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Child-led, Creative Exploration of Paediatric Incontinence

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Abstract
This paper describes a novel collaboration between a health science initiative, a MedTech Co-operative and a university design research department alongside a group of children with incontinence, their parents and siblings. This collaboration hoped to inform the development of technological interventions specifically aimed at supporting paediatric incontinence.

Together, we used a range of bespoke tools to creatively and collaboratively explore questions of 'What are your main challenges? How do you currently address them? And how would you like to address them in the future?' These tools aimed to place the children as the experts in the rooms, reflecting on their wider life (i.e. their hobbies, friends, family) and took an asset-based approach to highlight the skills and resources they already leverage to address their personal challenges. Later, ideation activities were used to empower the families as inventors to highlight and address any unmet health needs. Central to each of the activities was the aim to reframe a traditionally 'taboo' topic as something that is safe, and even fun, to explore through creative means.

This study concludes that by using context-specific, sensitive and creative tools, children from a range of ages can (and should) be included in setting the agenda for future healthcare technology development, even in topics that are traditionally difficult to discuss.

Keywords: paediatrics, co-design, incontinence

Introduction
Background
Incontinence, a lack of voluntary control over urination or defecation, can occur for a variety of reasons, on a spectrum of severity, and is more commonly associated with older adults. However, approximately 900 000 children and young adults are affected by continence issues in the UK (BBC 2015), whether as a result of medical problems or not having undertaken correct toilet training. Although children represent a smaller percentage of the population with continence issues, the impact upon them should not be underestimated. The effect on a child's wellbeing at school, risk of bullying, and potential lack of confidence in participating in social or sporting activities may have lasting implications for the rest of their lives. Despite this, incontinence is not a popular subject of research.

Aim of the Work
IMPRESS (Incontinence Management & PRevention through Engineering and ScienceS) is a research project funded by the Engineering and Physical Sciences Research Council (EPSRC)

and the National Institute for Health Research Healthcare Technology Co-operative (NIHR-HTC). Their aim is to encourage more engineers and scientists to work on researching new technologies for incontinence. In previous work, IMPRESS identified a significant gap in provision for children with incontinence, when problems persist beyond toilet training or pre-school age.

In response to this need, IMPRESS organised a Family Day event to learn about the lived experiences and unmet needs of children living with incontinence, and their families. The aim of this workshop was to inform future innovation of relevant medical technologies in this area, to better support these families in their day to day lives. To support this work, they invited the input from Devices for Dignity (a Sheffield-based NIHR-HTC who aim to catalyse the development of new medical devices, healthcare technologies and technology-dependent interventions within the NHS) and Lab4Living (a Design and Healthcare research department within Sheffield Hallam University, who use creative means to facilitate shared understanding between multiple stakeholder groups in a range of healthcare contexts) to develop a co-design workshop to explore these topics.

Research Questions
To meet the aims of this work, several research questions were developed that took an asset-based approach to enquiring into children and family's lives, and the impact of continence issues upon it:

- What are your main challenges of living with continence issues?
- How do you currently address these challenges?
- How would you like to address these challenges in the future?

The co-design activities developed to answer these questions sought to draw on participants' creativity, as well as support them in sharing their existing knowledge and coping strategies – each key principles of co-design. The efficacy and lessons learned from conducting these activities will be the focus of this paper, rather than the clinical insights generated from them (which can be found at tinyurl.com/ya3wa6mx).

Challenges
Both the context and the community involved in this work presented particular challenges for co-design. As described above, the impacts of incontinence can be complex and far-reaching (including the lives of parents and siblings), making it a difficult topic to explore and generate a meaningful understanding. In addition, children may find it harder to articulate their needs due to less developed language skills, and the particular sensitivity of the subject. As such, the design of this Family Day workshop focussed on creating a safe space for children and families to 'open up,' to trust the facilitators and to draw support, not embarrassment, from meeting new families on the day.

Developing the Workshop Plan
Prior to designing any workshop activities, an initial literature review was conducted exploring how children are currently engaged in co-design activities. According to the literature, there are mixed opinions of whether children should be expected to participate in service, architectural or product development (Newman and Thomas 2008), but if so,

their involvement should be fun (Baek and Lee 2008). Whilst there are several theoretical frameworks available that discuss the roles available to children in such activities (Druin 2002; Guha et al. 2005; Hart 1992), we found the following key lessons useful for our work:

- Play is the most natural form of expression for children (Baek and Lee 2008, 174).
- Activities that focus on self-expression, rather than 'right/wrong' activities, are effective (van Rijn and Stappers 2008).
- Due to a potentially shorter attention span, longer activities for children should be built of short steps that build upon each other (Baek and Lee 2008)

However, very few examples of co-designing with children in healthcare contexts could be found (see Hussain and Sanders [2012]); instead the literature largely focusses on the development of school environments or learning resources.

To begin planning the workshop, members of the IMPRESS team briefed colleagues from Devices for Dignity and Lab4Living on the context of childhood incontinence and key areas of focus for the workshop. From this, the first author drew on the literature review findings and previous experience of engaging children in co-design activities to develop a draft workshop plan. The authors then met and iterated the workshop plan over several months to consider; the age range (and therefore attention span) of participants; the presence of siblings and parents; and logistics of the venue. Once a plan was established, a professional illustrator was commissioned to further develop bespoke tools for the activities, to help facilitate the workshop and support the dissemination of the findings (as will be discussed below).

Conducting the Workshop
A range of tools were developed to support activities of reflection and communication of unmet needs, followed by ideation of how these needs could be better met. The morning of the 'Family Day' was dedicated to primary school-aged children and families, and the afternoon to secondary school aged-children and families. As such, the tools were adapted to each age group. For clarity and brevity, this paper will focus on the morning session, with younger children (aged 4-11).

The co-design activities aimed to be ambiguous enough (i.e. not overtly focussed on the medical condition) to be fun for siblings to take part in as well as the child with incontinence. This aimed to capture the unique perspectives of siblings, but also to avoid singling out the child with continence issues unnecessarily. The attending parents and a group of healthcare professionals were asked to help facilitate the activities with younger children, whilst the authors 'floated' around the room, providing additional help and instruction as needed.

A selection of key tools and the lessons learned from them are discussed alongside the three original research questions below.

Research Question 1: What are your main challenges?

It can be easy to consider our 'health' in terms of symptoms, so we found it useful to begin the workshop by prompting children and families to reflect on the continence issue's impact on their wider lifestyle. This was facilitated by a quick 'warm up' activity shown in figure 1:
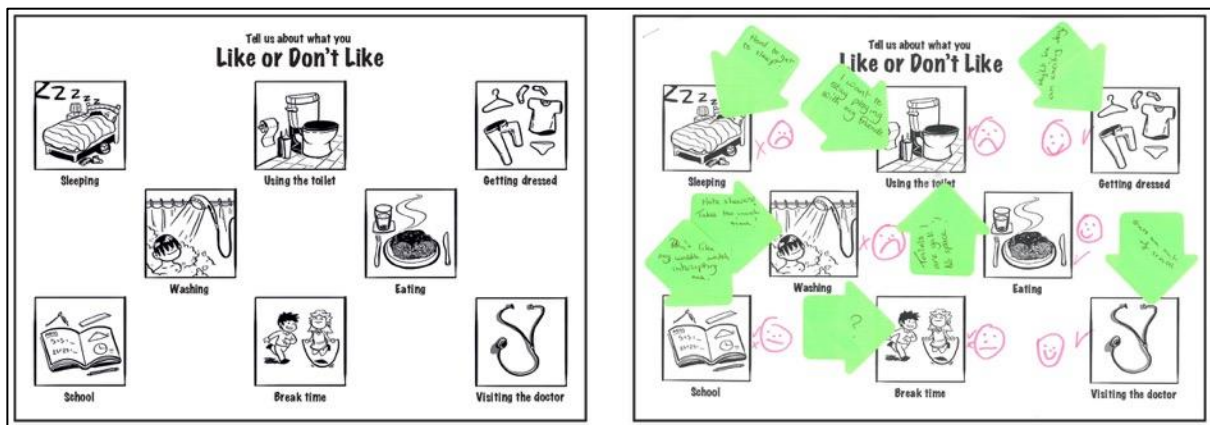

Figure 1: The Like/Don't Like activity (approximately 10-15 minutes) asked children to first draw a happy or sad face by each activity, then to use Post-its to tell us why their continence impacts these activities (see Gielen [2008]).

This short and easy to understand activity was motivating and provided a 'quick win' for children. It also gave facilitators an idea of the children's interests and key issues, to inform their conversations with them as the workshop progressed.

Next, we continued our reflection in more depth with the 'Map my World' activity, shown in figure 2 below:

Figure 2: The 'Map My World' activity.

After drawing themselves in the centre of the page, and choosing from a set of prompt cards (words such as 'Home,' 'School,' 'Hobbies' and 'Friends'), children were asked to use a range of stickers, printed images and their own drawings to create a collage of what was important to them. This aimed to reinforce notions of self-expression, treating them as people, not symptoms. Following this, children and parents were asked to use Post-its to tell us about the 'challenges' they encounter in the different areas of their life. We chose the

term 'challenges' rather than 'problems' to infer an issue that can be addressed, maintaining a positive, productive tone to the activity. This opened up the agenda for conversation, and gave facilitators an insight into children's unmet needs alongside the relevant context and/or reasons, whilst also preparing participants for the next activity.

Research Question 2: How do you currently address these challenges?
Continuing the 'Map My World' activity, families were asked to revisit the challenges raised and annotate them with ways in which they currently address them. This provided an opportunity to learn about their current coping strategies, which may in turn inspire medical technology innovation in this area. This activity placed participants in the position of experts, and created a forum for families (who are rarely brought together) to learn from each other too. We found this was also an empowering activity, as it highlighted to families how well they are doing, and how much they have already overcome themselves.

Research Question 3: How would you like to address these challenges in the future?
Changing the tone of the workshop from 'what is' to 'what could be', idea generation was facilitated in a playful way with the 'When I grow up' activity, shown in figure 3:
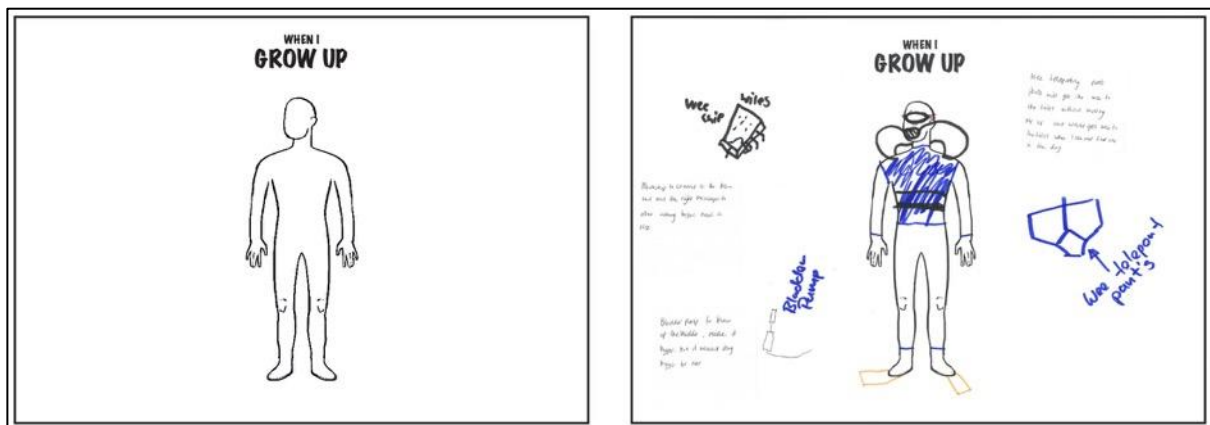

Figure 3: Children were first asked to draw themselves as a grown up, adding details to show what job they will do, if they will have pets, etc. Then, they were asked to imagine they are an inventor in the future, and draw any gadgets or equipment would they like to overcome the challenges they have now, to get to that future.

This activity led to 'blue sky' ideas which catalysed interesting conversations. For example, one child's 'teleportation pants' invention, which automatically transported any 'accidents' without anyone knowing, led to discussions on his fears about children at school finding out about his continence issues. We feel such candid conversations, and inspiration for technology innovation, may not have arisen from traditional, questionnaire-based research techniques, nor leave scope for children to prioritize their issues.

Discussion
This paper has demonstrated how health- and design-based approaches can work together to explore children's perspectives on complex healthcare issues, in their own words. We found that short, easy to complete activities which build upon each other and focus on

playful forms of self-expression were effective, in accordance with the current co-design literature.

We propose a contribution to the literature in this area with our use of an additional activity that occurred in parallel throughout the workshop. Our professional illustrator created a mural that was responsive to the outcomes of the workshop activities as they progressed, in real time. The mural was based on an island, made of three territories that corresponded to our three original research questions:

- 'Challenge Swamp' linked to 'Research Question 1: What are your main challenges?'
- 'Solution Forest' linked to 'Research Question 2: How do you currently address these challenges?
- 'Idea Island' linked to 'Research Question 3: How would you like to address these challenges in the future?

The illustrator would move between groups of children and their families during the workshop activities, take notes on their insights, and draw simple representations of their issues and current/future solutions in the corresponding territory, as shown in figure 4 below:
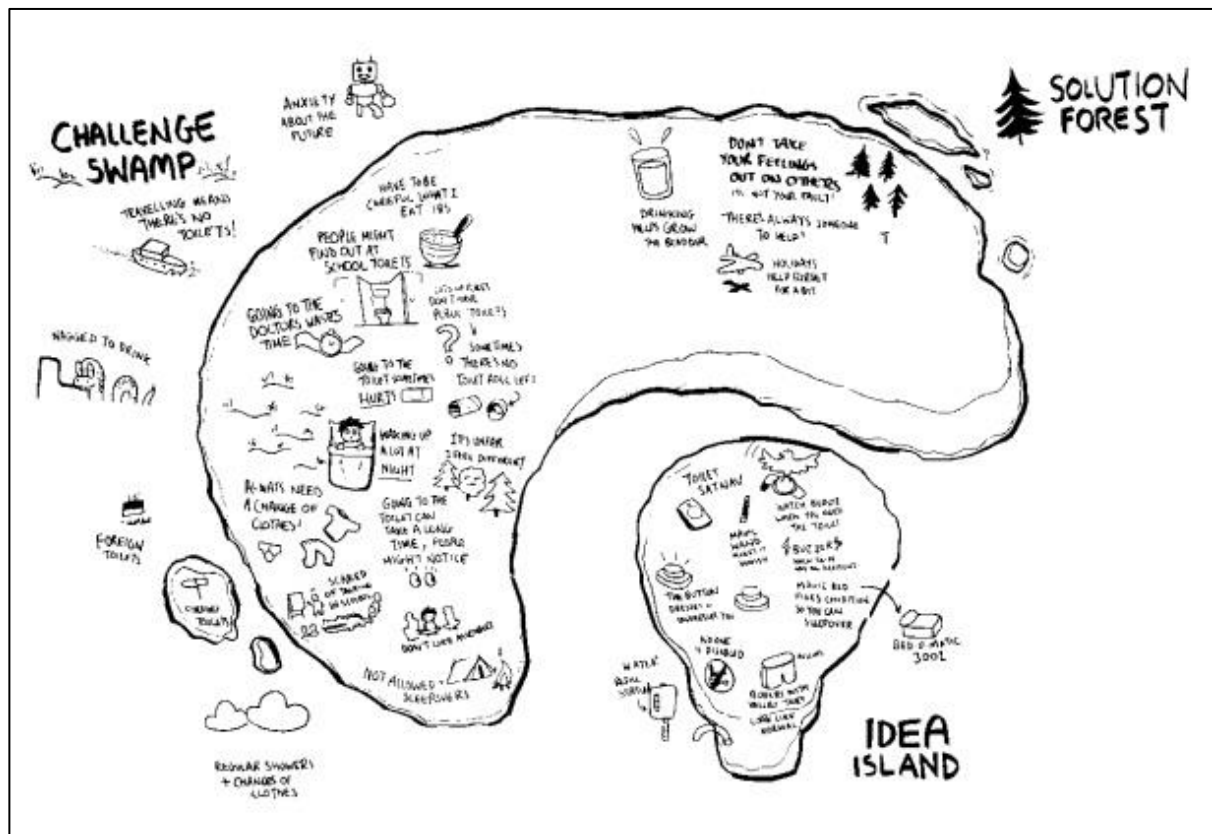

Figure 4: The Island Mural.

In this way, the progress made across the island acted as a 'guiding narrative' throughout the workshop and a clear indicator of progress (see Dindler and Iversen's notion of 'fictional inquiry' [2007]). The mural also provided a level of abstraction that aided creativity – by

framing the activities around this playful idea we aimed to create a more comfortable atmosphere for children who may not be used to talking to adult strangers about sensitive health issues. With this in mind, the mural was also a useful tool for children to volunteer ideas for each of the territories anonymously, and could frame their suggested ideas as something that might be useful for children with continence issues generally, rather than for them personally.

At the end of the day, the mural became a clear, tangible outcome that the children could see that they had contributed to – they had completed a 'journey' across the island together and we had listened to their expertise. The mural also created a 'quick win' in terms of research findings, by providing an overview of key issues, coping strategies and unmet needs. In turn, this overview helped to inspire and inform a six-page comic, which incorporated the findings of the day (and some of the children's original drawings) in narrative form. This helped to distribute the research approach and results in a participatory manner that is understandable to the children and young people involved (see figure 5 below and visit tinyurl.com/ya3wa6mx to download the full comic).
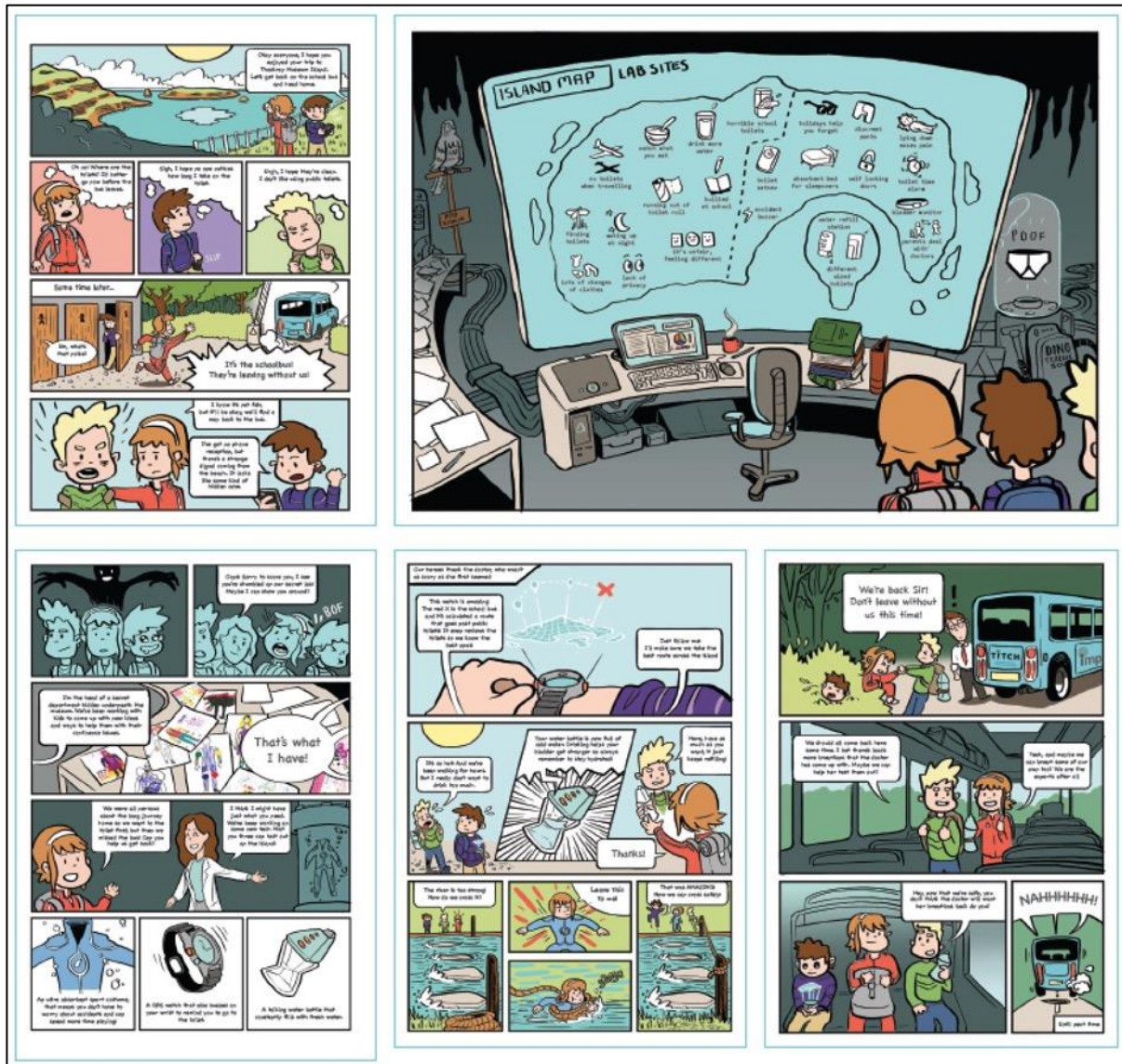
Figure 5: The Toilet Talk comic.

We feel it is important not to consider workshops such as this as one-off events, but to cultivate a culture of participation with families, especially in potentially isolating conditions such as this. As such, we recommend continued involvement of workshop participants if possible, and find that creative methods are particularly engaging for younger audiences.

Beyond workshop methods, events such as this must give careful consideration to logistics. We received a high turnout of children and family members by conducting the workshop on a Saturday (to reduce clashes with work or school commitments) and by researching appropriate venues. We chose a medical history museum as a 'neutral space' (i.e. not a hospital or school) that offered additional fun activities before and after the workshop (giving more incentive for parents to travel and providing alternative entertainment for siblings). We also argue that such a high response rate (60 registered participants from across Scotland, England and Wales) highlights a need for further research in this area.

Finally, we argue that facilitators of events dealing with sensitive healthcare issues of young people should endeavour to tailor the approach they take with each child. We found that each family framed and talked about the child's continence issues differently, and it is important to respect this. Terminology can also be picked up and adopted, for example, one child referred to their urinary incontinence as their 'naughty bladder.' Above all, it is important to engage children as children – unique individuals who aren't defined by their healthcare condition.

Conclusion

Through our Family Day co-design workshop for children with continence issues, alongside their parents and siblings, we have demonstrated a range of creative tools that facilitate meaningful, sensitive, and even fun ways of discussing healthcare needs. We have found that discussing 'challenges' alongside current and potential future solutions is an empowering way to discuss healthcare issues, and is likely an approach applicable to a range of contexts with children and adults alike. In addition, the use of a mural that evolves according to the children's input was a motivating method of demonstrating progress through the workshop, highlighting the value we placed on their contributions, and a useful tool to facilitate further discussion on a potentially 'taboo' topic. We argue that children and young people can, and should, play a key role in defining the future of medical technology innovation, and that creative, collaborative methods can help to ensure such innovation is responsive to their lived experiences and future aspirations.

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