they need to for the information, whether it's presented with an option of a verbal instruction as well, to fit so many different clients' (occupational therapist, paediatric rehabilitation). 'It would be great to see, when they've achieved a goal, there's a medal or point, something that just makes it a little bit encouraging. I guess that's what I mean when I say paediatric, compared to if it was just for adults, it would be very plain. Maybe a bit interactive and fun. And rather than having mum and dad, or whoever the caregiver is, managing the app, something they could sit down with their child and the child could feel like they can push the button, or they can type it in or whatever that is. Just a little bit more of an opportunity for them to be involved' (social worker, paediatric rehabilitation).
Collaboration & shared understanding	A digital platform has the potential to improve collaboration and create a shared understanding of the young person's goals.	'It might actually feed back into the goal if that makes sense. So, "Oh, they've started doing that, I can see how they're doing … oh, that's great. We didn't think they'd be interested. What about if we did that, that and that?". So, all of a sudden that could become related to a more specific goal' (physiotherapist, private practice). 'A way for us as clinicians, with permission, with consent, to be able to look at and perhaps even contribute to. Maybe not change a goal but make some kind of comment or something like that to encourage, maybe looking at a specific area, would be great' (medical specialist, paediatric rehabilitation). 'The most important thing would be collaboration. For me, the biggest positive I could see out of a digital platform for goal setting is collaboration from the whole team because it's something that everyone would be able to access' (occupational therapist, private practice).
Communication in your own time	Families and service providers could interact with the platform at a time that suits them.	'Potentially providing the client access whenever it suits them. We're a part time service as well. Sometimes when we call families and update them and things like that, it's not always the most ideal time. Something that they can log into at a time that suits them, potentially just gives them a bit more power over that relationship' (speech pathologist, paediatric rehabilitation). 'So, the timely, asynchronous communication is really important because that push for always synchronous communication, it doesn't always work for me as a service provider, it doesn't always work for families in their roles. So, I think, the most important thing for me would be the communication at the time of the most relevance' (physiotherapist, private practice). 'It could also, then, if families were motivated and wanting to put stuff down out of session, that would be great because there'd be some talking points that you could discuss at the next clinic meeting or therapy session or whatever' (paediatrician, paediatric rehabilitation).
Everything in the same place	A platform could be useful for monitoring goals & keeping all information in the same place.	'It would be fantastic to have everybody on the same page, to only have to do things once and everybody sees it. That will be fantastic. Time saver all in one place, that sounds great' (caregiver of an 18-year-old). 'So, the fact that it's a bit more similar to a child's file where there would be a structure to that. So, for example, if we had a child who had maybe three therapists and the family. So, there's four people and the "reply all" emails pile up and pile up and then, it takes a lot of wading through and they're not in one thread, they're all buried in amongst all your other emails, so that's where I see the real benefit' (physiotherapist, private practice). 'It was really important that everyone was on the same page, and I didn't have to email everyone or text everyone or wait until we saw everyone' (caregiver of a 6-year-old).
Functionality and preferred features	Ideas about how the platform should function and preferred features.	'And like I said, the less writing, I think the better. As far as the, because it is going to be a goal based, I still feel that multiple choice or those, what are they called? Radio buttons where you could just click, I think that would help. That would be good. Or even text to voice or voice to text. That would be good. What else? Maybe tables to say, has this been implemented or is this goal reached? If they could just tick it off and then next goal. Automatic goes, okay, what's the next goal? I suppose email functionality between them' (caregiver of an 18-year-old). 'It would be great if, from a print point of view, if it was print friendly, if it created a nice looking simple document that was kids, paediatric

(continued)

Table 2. Continued.

Sub-category	Description	**Supporting quotes**
		friendly, as well as family friendly. And also, if it did have the shareability, with families' consent. If you can put email addresses in there, once you did that, it could shoot it off to all those other people involved, that would be fantastic. That would just save a lot of work' (speech pathologist, paediatric rehabilitation). 'I did have actually have a thought pop into my head around the app, for kids, how great would it be if there were then resources linked to that app? Siblings space and a space for parents with resources' (social worker, paediatric rehabilitation).
Potential to empower families	A digital platform might allow caregivers and young people to have more ownership & control over their goals.	'There would be greater collaboration, for sure, and more ownership from the families, I think. At the moment we write down their goals and then we only kind of speak about them at key points in their rehab, even though it's forming our practice, so many more of the conversations about goals happen without the family. I think it would be a really nice opportunity for families to have more ownership and control over what that looks like and remind them of what the goals are and what's going on' (social worker, paediatric rehabilitation). 'I think the thing that works well is empowering them, so they feel like they've got control and they're driving something' (occupational therapist, paediatric rehabilitation). 'I think that's an important part of it as well, is that the families have full autonomy about what they want to share and what they don't want to share' (occupational therapist, private practice). 'The other thing is knowing how there's a therapy treadmill happening out there that can be not very helpful, having some kind of goal achieved, an exit plan articulated, would probably be helpful too' (medical specialist, paediatric rehabilitation).
Some families might not engage with it	Some families may not engage with a digital platform for a range of reasons.	'I think with some families it would be a useful tool, I think with many of our families they're just so, they're only just managing to keep everything together and so for them to go in and view a document with goals, some, certainly a small cohort would, but others I think are flat out just getting the kids to appointments and surviving themselves' (physiotherapist, paediatric rehabilitation). 'Probably the families that are less engaged with our service as well would be less engaged with logging in and accessing something like that. Then vice versa, the families that are highly engaged with the service, I think, would' (speech pathologist, paediatric rehabilitation). 'I feel like some would engage with it really well. I think there'd be others who would, like I've mentioned, those more vulnerable families who have lots of other competing life things going on and maybe other children with disabilities, or even just other children in general, or their own health problems, and the families whose health literacy is low, families who English is a second or third language as well might struggle a bit more with interacting with it' (paediatrician, paediatric rehabilitation).
Using new technology	Considerations related to adopting new technology (e.g. training needs and privacy concerns).	'But imagine if you're not [digitally savvy], there's lots of people who they're not interested, and they…yes they can see the benefits, but would they use it or could they be bothered? Probably not. So, it's not going to suit everyone' (caregiver of an 18-year-old). 'And then the only other one would be security, I suppose. In terms of if it's a code or a login and a school has got it or a family has got it, and that email chain, accidentally someone else gets added into it and they've got access to a whole lot of information, that would probably be the only other thing' (speech pathologist, paediatric rehabilitation). 'I think the response [from service providers] would probably be, there might be a sense of hesitation that comes with something new, and a change, and it being I.T. there may be some resistance' (social worker, paediatric rehabilitation).

(continued)

Table 2. Continued.

Sub-category	Description	Supporting quotes
Workload	Considerations related to whether a digital platform would create more work or reduce the workload for families and service providers.	'I would think that they would find it problematic because I know that the therapists and the support workers, and I would assume any medical professional as well, are already under the pump. And whether they would contribute much to it, I don't know. They might find it difficult' (caregiver an 18-year-old). 'That's what I really liked, is that everyone can read the same report, and I don't have to send it to everyone. It reduces that step' (caregiver of a 6-year-old). 'You've got to be wary of not adding to their load as well given that with NDIS they have to have a particular document that they have to use, a report they have to make, whether if we had a digital platform that they could hook into, whether that would assist them in that task perhaps' (physiotherapist, paediatric rehabilitation).

analysis were organised into two categories (*experiences of sharing and collaborating on goals* and *views on a digital platform for goal sharing*) and associated sub-categories.

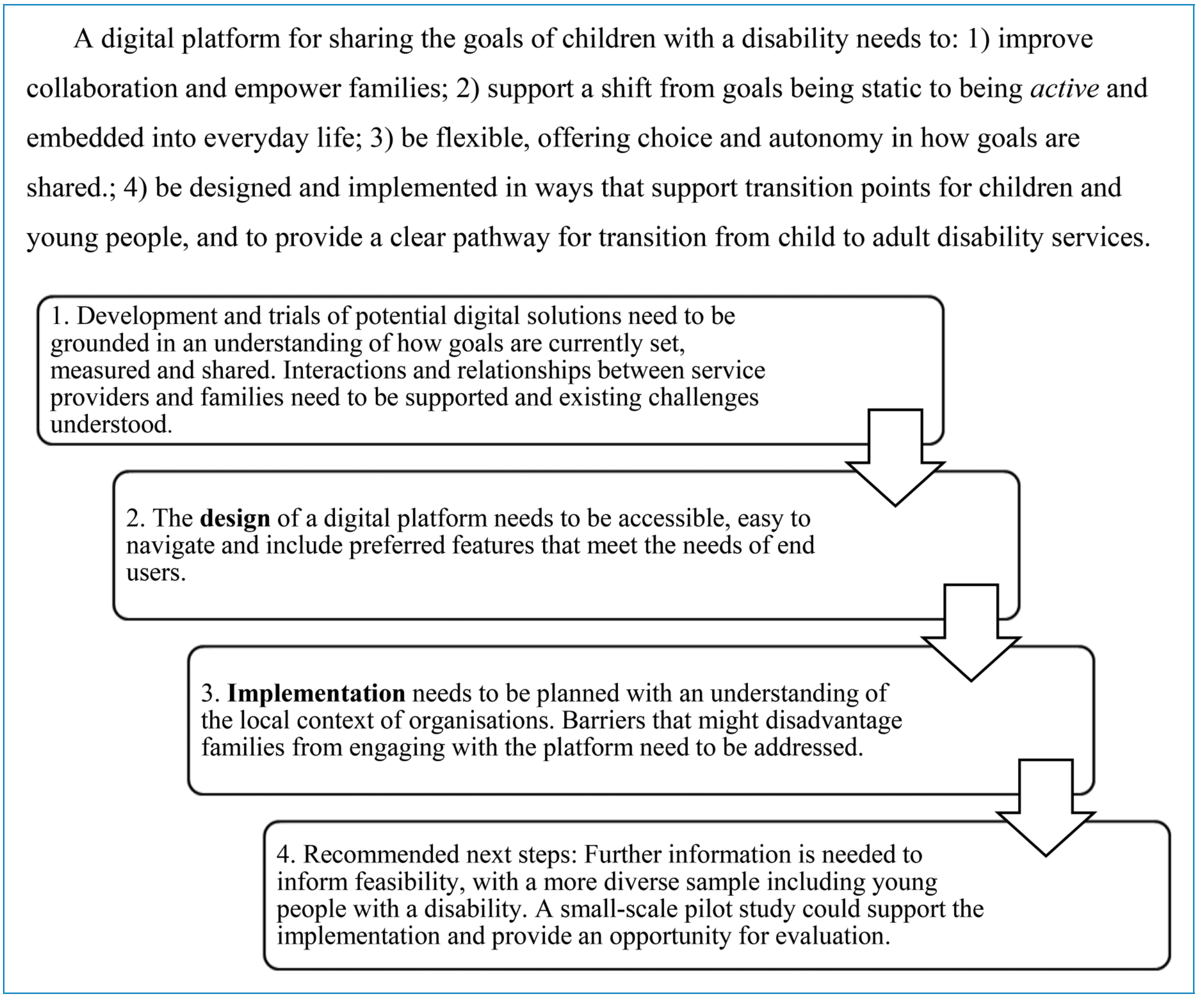
Experiences of sharing and collaborating on goals

Service providers and caregivers highlighted the importance of relational factors when setting and sharing goals. These factors included: *collaboration and building relationships; conversations and listening to families' needs;* and adopting a *family-driven approach,* involving caregivers and young people. These interpersonal elements are central to family-centred practice.[2] Participants reflected that if a digital platform was introduced to improve goal sharing, it would be important for it to complement rather than attempt to replace the collaborative and relationship building interactions that currently occur during the goal setting process. While collaboration and communication were seen as essential to goal setting and sharing, *challenges and barriers* were experienced. Challenges involved limited communication (particularly across organisations), difficulty collaborating with families, limitations of existing platforms, and limited resources and funding. These findings suggest that there are areas where participants see potential for improvement in current goal sharing processes. The identification of challenges is consistent with extant research that has found that while family-centred practice is considered important, the implementation of these principles is not always achieved.[2,3]

Participants shared their experiences related to the setting and management of goals (e.g. *big picture and specific goals, goals need to be meaningful, using a structured approach, communicating and documenting goals,* and *NDIS goals*). Understanding how a new platform would fit with and add value to existing approaches and systems is important to consider, within the local context. Each service system presents unique strengths and challenges. For example, a recent Australian study[10] found reported that service providers experience challenges in achieving collaboration in early child intervention services under the NDIS, partly due to the transition from relationship-based early childhood intervention teams to individual therapy-focussed practitioners. A range of factors that could influence implementation, including the inner and outer settings (e.g. organisations and the community), processes, innovation characteristics, and the characteristics of the relevant stakeholders need to be understood.[22,26]

Views on a digital platform

Service providers and caregivers shared their views about using a digital platform that is secure, family-centred, and designed to share goals. The interview data indicated that participants could see potential for an improved process supported by a digital platform, reflected in the sub-



A digital platform for sharing the goals of children with a disability needs to: 1) improve collaboration and empower families; 2) support a shift from goals being static to being *active* and embedded into everyday life; 3) be flexible, offering choice and autonomy in how goals are shared.; 4) be designed and implemented in ways that support transition points for children and young people, and to provide a clear pathway for transition from child to adult disability services.

1. Development and trials of potential digital solutions need to be grounded in an understanding of how goals are currently set, measured and shared. Interactions and relationships between service providers and families need to be supported and existing challenges understood.

2. The **design** of a digital platform needs to be accessible, easy to navigate and include preferred features that meet the needs of end users.

3. **Implementation** needs to be planned with an understanding of the local context of organisations. Barriers that might disadvantage families from engaging with the platform need to be addressed.

4. Recommended next steps: Further information is needed to inform feasibility, with a more diverse sample including young people with a disability. A small-scale pilot study could support the implementation and provide an opportunity for evaluation.

Figure 2. General principles and proposed implementation steps.

categories *collaboration and shared understanding; communication in your own time; potential to empower families;* and *everything in the same place*. Previous research exploring what parents of children with disabilities want from their services has indicated a need for coordinated, individualised, and family-centred care.[3] There are specific and practical ways that digital innovations could support these needs and optimal outcomes through increased flexibility, coordination of teams and scheduling, information sharing, sharing of videos, and improved connections between therapy and home.[15]

When introducing a digital platform, understanding what families are looking for from their services is critical. It is also important recognise that not every family has the same needs and may have different requirements and preferences. For example, Terwiel et al. (2017) found that parents of children with cerebral palsy varied in how they rated the importance of family-centred service elements. The authors highlighted that understanding what parents find important, and tailoring support, is essential for optimal service delivery.[27] From an implementation perspective, the construct of relative advantage or evaluation of whether a digital product leads to an improved process for all consumers should be considered.[22,26]

It was acknowledged by participants that there were known factors that could impact uptake and implementation of a digital platform, including *workload,* concerns about *using new technology* and recognition that *some families might not engage with it.* Barriers related to engagement and uptake of technology have been identified in digital health care implementation trials.[18] Barriers such as lack of motivation, privacy concerns, increased workload, and difficulty navigating new technology can be anticipated and considered in the introduction of a new platform. Participants expressed views on what they would like the platform to be able to do, including *functionality and preferred features*. It was identified as important that the platform would be *accessible and user friendly*. A feasibility investigation of an existing care planning digital innovation (PEM+) for children with disability found that while caregivers reported positive experiences (e.g. increased engagement in care planning) there were also concerns about the burden of using the tool.[14] The authors discussed the importance of exploring acceptability, usability, and optimising the design.[14] Similarly, for a goal sharing platform, feedback from end users (caregivers and service providers) will provide important information for design and implementation.

Recommendations

Analysis of qualitative interview data, the preliminary results workshop, and consultation with the project steering committee informed the general principles and proposed implementation steps presented in Figure 2.

Strengths, limitations, and future directions

A strength of this study was the inclusion of the perspective of caregivers and service providers, at an early pre-implementation stage of the research process. Within the service provider subset, a range of professional disciplines were represented, including participants from three states of Australia and from public (hospital) and private organisations. This diversity of views was useful for identifying factors that are relevant to a range of stakeholders who may be users of a goal sharing digital platform. In other ways, the sample could have been more diverse. For example, all participants identified as female and Caucasian, Anglo-Saxon, and/or Australian. Since it was identified that some families may be at a disadvantage in engaging with a digital platform, investigating the views of caregivers and service providers from a variety of cultures will be an important future direction. Purposive sampling could be used to recruit participants from under-represented groups.

The sample of the current study included more service providers than caregivers. We were particularly interested in the barriers that exist for service providers in organisational settings. While this was intentional, it should be noted that including a greater number of service providers resulted in data more representative of this perspective. To extend on these findings, it would be beneficial to explore the experiences and views of more community and private service providers, as most of the sample were service providers employed in public paediatric settings. It would also be useful for implementation pilot studies to evaluate the effectiveness and acceptability of a digital platform from different perspectives within organisations (e.g. managers, clinicians, and administrators).

A future direction will be to explore the views of a larger sample of caregivers, including families with younger children, who were not well represented in this study. The perspectives of parents with younger children who are newer to navigating and coordinating services for the children would likely contribute different insights important for the design and implementation of a platform.

Participants of the current study and previous research[6,28] highlighted the importance of involving children and young people in their goal setting. Unfortunately, this phase of the research did not include the voice of young people with a disability. To complement the caregiver perspective, it will be important to explore how children and young people with a disability participate in their goal setting, sharing, and collaboration.

Conclusion

This study aimed to better understand experiences of sharing and collaborating on the goals of young people with a disability and views on using a goal sharing digital platform. The findings identified a range of factors related to experiences of goal sharing, preferred design features, possible advantages, and implementation considerations. These factors represent important considerations for the development and implementation of a digital goal sharing platform for children with disability in the health context.

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Contributorship: MW was involved in conceptualisation, methodology, investigation, formal analysis, writing – original draft, and writing – review and editing. BO was involved in conceptualisation, methodology, investigation, formal analysis, and writing – review and editing. MD was involved in formal analysis and writing – review and editing. AS, CI, RB, and DH were involved in conceptualisation, methodology, formal analysis, writing – review and editing. GC was involved in conceptualisation and methodology. SK was involved in conceptualisation, methodology, formal analysis, writing – original draft, and writing – review and editing

Consent to participate: All participants provided informed verbal consent (recorded by researcher) prior to their participation in the research.

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