Using a co-design approach to develop technological interventions to help children with Arthritis to be more active and independent

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996.5. Using a co-design approach to develop technological interventions to help children with arthritis to be more active and independent

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ABSTRACT 15,000 Children and Young People (CYP) in the UK have Juvenile Idiopathic Arthritis (JIA). 1,000-1,500 new cases are diagnosed every year. Currently there is no cure for JIA. Management interventions are available, but these are often stigmatising and children disengage. Improving self-management skills for children is particularly important as they transition to adulthood. The aim of this project was to understand different perspectives and needs of all stakeholders affected by JIA, and to develop a design response to better support them. A co-design approach was used to explore these issues and to develop the response. Phase 1 focused on using surveys, with rapid response rates highlighting the lack of current products, 1:1 interviews to establish key areas of unmet need within the different stakeholder groups, as well as storyboarding and rough prototyping. As the prototypes took shape, stakeholders continued to contribute particularly around ergonomic and tactile issues. The different priorities of each stakeholder were emphasised: the children wanted help with their joint pain whilst the healthcare professionals wanted to improve physiotherapy adherence. The parents wanted to keep better track of the condition whilst the teachers wanted to improve communication with the child. Stakeholders initially dismissed other stakeholders' views, believing they knew best. Through these discussions, the complexity of JIA management was highlighted and therefore the importance of a multi-product approach became apparent. One of the key difficulties in managing chronic illnesses (particularly for children) is the lack of communication between different stakeholder groups but also between healthcare professionals across different disciplines. Through incorporating different stakeholders' opinions, the technologies created resulted in effective methods to not only address the problems mentioned but also to facilitate discussion around these issues throughout the design process, eliciting previously unknown needs and developing a more engaging and successful product. Further funding is being sought between university and hospital partners to continue developing the products collaboratively with children, families and clinicians.

Keywords: co-design, self-management, Juvenile Idiopathic Arthritis, paediatric healthcare

Introduction

Juvenile Idiopathic Arthritis (JIA) is one of the most common causes of physical disability in childhood (Versus Arthritis 2019) and is defined as an autoimmune disease that causes inflammation of the joints (Versus Arthritis 2019) resulting in pain and stiffness, which can make everyday activities difficult to achieve. This can affect physical and emotional wellbeing and cause delayed development, meaning children with JIA struggle to be active and independent.

Most self-management tools that assist with daily tasks are aimed at adults, so they can be difficult and stigmatising for children to use. The products that are currently available do not take into account the wider stakeholders involved and how their support, or lack of it, impacts the child's overall health.

This project's aim was therefore to address this gap in the market by using a co-design approach to understand the challenges faced by the key stakeholders involved: the child, parent/carer, healthcare professionals (HCP's) and the child's teachers. These challenges were then explored to realise a suite of self-management tools. This paper focuses on the process involved, specifically the importance of sustained multi-stakeholder involvement, and how the design-led approach facilitated their involvement and the development of an engaging and successful outcome.

Background

A major priority for health services is helping people with chronic long-term conditions, including arthritis, as highlighted in the 2030 Agenda for Sustainable Development. Arthritis can be life-limiting with emotionally and physically debilitating effects, as well as making simple tasks painful and difficult to achieve. At a macro level, it can restrict an individual's access to employment, putting increased pressure on the economy and healthcare resources. The current COVID-19 climate further highlights the need for these patients to self-manage effectively as healthcare professionals are being diverted to help support the recovery of COVID-19 patients. This withdrawal of or limited access to key supports can have a considerable negative impact on the physical and mental wellbeing of chronic disease patients. The development of self-management tools is therefore key to helping relieve pressure on healthcare professionals and to alleviating the concerns of patients. Harnessing the wider informal support network surrounding each patient was a specific focus of this project, recognising that this support network also needs resources (tools, knowledge, information) to enable them to provide the best support.

Arthritis is generally associated with older adults. The fact that it affects children is little-known, resulting in a lack of tools to support them. Children develop by interacting with the world through play, 'allow[ing] children [to develop] their imagination, dexterity, and physical, cognitive, and emotional strength' (Ginsburg 2007). However, 'CYP with JIA live with recurrent pain and disability, limiting their ability to complete daily physical tasks and participate in school and social activities' (Tong et al. 2012). Existing studies describing the experience of living with JIA are not recent, and do not reflect new initiatives or treatments. Those that do exist tend to focus exclusively on the child's experience or only focus on the physical symptoms, neglecting both the wider life impact and insights of other stakeholders.

A co-design approach was chosen to ensure wider stakeholder views were incorporated. Co-design is defined in this context as 'the creativity of designers and people not trained in design coming together in the design development process' (Sanders & Stappers 2008). This approach is particularly useful within healthcare contexts as it helps to give equal consideration to the knowledge that each stakeholder brings. Families can often feel as though their lived experience is ignored or that the medical opinion of their healthcare professional holds greater weight than their own. It was a conscious aim of the project to continually involve children with JIA, their families, healthcare professionals and the children's teachers equally. Their collective input directly steered the focus and prototype iterations.

Methods

Fully informed consent was obtained at the start and strict ethical procedures were followed throughout. The clinical stakeholders involved were part of Sheffield Children's Hospital (SCH) Rheumatology department, with this link aiding the recruitment of families. Further family stakeholders were recruited through online support groups, ensuring a wider population was involved. Both teachers and teachers in training were recruited to capture their experience and knowledge of new teaching practices being implemented.

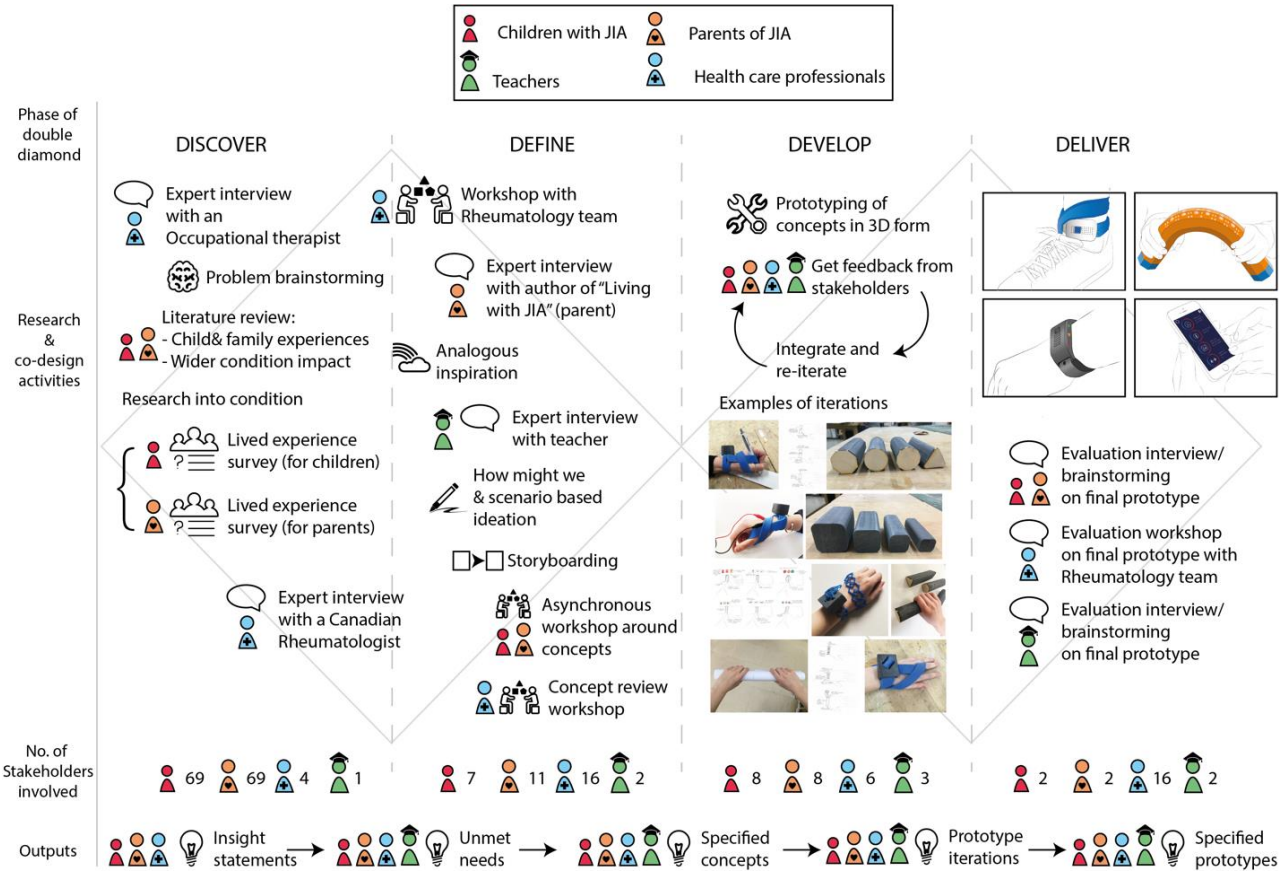

Figure 1: Method Diagram using the Double Diamond Framework (Design Council 2015)

Stakeholder input was sustained throughout, with each phase involving a mix of research activities and independent design work, described below.

DISCOVER

Aim: To discover the breadth and characteristics of unmet needs from different stakeholders. Activities included:

- Research into the condition and a literature review for context.
- Expert interviews with healthcare professionals to expand on the problems, in an open format to encourage discussion of current treatments, children's and healthcare professionals' issues and products they did/didn't recommend.
- Online lived experience survey to understand the problems that children and their parents face, enabling participants to answer in their own time, reducing potential pressure, resulting in richer lived experience data. This accessed international patients.

DEFINE

Aim: To define the problem(s), and develop initial concepts. Activities included:

- Independent sketch ideation by the designer as a starting point to consolidate findings from 'discover' in a format that can be used to stimulate further discussion.
- Workshop with a Rheumatology team. Ideas were presented in rough sketch form to facilitate discussion.
- Expert interview with the author of a guide to living with arthritis (parent of a child with JIA, USA), on her wider experiences and responses to initial ideas.
- Expert interview with a primary school teacher in training, focusing on strategies she used to help children who struggled physically in the learning environment.
- Consolidation of stakeholder-identified needs and prioritisation of key issues to take forward: pain management, encouraging physiotherapy, help in the classroom and condition management
- Development of concepts using design methods including: scenario-based ideation and storyboarding activities around who the ideas would benefit and how.
- Asynchronous design workshop involving children and their carers around the concepts. Creating a co-design space where families could use post-its and emoji stickers to build on comments and ideas.
- Concept review with healthcare professionals, building on insights gathered from the asynchronous workshop.

DEVELOP

Aim: To prototype the concepts based on feedback. Multiple prototype iterations took place, following the process of making prototypes, getting feedback from stakeholders, integrating and re-iterating. The prototype iterations covered the following elements such as accessibility, physical properties, digital security and aesthetics (see figure 1).

DELIVER

Aim: To test user response to final prototypes. The stakeholders were given the prototypes during these interviews, allowing them to interact with them naturally and explore what worked well and what they would improve.

Findings

Theme	Challenge/ unmet need	Priority for which stakeholder?			
		HCP's	Children with JIA	Their parents/ families	Teachers
Symptoms	Pain as a symptom				
	Obesity				
	Unique symptoms				
Impact on school	Missing school				
	Writing as a major difficulty				
Treatment	Pain from treatment				
	Current aids are stigmatising with children not engaging as they are obvioudly different				
	Lack of compliance with physio stretches				
Emotional impact	Feeling isolated/ different				
	Invsibility of disease leads to disbelief				
	Feeling the disease controls them				
	Emotional burden from changing symptoms				
	Feeling helpless as your child suffers				
Wider desires	Increased understanding from key stakeholders				
	Incresed awareness/ reduction in trivialisation of disease				
	Desire for independence				
	More knowledge on condition				
Monitoring	Diagnosis of JIA can take a long time				
	Keeping track of symptoms				
	Need to juggle workload/ child's condition				

Figure 2: Unmet needs

Challenge/ unmet need	Quotes/ Evidence to support	Priority for which stakeholder?			
		HCP's	Children with JIA	Their parents/ families	Teachers
Pain as a symptom	"It would be great to know what it's like to not be in pain… I'm in pain all the time" (Tong et al., 2012)				
	Better pain relief daily was cited as the product that was wanted to help				
	"Something to help with pain so that I don't have to stop doing fun things because my hands or knees hurt"				
	76% of chidlren reported pain on >60% of days despite taking medications (Schanberg, Anthony, Gil, & Maurin, 2003)				
	Distracting child from painful symptoms was highlighted as key challenging aspect				

Figure 3: Unmet needs with supporting quotes

The iterative co-design process meant that the concepts and prototypes continually changed in response to feedback. The needs accumulated through the different stakeholder activities have been collated in figure 2, with examples of the evidence supporting one of the needs, highlighted in figure 3.

The key priorities for each stakeholder, that drove the concepts, were:

For the **children** with JIA, their priority need was help with joint pain as this hindered their ability to be active and independent, making them feel different. They wanted 'something to help with pain so that [they] don't have to stop doing fun things'. While aids were considered stigmatising, children emphasised the problem of having an invisible condition as it often led to disbelief. Missing school and the lack of understanding from key stakeholders were highlighted; 'I struggle with PE and some teachers just say: 'Come on, you're fine''.

For **parents/carers**, recurring themes were how to easily keep track of the condition to help reduce lengthy diagnosis times, help to identify an upcoming flare up 'allowing a full episode to be averted' (Miller, 2013), ways to improve diagnosis as 'it was scary and frustrating knowing something wasn't right, but not having a reason' and expanding knowledge of the condition.

For **healthcare professionals**, the priority problem was lack of compliance with physiotherapy stretches, despite pain relief when done regularly. Children cited pain, lack of motivation or fatigue as deterrents to physiotherapy. Other problems included the uniqueness of JIA symptoms, 'The key problem with treatment is working out which treatment is the right treatment for each kid' (Mosher, 2019) and potential obesity through lack of exercise.

For **teachers,** the priority issue was understanding when children were in pain or needed help, closely linked with problems of disbelief and lack of awareness around the condition. Children said teachers had accused them of feigning their pain. Children were reluctant to use current systems such as traffic light cards to indicate when help is needed, as they were embarrassed by their difference in front of their peers.

These unmet needs were developed through a prototyping process resulting in four products in a suite of self-management tools. Photographs of the prototypes have been omitted for Intellectual Property reasons. The concepts are shown in Figures 4, 5, 6 and 7 and show how stakeholder input drove every decision.

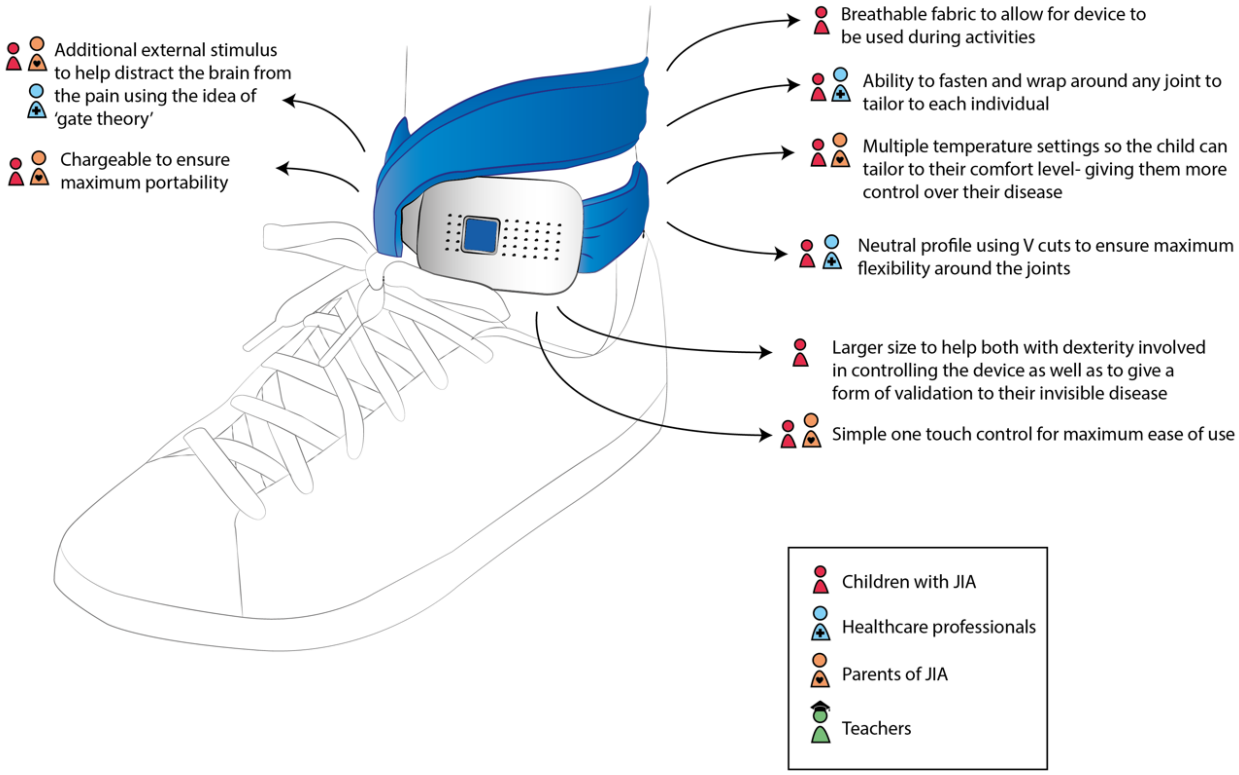

Figure 4: C1: Pain Management Tool

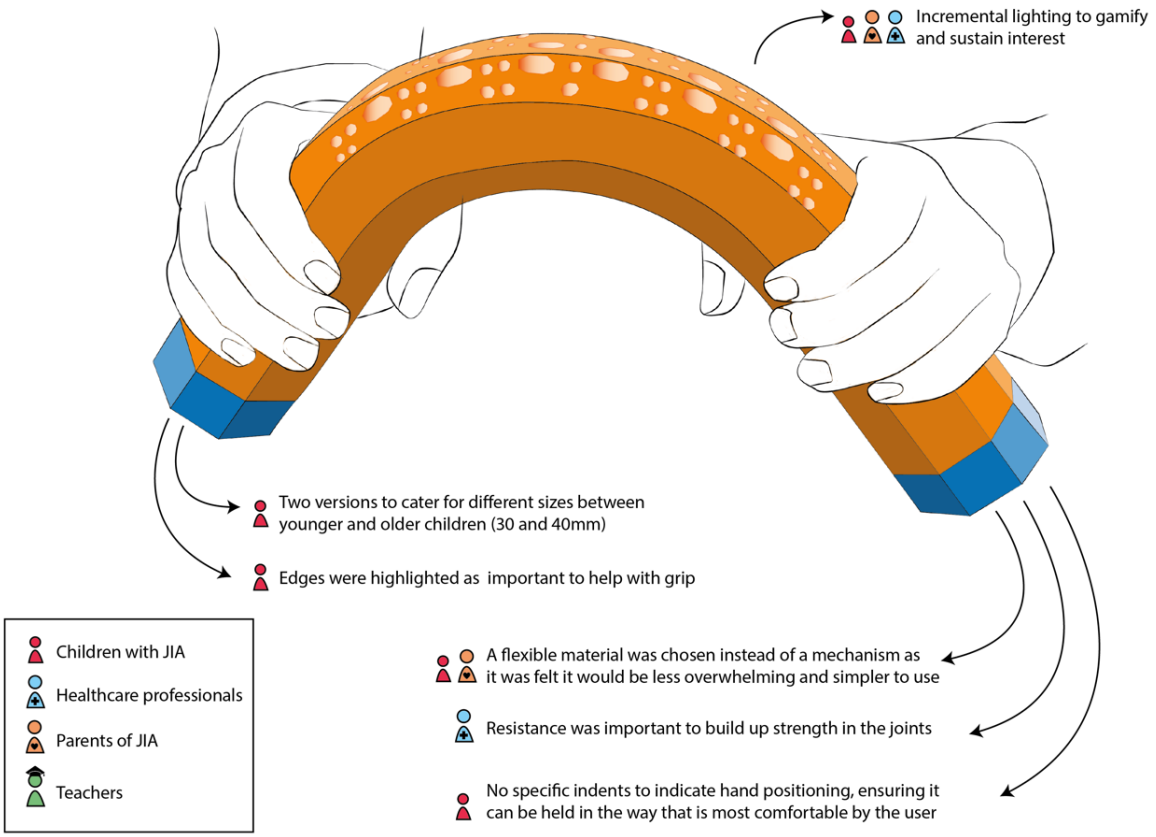

Figure 5: C2: Motivational Physio Tool

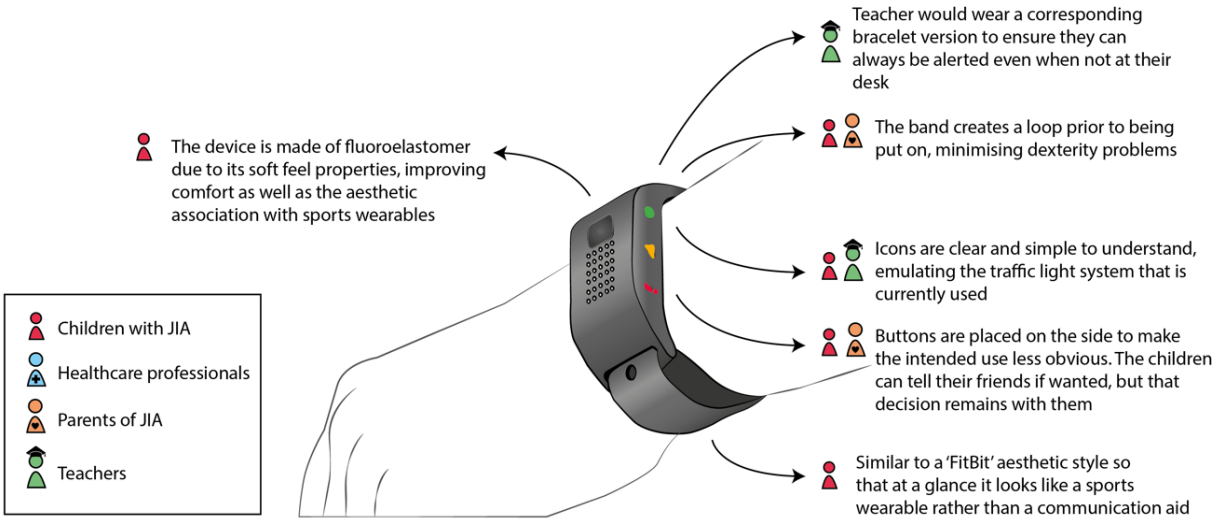

Figure 6: C3: Communication Tool

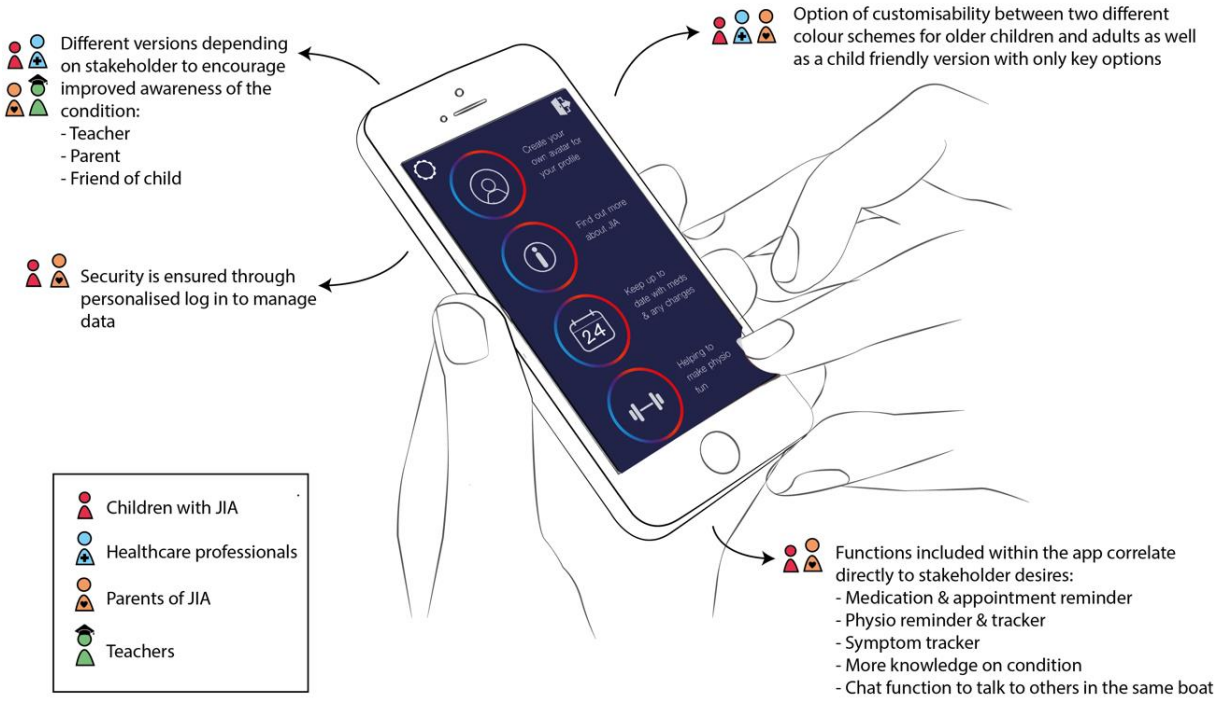

Figure 7: C4: App to manage the condition

Discussion

The wide range of unmet needs identified in Figure 2 highlights the extent to which JIA impacts a child's life including their emotional, academic and social wellbeing, which in turn impacts their condition and treatment. Current products often ignore this wider context which leads to a lack of engagement. The key issue is that previous products are often designed with only one, possibly two stakeholders in mind (the child and their carer), neglecting to take account other critical stakeholders involved. As one parent emphasised 'your child's teacher spends more waking hours with him or her during the week than you do' (Miller, 2013), similarly the healthcare professional is heavily involved. By including these other stakeholders, challenges related to communication, awareness and disbelief, and their impact on each child with JIA could now be addressed collectively. The co-design approach enabled multiple perspectives to be taken into account, by expanding the context of the disease and offering a cohesive response to all the issues.

The sustained multi-stakeholder input provided constructive challenge through all stages of the design development, steering the direction of the solutions. For example, during phase 1, the desire to and the importance of being active was emphasised by all stakeholders. The initial design response was therefore a product that encouraged activity, tailored to the individual's specific limitations. The co-design process then uncovered two key underlying issues: 1) from the healthcare perspective, the need for daily physiotherapy exercises to extend the range of motion and 2) from the child's perspective, a product to help with pain management, to enable them to do their physiotherapy exercises whilst also engaging in general physical activities. These insights were only achieved through the mutual trust and sustained involvement of all stakeholders.

The designer's adaptability is key for a successful co-design approach, as they must adjust the resources and design setting to enable input from different stakeholders. An example was the asynchronous workshop in phase 2. The fact that children with JIA often miss a large amount of school had been previously highlighted. As a result, the setting for this workshop was timed to coincide with clinic at SCH. This co-design space enabled multiple children and families to comment on the concepts independent of each other, thus building on each other's insights. Stakeholders usually comment simultaneously within a singular workshop, but an asynchronous approach made the best use of the participants' availability and gave them the safe space to comment freely. With regards to the tools, younger children often want activities that are fun with immediate reward whilst older children want to be treated as an equal and resist patronising elements. As a result, storyboards were used to engage younger children whilst concept sketches were used to appeal to older children. The storyboards felt like a game but allowed younger children to understand the context, whilst the concept sketches enabled older children to expand upon their opinion, validating their lived experiences. A design-led approach is what enables this flexibility, altering tools to engage the different users and offering full voice to all participants, resulting in richer outcomes.

Prototyping is key to co-design, embodying stakeholder preferences as well as designer's own expertise and judgements for continued reflection and development as shown in (Langley 2019). This iterative process was particularly useful when sizing C1, the pain management tool (see Figure. 4). The design challenge initially appeared to be balancing the constraints of the technology with the child's embarrassment of using an aid. Two crucial insights were then gained when the children interacted with foam models: arthritis is known as an invisible condition with scepticism being a common reaction; so in reality a visible, physical aid validated their condition and combated disbelief. However, users also explained the lack of engagement around current aids; these are clunky and medical-looking, and children wanted something 'cool' to show to their friends. Prototyping also challenges perspectives, as when deciding the form for C2, the motivational physiotherapy tool. Most physiotherapy aids are spherical in form, for comfort. Alternatives were prototyped including cylindrical, triangular, octagonal and dodecahedral, to challenge received wisdom, but it was assumed cylindrical would be selected. Through interacting with the prototypes, the children highlighted that profiles with edges were crucial for comfort, providing a more sustainable grip. Only through interacting with the prototypes was this ergonomic need uncovered, highlighting the importance of both prototyping and co-design, with sustained stakeholder involvement.

This project and research into other self-management tools identified a tendency for designers to align a product with one stakeholder over another or to compromise, with less than satisfactory results. In contrast, this project demonstrates the value of working with varied and sometimes contradictory perspectives to develop stronger outcomes that answer multiple needs. By addressing the main priority from each group, the stakeholders all felt validated in their contribution. This encouraged them to input on the other tools which didn't appear to answer their particular need. What began as four different tools addressing four separate priorities, became a suite of tools that had benefited from insights and decisions from every group. This co-design approach shows how the differences between people's opinions can be used to challenge potential solutions and create stronger design outcomes that take into account whole life impact.

Limitations

The findings of this project are not representative of the views of all stakeholder groups within JIA due to the limited number of healthcare professionals, families and teachers involved. In mitigation, the international response rate to online surveys within the JIA community during the project - 20 responses in 20 minutes – was indicative of a real need.

Conclusion

The co-design process of incorporating different stakeholders' opinions, and facilitating discussion around their individual issues throughout the design process, resulted in eliciting previously unknown or unexpressed needs and effective design outcomes to self-manage the condition as well as alleviating the whole life impact of JIA. The design decisions around each product thus relate directly back to the co-design involvement of all stakeholders.

This outcome of a suite of self-management tools aims to fulfil its purpose on a product level of improving activity and independence for children with JIA. It also aims to highlight on a more conceptual level, the value of stakeholder involvement, and how an initial lack of consensus should not be seen as a weakness, but as an opportunity to challenge potential solutions and thereby achieve more viable outcomes. Further funding is being sought between University and Hospital partners to continue developing the products collaboratively with children, families and clinicians.

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