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Mapping out the invisible needs: using creative methods to meaningfully involve children and young people in exploring their condition management

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Abstract

This paper discusses preliminary findings from the first of a series of co-design sessions which collaboratively explored and mapped out invisible aspects of paediatric condition management (CM), highlighting areas of unmet need and factors that may impact future assistive technology innovation. These creative sessions involved children and young people, their parents, healthcare professionals and teachers to map out a multi-perspective understanding of CM within the Cerebral Palsy (CP) and Juvenile Idiopathic Arthritis (JIA) populations. Using creative tangible methods, externalised and made many aspects of the CM landscape visible from each stakeholder perspective, enabling an in-depth and holistic understanding, highlighting areas of unmet need to focus our co-design on. By grounding innovations within a holistic, multi-perspective understanding of the complex CM landscape from the outset, resulting assistive technologies will better respond to the unique needs and contexts of the paediatric population.

CCS Concepts

• **Human-centred computing** → Participatory design; Empirical studies in HCI; Interaction design process and methods.

Keywords

Co-design, Children and young people, Assistive technologies

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1 Introduction and related work

Paediatric long-term condition management (CM) is complex and multi-dimensional, often likened to an Alice-in-wonderland-like system [8], involving a variety of stakeholders with needs and responsibility shifting over time as the child grows. Within CM, there are both visible aspects such as physical symptoms, but also invisible and intangible aspects. These invisible aspects can be divided up into physical aspects (hidden pain, participation impacts), emotional work (disbelief, emotional burden, understanding limits), cognitive work (pacing, planning energy levels) and communication (pain levels, ability, CM literacy with health professionals, family and teachers) to name a few. These often-overlooked invisible aspects are crucial to achieve effective, integrated care for children and young people, as they permeate throughout the wider life of each child. They are the hidden factors, stakeholders and their inter-relationships. Despite their importance, understanding these invisible aspects and their impact, remains limited in the current literature. Existing studies tend to focus on single stakeholder perspectives rather than considering the complex, inter-related dynamics at play. This gap restricts opportunities for meaningful innovation, as a comprehensive understanding of these needs is essential for developing effective interventions.

Whilst self-management is crucial, there remains a lack of appropriate tools for this population [5]. This is further compounded in conditions that have smaller demographics such as Cerebral Palsy (CP) and Juvenile Idiopathic Arthritis (JIA). Those that do exist are often seen as patronising, difficult to use, stigmatising or unsuitable for the unique needs and contexts in which they are used [1]. This is in part, due to a lack of understanding of the reality of paediatric CM and the hidden factors and dynamics that impact successful use of assistive technologies.

Children are not mini adults. Devices need to be designed for them, as opposed to simply shrinking devices designed for adults. From an interaction and device design standpoint, responding to the wider life impacts of a child's condition is crucial, helping enable successful adoption. Successful examples include 'PALM', a child specific asthma inhaler designed to respond to the difficulties children have with timing their breathing to coordinate with the medication release [7] and the MRI Toolkit, a play based tool to combat procedural anxiety around having an MRI scan reducing the need for general anaesthesia [12]. Both examples are designed for the child's unique context and reality, positively impacting CM. The latter also uses the idea of playification where "play-based interaction in situation and non-play contexts [is used] to make [an intervention] more engaging, enjoyable and motivational" [11], in this instance lessening anxiety and building confidence.

Co-design is defined as "the creativity of designers and people not training in design coming together in the design development

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process" [10]. It uses creative methods and tangible tools to catalyse shared making and explore individual experience and difficult-to-articulate concepts. As highlighted by Borzenkova et al, "engaging children in the design process as partners is crucial for developing an understanding about their needs and wishes" [3], alongside this is the need to provide tools to allow this collaboration to occur. There has been significant work around co-designing assistive technologies with children [2], [6], considering the different role they may take, alongside principles, guidance and strategies for working with children with complex needs or disabilities and the resulting technology. There is less of a focus on the specific design tools used at the beginning of the co-design process to enable this partnership and the revealing of unmet needs, from which to design the technology. This paper therefore explores how co-design, play and tangible tools can enable a deeper exploration of tacit experience of CM, uncovering hidden unmet needs. The data from this will then be used to co-design assistive technologies to address the highlighted unmet needs.

2 METHODS

Children and young people, their parents, healthcare professionals, and teachers were recruited to five co-design sessions. This paper discusses the specific method used in the first co-design session which focused on using tangible creative methods to explore experiences of living with or managing CP and JIA respectively.

This method transformed the iceberg metaphor, whereby one only sees 10% of a given reality with the remainder hidden beneath the surface [4], into a physical activity. Participants were invited to build their own icebergs to describe their own, or involvement in, condition management (CM). The purpose of this being to make visible the often hidden and overlooked aspects of CM, while enabling participants to reflect on impact, current supporting structures and barriers. This aimed to create a richer and in-depth understanding of the CM landscape, highlighting areas of unmet need for the subsequent co-design sessions as well as factors that may impact the success, or use, of the resulting innovation.

Whilst the metaphor for each stakeholder group was the same, the format differed. For teachers and healthcare professionals, paper-based tools were used to draw and annotate icebergs, responding to the need for the sessions to be undertaken in their place of work and therefore ease of portability whilst ensuring engagement. For the children and parents, 3D printed tangible tools to build icebergs were used, responding to the need to embed an element of play, maximising interaction to promote sustained engagement. The 3D format also supported extension of the metaphor to include additional parameters in the discussion such as creating representations of the impact or effects of specific hidden or visible CM factors. Participants were recruited using purposive maximum-variation sampling to ensure representation of differing lived experiences, recruiting across condition severity, age, gender, geographical location and stakeholder role. The sessions took place individually with the design researcher, lasting 60-90 minutes, involving n=20 children and their parents, n=10 healthcare professionals and n=10 teachers. This data collection is ongoing, with this paper reporting preliminary findings from sessions undertaken to date. Table 1 details the different activities involved within both the child and parents and the professional's session.

The resulting iceberg map, physical or paper-based, was then used to scaffold further conversation acting as visual representations of that individual participant's viewpoint of CM. Figure 1 shows completed versions of both the tangible and paper-based iceberg maps.

These sessions took place both online and in person dependent on participant preference. For children and parents, the exact same method as detailed above was used in both contexts, using 3D printed tangible parts. For professionals, online sessions used illustrated Miro boards whilst in person used illustrated scenes, paper and stickers. All sessions were recorded to capture the richness of conversation. Fully informed consent was obtained at the start, and strict ethical procedures were followed throughout, ensuring data privacy and sensitive handling.

Thematic analysis was used to analyse the interview transcripts alongside the iceberg maps themselves, with codes and resulting themes being developed inductively from the workshop data. The steps involved included familiarisation with data through the interview recordings, transcripts and tangible artefacts. This was followed by inductive generation of initial codes which were subsequently themed. The data from each condition population was first analysed separately identifying condition specific experience and unmet needs, followed by comparative analysis across codes and themes to explore how experience differs between visible and invisible conditions.

3 INITIAL FINDINGS and discussion

This study is currently in progress and therefore findings are preliminary at this stage. Recruited participants and interviews undertaken to date include n=10 healthcare professionals, n=3 teachers and n=10 children and parents (split across both conditions). Initial data suggests the iceberg map is successful in exploring a child's condition management from each different stakeholder perspective, specifically in drawing out the hidden elements of the condition. The findings are broken down into those focused on CM and innovation impact insights and those focused on the method.

3.1 Condition management and innovation impact insights

Whilst JIA is seen as an "invisible disease" and CP as more visible, both populations highlighted the invisible nature of elements of the condition both in a physical and emotional sense with multiple icebergs having a significant invisible weighting. Children highlighted an ongoing concern and dislike of telling people about their condition, with some treating it as "top secret", which impacted friendships and communication ability with other key stakeholders such as teachers. Within JIA, multiple children emphasised "some of them [teachers] just don't believe me", particularly with regards to PE or needing to leave a class early to take the lift. On a physical level, invisible aspects included pain, medication side-effects such as nausea, motivation to do physio stretches, discomfort of wearing splints/insoles and hospital appointments which impacted school attendance and keeping up with peers. On an emotional level, children emphasised a lack of awareness or understanding around their

Table 1: Table showing the activities involved in the session

Children and parents		Healthcare professionals and teachers	
Purpose	Activity	Purpose	Activity
Identifying challenges within CM	Write challenges on white pebbles (max 30).	Identifying challenges within CM, that either they find challenging or that patients report to them	Participant talks through different ones as I write down on yellow stickers on a sheet.
Exploring visibility and invisibility of CM	Ask the participant to decide which challenges are visible and which are invisible explaining why.	Exploring visibility and invisibility of CM	Ask the participant to position the yellow stickers on an image of an iceberg above and below the sea, explaining why.
Indicating impact of challenges on daily life with element of prioritisation	Ask the participant to select small, medium or large iceberg segments for small, medium or large impact (5 of each available) explaining why.	Priority identification	Ask the participants to circle the challenges/ aspects that they would prioritise to develop technology for.
Grouping and theming the challenges	Ask the participant to write categories eon iceberg topper .g. 'home' 'treatment' and slot onto acrylic poles.	Identifying supporting systems and approaches	Ask the participant to consider people, devices, interventions or strategies that help and write on lifering stickers.
Identifying supporting systems and approaches	Ask the participant to consider people, devices, interventions or strategies that help. Write them on a lifering and add to map.	Identifying barriers to providing support	Ask the participant to consider elements that impact supporting the challenges and write them on anchor stickers.

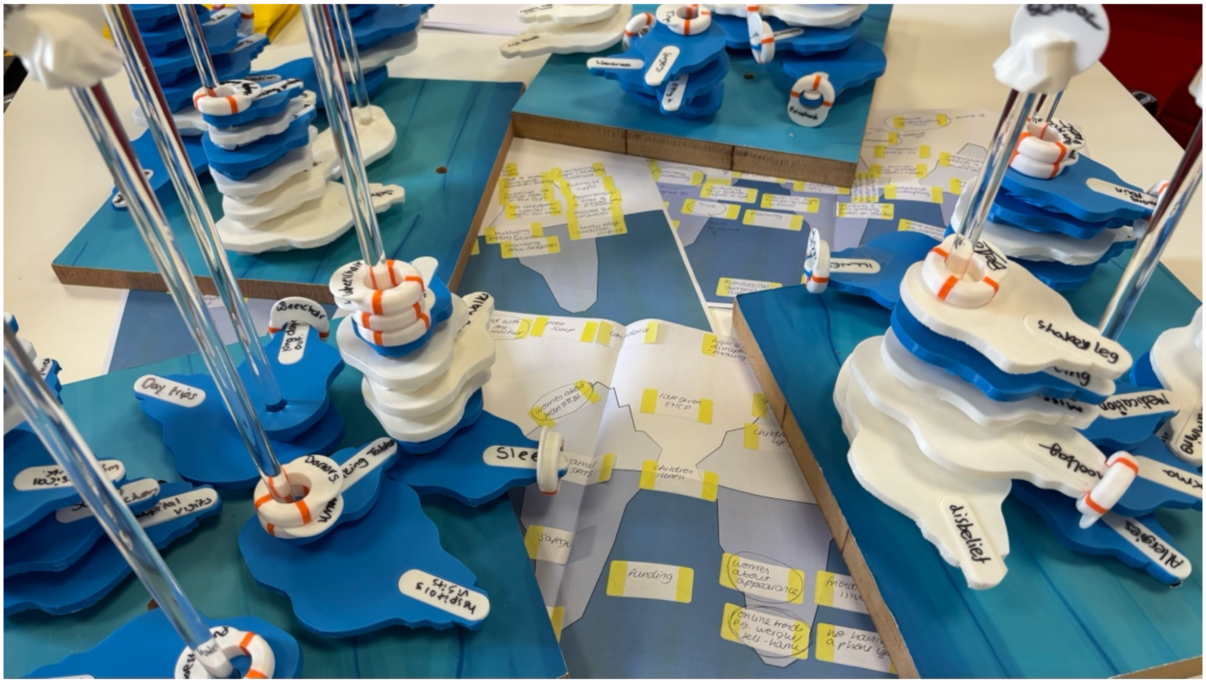

Figure 1: Completed tangible and paper-based iceberg maps. Photograph by Ursula Ankeny

condition, in the case of JIA, often being disbelieved, whilst those with CP were assumed to have a lower functional or intellectual ability than was the reality. The pain point around splints was both physical and emotional, with one child saying “no one’s mean. It’s just everyone’s asking me questions. You have to explain. You have to explain every single time. It just annoys me”, highlighting the difficulty around wearing something that marks them out as different, and the line between curiosity and feeling alienated. The ongoing worry around upcoming appointments, fear of increased medications or surgery options and the impact of their condition on future employment.

Additional aspects mentioned by parents, teachers and healthcare professionals included the length of time to diagnosis and the subsequent coming to terms with the condition, waiting times for appointments, the complex multi-stakeholder network that manages the condition, inaccessibility of physical environments and the balance of enabling independence for the child whilst ensuring sufficient condition knowledge through transition periods.

Through the life ring activity, people, devices, interventions and strategies of benefit were highlighted such as outreach programmes, assistive technology, signposting to key websites and the importance of a positive relationship with those involved in the child’s care. Whilst there were life rings added, there were far fewer in comparison to the number of iceberg segments (challenges), highlighting the level of remaining unmet need and lack of current tools available. The iceberg maps also acted as landscapes of the complexity of CM, highlighting the different factors to be aware of when innovating and the different contexts and environments in which an innovation needs to seamlessly blend.

3.2 The method

For children, they engaged well with the metaphor and building approach, allowing them to consider different aspects of their condition in a play-based way. The tangible approach worked well as a method to encourage shyer children to contribute as it removed the focus on purely verbal communication, enabling them to have their voice heard through physical means. As highlighted by one child “I like to be creative and I feel I can show someone how I’m feeling better that way”. This then prompted conversation but from a challenge they had built in a physical metaphor form, as highlighted by one parent “your landscape was an innovative way to look at [CM] and it made us think and talk”. The breaking down of the process into manageable stages enabled the child to start with more obvious aspects (visible) and then naturally iteratively uncover those that were more hidden, giving space to contribute without an over focus or pressure. For the parent, they often took on a role as additional facilitator and had to be prompted to give their own opinion. The tangible method was useful leading this, with the child and parent adding their own aspects they had thought of and then discussing between the two of them level of visibility and impact. The recording acted to highlight points of disagreement, adding an extra layer to the data captured. For healthcare professionals and teachers, the low-fi paper method worked well as it implied a faster task, building trust in the process, portraying the task as more manageable within a strict timeframe. The placement of the challenges on the icebergs was used to communicate more than the challenge itself, for example one teacher put ‘transition’ at a slant to indicate it’s increasing visibility over the school year, whilst other participants placed challenges on the sea line to show they had aspects of both visibility and invisibility. This highlighted the methods ability to show nuance and prompt discussion.

Across all stakeholder groups, the physical building and interaction allowed participants to reveal richer insights through making, drawing out tacit knowledge and latent needs, echoing Sanders and Stappers Say, Do, Make triangle [9]. From a visual perspective, both the tangible version and paper version communicated the metaphorical weight of managing a condition and the variety of different aspects, highlighting the complexity of this area to the researchers involved.

The limitations of this study include the fact that it is a small population sample size of each condition and therefore is not representative of the whole population. It is not intended to be representative but rather to build knowledge through experts by experience. From an empirical and methodological standpoint, further research both within these populations to expand upon lived experience, and across different conditions, to explore and expand the tangible mapping approach would be beneficial.

4 CONCLUSION

This work-in-progress paper describes the first of five co-design sessions. These sessions are ongoing with the data being iteratively analysed. The iceberg maps embody an interactive and creative method to meaningfully involve children in understanding and mapping out their CM, making it engaging and fun, eliciting deep, rich and contextual findings. The subsequent work will involve the co-designing of interventions in response to the iceberg maps created, considering the extent to which a deeper understanding of the CM landscape has on engagement with and use of assistive technologies.

5 SELECTION AND PARTICIPATION OF CHILDREN

This research was reviewed and approved by both Sheffield Hallam University Research Ethics Committee and HRA Research Ethics Committee. Recruitment flyers were circulated through clinical champions and charities, inviting parents and children to participate. Children were selected to participate if they fulfilled the criteria of 7-16 years old, diagnosis of CP or JIA, and not significant cognitive impairment to ensure ability to take part in the co-design sessions. Equal access was ensured during recruitment. Once participants expressed interest, participant information sheets were sent (one written for the child and one for the parent), participants then contacted the researcher if they wanted to proceed or had any queries. The consent form was then signed by the parent and assent form by the child to ensure they were both fully aware of the research requirements. The co-design materials and activities were developed and adapted as needed for different accessibility needs such as dexterity issues, given the nature of the conditions involved. Families were offered a £100 thank you voucher for taking part in all 5 co-design sessions (of which this paper reports the first), they also received a 3D printed thank you gift in the form of a lithophane after each session. Participants were given the option to tick if they would like to receive a copy of the project report on the consent form. Strict ethical procedures were followed throughout.

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