

What do families think about using technology to manage a young person's health condition at home?

Patient and Public Involvement Report

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**Led by the
National Institute for Health and Care Research
HealthTech Research Centre in Paediatrics and Child health,
hosted by Sheffield Children's NHS Foundation Trust**

and

**National Institute for Health and Care Research
Great Ormond Street Hospital Biomedical Research Centre**

and

**Insigneo Institute at
University of Sheffield**

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Disclaimer

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Glossary of acronyms

CYP	Children and Young People
Eoi	Expression of Interest
NIHR	National Institute of Health and Care Research
NHS	National Health Service (based in the United Kingdom)
PPIE	Patient and Public Involvement and Engagement

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01 Executive summary

Investing in the health and healthcare of children and young people is an investment in our future. Early identification of and intervention in health problems of children and young people can address socioeconomic disparities later in life, and it is estimated that each £1 spent on children's health will return over £10 to society over a lifetime. As technology becomes increasingly integrated with all aspects of our lives, there is an urgent need to invest in the development of effective, sustainable, accessible health technologies for children and young people.

The NIHR Great Ormond Street Hospital Biomedical Research Centre, the Insigneo Institute, and the NIHR HealthTech Research Centre in Paediatrics and Child Health are working together to support four PhD candidates in developing new health technologies for children and young people across the following areas:

- New technologies to monitor breathing problems during sleep at home;
- Developing virtual reality for paediatric neurorehabilitation following cancer treatment;
- Technologies to support lifestyle behavioural changes in children and young people attending clinical settings; and
- Improving oxygen monitoring technology for infants and young children to reduce A&E attendances.

To ensure these students are equipped with a nuanced, empathetic understanding of the challenges across these areas, a Patient and Public Involvement and Engagement (PPIE) project was undertaken, as detailed in this report.

The project began with a literature review, supported by the Illingworth Library team at Sheffield Children's NHS Foundation Trust, around the topic of health technologies to manage long-term conditions in children and young people, and families' opinions and concerns around them. Following this, an online survey was conducted to validate and prioritise the initial findings of this literature review with children, young people, and their families who live with these challenges today, as well as identify any new issues. The survey was open to families who did and did not include children living with a long-term condition, with a high response rate from both communities. These findings were further explored in two in-person and one online workshops with children, young people, parents/caregivers, and professionals from healthcare and academia. The workshop format, using a range of creative tools in multidisciplinary groups, allowed for more nuanced discussion that considered multiple perspectives together, and created space for future-focussed, "blue-sky thinking" to inspire the PhD students further in their studies.

"Health technologies" covers a broad range of digital and non-digital technologies and devices, from apps to wearables, virtual reality, life-support equipment, and more. This is reflected in the results of this project, and as such some of the findings can be generalised whilst others are context-specific. Several key themes were present at each stage of the project, including the importance of usability, reliability of the technology and any information it provides, feedback on whether using the technology is having a positive effect or not, data privacy and security, and involving families in the design of the technology itself. Project participants (through the survey and/or the workshops) also highlighted the need to consider how the technology fits within the wider healthcare system, in addition to its impact on the home environment. Although the ability to stay together as a family at home was seen as a strong motivational factor for using healthcare technologies, as well as the ability to avoid missing school or work, researchers in this space should understand the impacts of altering the looks, sounds, and smells of the home environment, as well as the time it takes to use health technologies.

The lifespan of the technology is also important to consider, for example who is responsible for updating the device, maintaining it, and any waste management required. It was highlighted that sustainability is core to many young people's values, but that safety (i.e., infection control) must always come first.

The provision of high quality, tailored training was seen as important for both families and healthcare professionals. It was suggested that, as well as explaining *how* to use the technology, training could also explain *why* using the technology would be beneficial, and could address any assumptions and concerns families may have in advance, (i.e., "What if using this technology means I don't get to see my doctor as often?").

Accessibility was important to many participants in this project, and it was highlighted that new technologies should support neurodivergent users, those with physical and/or learning disabilities, and provide multiple language support. The ability to personalise how a technology looks and/or works could support this, particularly in being able to provide age and developmentally appropriate information that can be adjusted over time.

The cost of healthcare technologies and the risk of digital exclusion was also a key concern. Existing literature supports the need to improve the consistency and quality of healthcare services for all, and in relation to health care technologies, project participants challenged the assumptions that everyone has access to a reliable internet connection, unlimited data transfer and smartphones that have adequate processing power and storage for new apps, or the assumption that they can afford to keep technology charged consistently.

An interesting theme that emerged from the workshop discussions was the notion of health technologies as mediators of relationships, on multiple levels. On an individual level, it was suggested that young people could develop a stronger sense of ownership over their long-term condition, through technology-enabled ways of learning about their condition and how to manage it. On a group level, discreet and/or personalisable design could reduce the risk of health technologies interrupting how children and young people socialise with their friends, and online connectivity introduces the potential for peer support from children with the same condition.

Technology was seen as having great potential in the context of tracking symptoms and treatment schedules, particularly as young people get older and begin to learn skills in independent self-management and how to advocate for themselves in the transition to adult health services. However, in parallel to this, many young people also begin to want more privacy from their parents, and workshop participants suggested that some young people may choose to disengage from using health technologies if their parents have continued access to detailed data on their daily lives. On the other hand, parents felt that removing their access too early would also remove an important "safety net," particularly in the early stages of young people taking on responsibility for their own self-management. As such, new technologies in this area will need to support families in finding a balance between parental supervision and young people's independence as they transition into adult health services, and beyond.

For the next steps of this project, this report will be circulated to project participants for their review. Once any amendments have been processed, this report will inform the research of the PhD candidates in this programme, but will also be of value to the wider child health technology community.

02 Introduction

2.1 Why is child health so important?

Investing in the health of children and young people through the development of innovative medical technologies results in significant and lifelong benefits to the child and to society (Belli, Bustreo and Preker, 2022). There is growing evidence suggesting that intervening early and effectively in the health problems of children and young people can address socioeconomic disparities later in life (Currie and Stabile, 2003). It is estimated that each £1 spent on children's health will return over £10 to society over a lifetime and that poor health in childhood leads to reduced workforce participation and productivity and lowers national wealth. The UK has one of the highest birth rates and proportion of young people in Europe, and therefore investing in the health of young people is of paramount importance to the future productivity and wealth of the country.

Children and young people under the age of 18 make up 24% of the UK population and use around 11% of NHS resources; however healthcare and health research spending does not reflect this. There is evidence to suggest that studies involving adults are significantly more likely than paediatric studies to be randomised controlled trials, systematic reviews, or studies of therapeutic interventions. Such studies are widely viewed as being the gold standard of research, and so the lack of high-quality studies can have implications for the quality of care for children and young people, and for funding and future directions in clinical research (Martinez-Castaldi, Silverstein and Bauchner, 2008).

There is also a clear need for healthcare interventions that are currently in development to reflect the physical, psychosocial, and functional needs of children and young people. Historically, medical technologies used in paediatric services have been simply repurposed from adult technologies, and thus have not been well suited to the unique needs of this population (Dimitri et al., 2021). Instead of developing technology specifically for the paediatric population, false assumptions have been made that making the device smaller in size would make the device suitable. However, this does not take into consideration a whole host of factors which differentiates the needs of an adult with the needs of a child or young person. At best, the device is inferior compared to the adult device, and at worst, the device could be unsafe, leading to negative side effects and complications.

In the coming years it is part of the NHS long term plan that digitally enabled care will become mainstream across the NHS. Over the course of the last 30 years almost all aspects of modern life have been revolutionised by innovation and technology, with an expectation that novel technologies will continue to further reshape how the population will access public services. As part of the digitally native generation, it is crucial to the success of new digital health technologies that children and young people are involved at each stage of the development process.

As such, the NIHR Great Ormond Street Biomedical Research Centre, the Insigneo Institute, and the NIHR HealthTech Research Centre in Paediatrics and Child Health are working together to support four PhD candidates in developing new health technologies for children and young people. To ensure these students are equipped with a nuanced, empathetic understanding of the challenges in this area, a Patient and Public Involvement project was undertaken, as detailed in this report.

2.2 Who are the NIHR Great Ormond Street Hospital Biomedical Research Centre?

NIHR Biomedical Research Centres (BRCs) are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies.

The NIHR Great Ormond Street Hospital BRC is a collaboration between Great Ormond Street Hospital NHS Foundation Trust and the University College London Great Ormond Street Institute of Child Health. They are the only NIHR-supported BRC solely focusing on paediatric research. They provide cutting-edge facilities and world-leading expertise and access to over 200 rare disease patient populations allowing NHS, university, and industry collaborators to conduct pioneering translational research into childhood illnesses.

For more information, please visit: <https://www.gosh.nhs.uk/our-research/our-research-infrastructure/nihr-great-ormond-street-hospital-brc/>.

2.3 Who are the Insigneo Institute?

The Insigneo Institute is a collaboration between the University of Sheffield, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Children's NHS Foundation Trust, and Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust.

Established in 2012, the institute has built a strong multidisciplinary network of 300 academics, researchers, and clinicians, who bring together expertise in biomedical imaging, healthcare data, computational modelling, and digital healthcare technologies.

For more information, please visit: <https://www.sheffield.ac.uk/insigneo>.

2.4 Who are the NIHR HealthTech Research Centre in Paediatrics and Child Health?

NIHR HealthTech Research Centre (HRC) in Paediatrics and Child Health is one of 14 HealthTech Research Centres funded by the NIHR. The HRCs are hosted by a number of NHS trusts around the country and each works alongside clinical teams, academics, businesses, and service users to support the development of new medical devices, healthcare technologies, technology dependent interventions, and in-vitro diagnostics for the NHS. The NIHR HRC in Paediatrics and Child Health is the only HRC dedicated to the health and wellbeing of children and young people.

Within the paediatric health space, the NIHR HRC in Paediatrics and Child Health focuses on the adoption and commercialisation of health technologies for children and young people across the early life course (0-25 years). Their portfolio is guided by 5 themes that are amenable to medical technology development. These 5 themes are: Early Life, Long-Term Conditions; Transition; Mind-Body Integration; and the Child Health AI Network. Each theme is led by experts and dedicated clinicians, all with intimate knowledge of NHS pathways, who provide oversight and direction to the work conducted within the HRC.

The NIHR HRC in Paediatrics and Child Health has a strong track record in working alongside clinicians, children, young people and families to support meaningful, sustainable innovation. The team are also passionate in advocating for the specific needs of children and young people, not just

as ‘little adults,’ but as unique individuals with their own challenges, hopes, goals, experiences and opinions.

The NIHR HRC in Paediatrics and Child Health led on this PPIE project in collaboration with the teams listed above.

For more information, please visit: <https://hrc-children.nihr.ac.uk/>.

2.5 Aims of this report

The NIHR HRC in Paediatrics and Child Health, NIHR Great Ormond Street Hospital BRC and the University of Sheffield Insigneo Institute are working together to support four PhD students focused on developing novel technologies for paediatrics and child health.

The PhD topics were decided collaboratively with the networks of the project partners, whereby clinicians and academics were able to submit an Expression of Interest (Eoi) form outlining potential PhD topics in this area and the types of support their institution could provide. These Eoi's were then discussed in multidisciplinary sandpit workshops (involving healthcare professionals, academics and representatives from each of the partner organisations) to refine the scope and identity opportunities to combine topics. Finally, the shortlist of PhD topics were circulated for review with the project partner teams, leading to the final 4 themes, with plain English summaries, listed below:

- New technologies to monitor breathing problems during sleep at home:
- There is a current lack of technologies that allow complex monitoring and assessment of children's sleep at home. This project aims to develop a new wireless monitoring and automatic analysis system that can accurately diagnose sleep disordered breathing in a home environment. Developing virtual reality for paediatric neurorehabilitation following cancer treatment:
 - Many young people struggle with severe long-term side effects following cancer treatment but current access to paediatric neurorehabilitation in the NHS is limited. This project aims to develop novel virtual reality that can offer a promising alternative to conventional therapies by enabling patients to access engaging and effective neurorehabilitation from home.
- Technologies to support lifestyle behavioural changes in children and young people attending clinical settings:
 - One in four children and young people undergoing surgery in the UK are currently overweight or obese, and are therefore at an increased risk of complications. Services such as the excess weight clinic offer specialist support to help children and young people reach a healthy weight before surgery, to reduce risks and improve outcomes. This project aims to create new digital tools to support and extend these existing services.
- Improving oxygen monitoring technology for infants and young children to reduce A&E attendances:
 - Measuring oxygen levels in young children and infants in primary care is important for assessing whether they need to be referred to a hospital specialist. However, the current technology is limited and often leads to unnecessary diagnoses and over-admissions of children to hospital. This project aims to develop a novel method of accurately monitoring oxygen levels in infants and young children to improve clinical decision-making.

PhD candidate applications were welcomed from across the world, from a diverse range of disciplinary backgrounds. It was important to all of the project partner teams that the successful

applicants have a clear understanding of the importance, and value of, involving children, young people, and families. As such, the PPIE project described in this report aimed to understand the needs, experiences, and preferences of families who use health technologies, whilst also upskilling the PhD candidates who were already in post ($n=2$). The priorities identified in this project will be important to inform the research of the PhD candidates in this programme, but will also be of value to the wider child health technology community.

03 Methodology

3.1 Introduction

In this project, multiple approaches were taken to include stakeholders with a broad range of backgrounds and disciplines, including healthcare, academia, industry and, crucially, children, young people, and their families and carers. This involved reviewing existing literature, running online surveys, and conducting in-person workshops.

The findings from each stage of the project were used to inform the next, as well as being useful in their own right. An overview of the project process is given below, with more details on the methodology of each stage given in the following chapters.

3.2 Literature review

A literature review around the topic of health technologies to manage long-term conditions in children and young people, and families' opinions and concerns around them, was undertaken with support from the Illingworth Library at Sheffield Children's NHS Foundation Trust.

As well as this being a practically useful first step in the project (developing an overview understanding of the relevant published literature to avoid duplication of effort), there are also ethical elements to reviewing existing literature prior to any involvement of children, young people, and their families. Through this literature review, and discussions with healthcare professionals in their networks, the HRC team could familiarise themselves with the key issues in this area (reducing the burden on families needing to explain common issues) and potentially sensitive topics (so that the team could facilitate in-person sessions safely and with compassion).

3.3 Survey

The online survey aimed to compare the lessons from the literature review, as well as the professional experiences of the NIHR HRC in Paediatrics and Child Health, alongside the experiences and ideas of children, young people, and their parents/caregivers.

This approach was useful in engaging families from across the UK equally, and was also important in providing a contemporary viewpoint in contrast to the published literature (since there can be a gap between conducting research and publishing the findings). This is particularly relevant in fast-paced contexts such as health technology development.

Moreover, the structure of the survey provided an opportunity for families to prioritise the previously identified issues in this context, as well as to add new emerging issues, which shaped the final stage of this PPIE project.

The equal involvement of families both *with* and *without* experience of managing long-term health conditions in children was also important in understanding the unmet needs in this space, as well as the assumptions of those who may come to use child health technologies for the first time.

3.4 Workshops

Two in-person workshops and one online workshop aimed to bring multidisciplinary groups together to explore the findings of the project so far, adding depth to them through discussion of their own expertise and experiences. Creative methods (such as 'board games') were useful to compare and reflect on participants' (sometimes differing) priorities, and working together to create "blue sky" solutions for the future deepened our collective understanding of today's unmet needs.

As mentioned in section 2.5, this stage was also an important first opportunity for the PhD candidates already in post ($n=2$) to learn and practise their skills in facilitating PPIE sessions.

3.5 Dissemination

This report will initially be shared with the wider project team, as well as the families and professionals who have contributed to the work so far, for their review. Once requested edits and/or additions have been made, this report will be used as an educational resource for the project partners.

04 Literature Review

4.1 Introduction

In preparation for the workshops, the NIHR HRC in Paediatrics and Child Health team conducted a brief review of current research around the opinions and concerns of children and young people with a long-term condition using technology to manage their health at home by examining relevant research publications identified through a library literature search.

4.2 Methods

A literature search was carried out with the support of Illingworth Library, Sheffield Children's NHS Foundation Trust. To assist in their search, the library team requested the following information:

4.2.1 The 'Clinical Question':

What are the opinions and concerns of children and young people with long-term health conditions and their parents/carers about using technology to monitor their health conditions at home, including issues regarding health inequalities and digital exclusion?

4.2.2 Background to the search:

The NIHR HRC in Paediatrics and Child Health is working in collaboration with the Great Ormond Street Hospital BRC and Insigneo Institute to offer four funded PhD places. PhD projects will focus on the use of technology to monitor the long-term conditions of children and young people outside of hospital. Projects will also explore health inequalities and digital exclusion that could be exacerbated by technology. The results of this search will inform the team on the opinions and concerns of children and young people, and their families prior to PPIE work to ensure work in this area is not duplicated.

4.2.3 Key words:

Innovation, medical technology, medtech, home monitoring, digital, sensor, wearable, app, health inequalities, digital exclusion.

4.2.4 Date articles published:

01/01/2013 - date of review (27/10/2023).

4.2.5 Age categories to include:

Infant (to 1 year); Child (unspecified age); Preschool child (1 to 6 years); School child (7 to 12 years); Adolescent (13 to 17 years); Adult (young adults).

4.2.6 Extent of review i.e. how many references are expected/needed:

A comprehensive search of healthcare databases (approximately 20 to 40).

4.2.7 Resources used:

Medline, Google, Embase.

4.3 Review Results

4.3.1 Overview findings

Based on the above criteria, the library team identified 12 articles, with very few quantitative studies included. Each article was examined and presented to the NIHR HRC in Paediatrics and Child Health team for discussion based on the criteria below:

- Aim
- Key findings
- Strengths
- Limitations
- Methodology (i.e., quantitative, qualitative, mixed methods)
- Publication type (i.e., research article, review, web piece, etc)
- Relevance (i.e., Is this applicable to children, young people, and their families using technology to manage a long-term condition outside of the hospital? Does it consider health inequalities and/or risk of digital exclusion? Does it evaluate the opinions of relevant stakeholders such as children, young people, families, healthcare professionals, and so on?)

The table below shows the overall summary of each article identified through the literature search, alongside the evaluation from the NIHR HRC in Paediatrics and Child Health team.

	1	2	3	4	5	6	7	8	9	10	11	12	13
Publication type	Web piece	Review	Review	Journal article	Journal article	Journal article	Review	Review	Review	Journal article	Journal article	Journal article	Web piece
Methodology	Qual	Qual	Qual	Qual	Qual	Qual	Qual	Qual	Qual	Qual	Qual	Qual	n/a
Publication date	2023	2022	2023	2023	2022	2022	2021	2020	2020	2019	2018	2017	2015
Investigates use of technology to monitor LTC outside hospital	×	X	×	X	✓	X (not at home)	✓	X	✓	X	✓	✓	✓
Specific to CYP / families	×	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓ Mentions CYP at the end
Evaluates opinions of patients?	✓ Not CYP	X	✓ Indirectly & not CYP	✓ Parents	✓ CYP & parents	X	✓ Indirectly CYP & parents	✓	✓ CYP & parents	✓	✓ CYP & parents	✓	✓ Indirectly
Evaluates opinions from HCPs?	✓	X	✓	X	×	X	✓	X	X	X	✓	X	X
Considers health inequalities / digital exclusion?	✓	✓	✓ indirectly	X	✓ Considers this as limitation of the study	X	✓ Considers this as limitation of the study	X	✓ Considers this as limitation of the study	✓	✓ Considers this as limitation of the study	X	✓

Table 1: Overview of publications identified through the literature review. Please note that the abbreviation “CYP” refers to “Children and Young People,” and “Qual” refers to “Qualitative.”

“Health technologies” covers a broad range of digital technologies and devices, and this is reflected in the studies identified in this review. Some studies have focussed on apps and devices that can support existing treatment and care pathways, for example providing additional information and self-management support of long-term conditions. Within these studies, the preferences and challenges of such devices have been explored, with recommendations to involve children and young people in their design and development. On the other end of the scale, the experiences of those using, and living with life-saving equipment for technology-dependent children should be considered, and the impacts of this technology on the concept of “home,” when it is used in the family home environment.

The key findings of the studies identified in this review are summarised below, with a bibliography available in Appendix 1 for further information.

4.3.2 What do young people want from technologies to support living with long-term conditions?

In a scoping review to identify children and young people's concerns and needs relating to their use of health technology to self-manage long-term conditions [9], it was identified that children and young people's main concerns were: labelling and identity; accessibility; privacy and reliability; and trustworthiness of information. Within the recommendations from this review, it was highlighted that research should involve children and young people throughout the development of technology, from identifying their unmet needs through to design and evaluation of interventions.

As children with long-term conditions get older, many wish to begin developing their independent self-management of their condition(s) and technology can provide a key role in supporting this. In a different scoping review identifying primary research investigating digital technologies for children and parents sharing self-management in childhood chronic illnesses [7], three themes were identified including: the feasibility and acceptability of using technology; the usability of technologies; and the effect of technologies on adherence and self-management skills.

4.3.3 Digital health apps

Mobile health apps, also known as mHealth apps, also strongly featured in the literature review results. A scoping review aiming to map and categorise the evidence on problems and barriers related to the use of mHealth apps [2] identified 10 categories ("validity," "usability," "technology," "use and adherence," "data privacy and security," "patient-physician relationship," "knowledge and skills," "individuality," "implementation," and "costs"). The most commonly-occurring categories were "use and adherence" (i.e., incorporating the app into daily life or dropouts from use) as well as "usability" (i.e., ease of use and design). Whilst usability is a common topic of research and development in app design, the authors urged researchers and policy makers to have a special focus on problems at a systematic level, and the need for quality assurance guidelines in this area.

In a separate study, mHealth apps were seen as a potentially positive way for young people with juvenile idiopathic arthritis to self-manage their condition. These young people felt it would be important for potential new mHealth apps to help them feel a sense of ownership and control, and that they should be an interactive, engaging resource that offers developmentally appropriate information and reminders, as well as enabling them to monitor their symptoms and access social support.

4.3.4 Impact of health technologies at home

Whilst health technologies can play an important role in allowing children with long-term conditions to live well at home, it must be acknowledged that the presence of, and need for, these technologies can have a significant impact on the child/young person as well as the family members living with them.

A Canadian study [4] explored this, conducting 14 semi-structured interviews with family caregivers (FCs) of children with medical complexity who are initiated on new medical technology in the hospital and transition to new daily life at home. Three key themes were identified: FC's response and readiness for medical technology use; the value of education and transition support for the initiation of new medical technology; and the challenges associated with managing new medical technology at home. FCs reported that, although theoretical and hands-on practice training instilled confidence in families, they felt overwhelmed when they transitioned home with new medical technology, feelings which can be compounded by significant psychological, emotional, and financial challenges while caring for their technology-dependent child. As such, the authors highlighted the need to implement a comprehensive education and transition programme that provides longitudinal support for all aspects of care.

In another study, young people and family members who have medical technologies at home were asked to take photos of meaningful areas of their home, followed by semi-structured interviews to discuss these photographs and their experiences relating to them [5]. Whilst some aspects of technology use were negative, such as altered looks and sounds of the home, families highlighted that it was worth it if it allowed the child to be at home, allowing them to stay together as a family.

Some larger, particularly medical looking technologies (for example, ventilators) can be upsetting for family members to see in the home environment, and for some parents, can highlight the differences and additional challenges their child faces compared with other children [13]. Whilst acknowledging that many caregivers prioritise being able to staying as a family together at home above any other challenges [5], it is important to remember that caring for technology-dependent children at home also brings significant challenges to the caregivers, many of whom reduce their working hours or leave their job to care for their child, as well as experience increased anxiety, exhaustion, and burnout [13]. It has previously been highlighted that, in such situations, women experience a disproportionate burden of caregiving.

4.3.5 Digital exclusion

In relation to reducing the risk of digital exclusion in digital health and care services, The King's Fund [1] ran several workshops with health service users, identifying the importance of "fixing the fundamentals," structuring services around people's needs and preferences, and improving the quality and consistency of services.

4.4 Conclusion

The term 'health technologies' can cover a broad range of digital interventions and devices, from apps to life-saving equipment, and as such some findings and priorities will be context-specific. Nevertheless, some key issues were found within the existing literature, including usability (on an individual user basis, as well as considerations within a wider healthcare system), reliability, accessibility, trustworthiness of information provided, and data privacy. The potential cost of new technologies, and potential challenges of implementation, have been raised as concerns, as well as potential impact on the concept of "home," although it has also been suggested that many families feel many challenges will be worth it to remain as a family together at home.

The literature review also raised the need to improve the quality and consistency of healthcare services to address issues of digital exclusion, and the need for good training for families in how to use new health technologies successfully.

The literature suggests that successful health technologies have the potential to support symptom monitoring and relationships between patients and healthcare professionals. To improve the efficacy of health technology design, some authors suggest that children, young people, and families should be involved in the design process (although literature on how to achieve this is limited).

05 Survey

5.1 Introduction

To complement the findings of the initial literature review, the NIHR HRC in Paediatrics and Child Health developed an online survey to further explore the opinions of young people who do, and do not, have a long-term health condition, and their parents/caregivers. The survey aimed to gain a better understanding of what families think about using technology to manage health conditions of children and young people outside of hospital settings, and questions were tailored according to which group the respondent belonged to.



To extend its demographic reach, the NIHR HRC in Paediatrics and Child Health worked with the GenerationR Alliance Young People's Advisory Groups (YPAG) network to distribute the questionnaire. The GenerationR Alliance YPAGs are funded by the NIHR and/or NHS organisations, and support the design and delivery of paediatric health research in the UK.

5.2 Response demographics

The survey received 32 responses, with the majority completed by young people who did not have a health condition, as shown in figure 1 below.

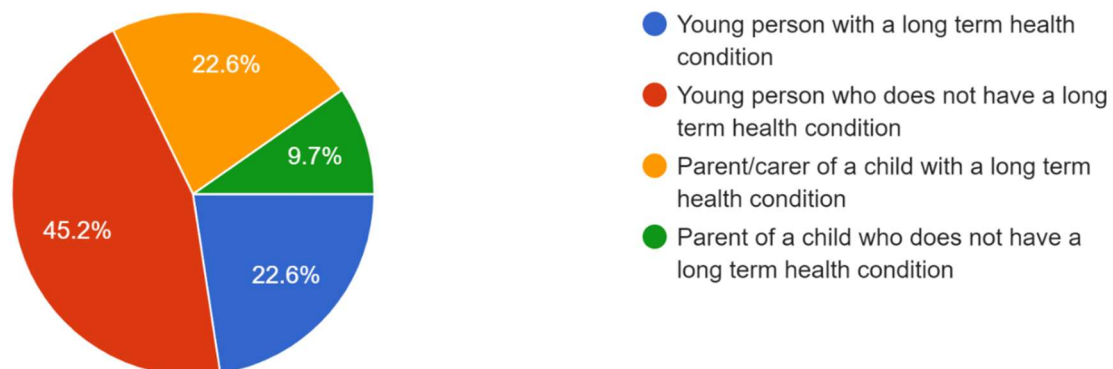


Figure 1: A pie chart showing the distribution of responses across the 4 participant groups.

	Young person with a long-term health condition	Parent/carer of a child with a long-term health condition	Young person who does not have a long-term health condition	Parent/carer of a child who does not have a long-term health condition
Total number of respondents	8	7	14	3
Age	12-15 years (n=3); 20-25 years (n=3)	12-15 years (n=4); 16-19 years (n=3)	12-15 years (n=6); 16-19 years (n=6)	12-15 years (n=2)
Gender	Female (n=6)	Female (n=5)	Female (n=10)	Female (n=3)
Do you currently use any technology to manage your health condition?	"No" (n=5); "Yes - at least once a day" (n=1); "Yes - at least once a week" (n=1); "Yes - at least once a month" (n=1)	"No" (n=5); "Yes - at least once a day" (n=1); "Other - To communicate with the hospital" (n=1);		

Table 2: Overview of survey respondent demographics.

Some of the long-term conditions experienced by young people included asthma, juvenile idiopathic arthritis, metabolic disorder, connective tissue disease, spina bifida, organ transplant, chronic pain disorders, and more.

5.3 Survey results

An overview of the survey results is given below, with a more detailed summary available in Appendix 2, and full survey data available to the PhD candidates.

5.3.1 Why do you think families might like to be able to manage the health conditions of children and young people at home?

Families including children with a long-term health condition	Families not including children with a long-term health condition
For parents/carers, priorities were allowing the child to avoid missing as much school and for them to avoid missing work as frequently. Both parents/carers and young people highlighted the potential to learn more about their child's long-term condition and be more involved in	Similarly, parents/carers suggested the opportunity to learn more about their child's long-term health condition, and how to manage it, might be a driving factor, whilst young people prioritised being able to spend more time as a family at home.

managing it.

5.3.2 What do you think would make it easier for families to use technology to manage health conditions of children and young people at home?

Families including children with a long-term health condition	Families not including children with a long-term health condition
Parents/carers suggested that being able to personalise how the technology looks/works would be important, and young people highlighted the importance of ease of use. Both parents/carers and young people felt it would be important to involve families in the design of the technology.	Both parents/carers and young people also selected ease of use and involvement of families in the design of the technology as priorities. In addition, young people felt it would be important to know that any information provided by the technology is trustworthy.
Access to good training on how to use the technology was also a priority for all groups.	

5.3.3 What do you think would make it harder for families to use technology to manage health conditions of children and young people at home?

Families including children with a long-term health condition	Families not including children with a long-term health condition
All respondent groups chose “not having enough internet data to use the technology” as a key factor in making health technologies harder to use, as well as unreliability and expense. In addition, families with experience of long-term health conditions highlighted that young people might want more privacy about their health condition as they get older.	

5.3.4 Is there anything that might stop you from trying a new technology to manage a child's health condition at home?

Families including children with a long-term health condition	Families not including children with a long-term health condition
All groups, to varying levels of priority, raised concerns over whether using a new health technology might mean they see healthcare professionals less often. Concerns over data privacy (i.e., how data is stored and who has access to it) was also raised by most groups, but rated more important by families with experience of a long-term health condition.	

5.3.5 How important do you think it is that young people can learn to use the technology by themselves as they get older? Give a reason for your answer

Young person with a long-term health condition	Parent/carer of a child with a long-term health condition	Young person who does not have a long-term health condition	Parent/carer of a child who does not have a long-term health condition
Average score: 4.71/5	Average score: 5/5	Average score: 4.43/5	Average score: 5/5
Respondents stressed that responsibility is an important part of growing up and living with their conditions, as well as the transition to adult healthcare services. One respondent felt that a reporting tool would help them track their own condition and give accurate information to their clinical team.	Respondents felt it was important for young people to have some independence, and to be able to advocate for themselves as they get older, so learning to use the technology would be key in this. One respondent highlighted that use of/reliance on artificial intelligence may hinder young people learning important interpersonal skills.	Respondents felt that becoming more independent was important for young people, especially as they start to spend more time away from their parents, holiday without them, and perhaps move out. Some suggested that it is important to not feel reliant on other people as you grow older, and this is important for the wellbeing of the carer as well as the young person.	Respondents stated that young people will need to become independent at some point, and it would be beneficial to prepare early in case anything happens to their carers and they must take more responsibility unexpectedly.

5.3.6 Is there anything else you'd like to share with us about using technology to manage the health conditions of children and young people at home?

Several respondents used this section to reiterate the importance of health technologies being easy to use, and that training is offered for both staff and families to avoid incorrect use and/or overburdening staff. Accessibility was also raised, making sure those who live with neurodivergence and/or disabilities, such as blindness, deafness, and dyslexia are equally able to use the technology, as well as making sure multiple languages are supported.

Other suggestions included being able to personalise the depth and complexity of any information that is provided based on the age of the child or young person, and ensuring there is a parent account available for younger patients.

5.4 Conclusion

The survey received a good response rate, particularly considering that this particular activity did not offer an incentive (i.e., voucher). Of the young people who responded, nearly twice as many did not have experience of a long-term condition compared with those who did, suggesting that the development of health technologies for young people is of interest to young people more widely.

Some of the responses to the survey corroborated earlier findings from the literature review. For example, families with experience of a health condition agreed that technologies had the potential

to support young people in learning about their condition, and those without experience of a health condition imagined that the ability to spend more time together as a family at home would be a strong incentive for health technology use. All families supported previous findings that ease of use, reliability, and involving families in health technology is important, and raised similar concerns of costs and around data privacy (although the latter was rated more important by families with experience of a long-term health condition).

Whilst the literature suggested a need for good training for parents in how to use life-support technology, the survey responses added to this further, suggesting that training is important for *all* types of health technologies, for the families *as well as* for the staff.

Compared with the existing literature, families with experience of a long-term condition showed a stronger focus on increasing young people's involvement in their condition management, as well as personalisation of how the technology looks and works, and a desire to avoid missing time in school (for the child/young person) or work (for the parent/caregiver).

Other suggestions included being able to personalise the depth and/or complexity of any information that is provided by the technology based on the age of the child/young person, and ensuring there is a parent account available for younger patients. Accessibility was also discussed more generally, in terms of neurodivergence, disabilities, language support, and whether or not a family has consistent, reliable internet access.

The topic of privacy was discussed in more detail in the survey responses compared with the literature. Respondents suggested that young people often want more privacy as they get older, highlighting instances where young people start to experience this (i.e., going out with their friends, holidays, etc). All respondents agreed that young people being more involved in their long-term condition management as they get older is important, and that health technologies could support this process (as suggested in the literature review findings, see section 4). The survey results highlighted further how this could support a positive and successful transition from paediatric to adult health services, which would be important for both young people and their parents/caregivers. Young people also suggested that technology could support them in providing accurate information to clinicians, and parents highlighted the need for young people to learn skills in advocating for themselves. Whilst technology could support this, several respondents suggested that they would be concerned over whether using such technologies might mean they see healthcare professionals less often.

06 Workshops

6.1 Introduction

To further develop and expand on the findings to date, two in-person workshops were organised: one at the University of Sheffield, Sheffield, and one at the University College London Great Ormond Street Institute of Child Health, London, in Spring 2024. The workshops aimed to equip attendees with the findings from the project to date, and provide the time, space, and tools to “play with” these findings in multi-stakeholder groups alongside their own knowledge and experience (see Langley et al., 2020).

6.2 Recruitment

The workshops were open to young people with experience of a long-term condition, and up to three other family members, as well as professionals from healthcare and academia in the child health technology space. Digital recruitment flyers (such as the leaflets shown in Figures 2 and 3) were circulated through NIHR HRC in Paediatrics and Child Health professional networks, the professional networks of project team members, youth forums at Sheffield Children’s NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust, and the Great Ormond Street Young Person’s Advisory Group.

Young people and their family members were offered travel expenses and a £20 Amazon voucher to thank them for their time, and all participants were offered lunch and refreshments as part of the workshop. Young people attending the workshop were also offered a certificate of participation and personalised letter of recommendation on request.



Figure 2: The digital recruitment flyer for children, young people and their family members.



Figure 3: The digital recruitment flyer for healthcare professionals.

There was a positive response to the recruitment for these workshops, with 56 registrations (excluding facilitators), 22 of which were children, young people, and/or family members and carers. Several participants were unable to attend due to clinical commitments or illness, leading to 42 attendees (12 of which were children, young people, and/or family members and carers) across the two in-person and one online workshops.

The families attending had a diverse range of experiences of long-term conditions and disabilities, including cerebral palsy, chronic lung disease, brain injury, and chronic migraines. Several young people used wheelchairs and/or had additional carer support (with non-verbal communication, feeding tubes, and ventilation via tracheostomy).

6.3 Workshop plan: In person

6.3.1 Set up and introductions

To allow for an informal and flexible arrival time at both venues, the half-day workshops began with a buffet lunch. Standalone, individually-led activities were available as a way of meeting other attendees if they came alone, such as the “Talking Wall.” Here, prompt questions were displayed on a blank wall or table (such as “One piece of advice I would give to families who use child health technologies is...”), and participants were invited to use post-it notes to add their responses and/or build upon the additions of other participants.

The workshop spaces were set up to encourage participants to self-sort into small mixed groups, with materials to support the upcoming activities (i.e., coloured pens, post-its, etc) available, as shown in Figure 2 below.



Figure 4: Set ups for the two workshops.

6.3.2 How to conduct board game 1: “What do you think would make things **easier** for families to use technology to manage health conditions at home, or in the community?”

When we were ready to begin, the workshop began with introductions to the project, the workshop plan, and each other. This included some background information on what a PhD is, to ensure all participants understood the context of the project and how they were contributing.

For the first activity, each table was given their first board game “kit.” The kit contained an A3 board, as shown in Figure 5 as well as a small envelope containing green cards, as shown in the examples in Figure 6.

The board is a large rectangular grid with a green header and a light blue left margin. The header text is: "What do you think would make it **EASIER** for families to use technology to manage health conditions at home, or in the community?". The left margin contains three icons of people and three upward-pointing arrows, with text labels: "Could affect a lot of people" (top), "Could affect some people" (middle), and "Could affect just a few people" (bottom). The main grid has three columns labeled "Very important", "Important", and "Slightly important" from left to right.

	Very important	Important	Slightly important
Could affect a lot of people			
Could affect some people			
Could affect just a few people			

Figure 5: The board used to support participants in considering “What do you think would make things easier for families to use technology to manage health conditions at home, or in the community?”

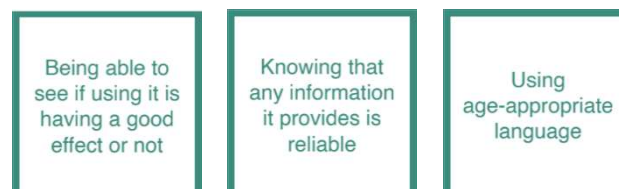


Figure 6: Examples of cards used in the first board game activity.

The aim of this “game” was to collectively discuss and decide the best place for the cards according to their priorities for developing new child health technologies. Participants were encouraged to consider the two axes of the board: 1) how **important** each card might be to help families use health technologies at home; and 2) **how many people might be affected** by it, as explained in Figure 7.

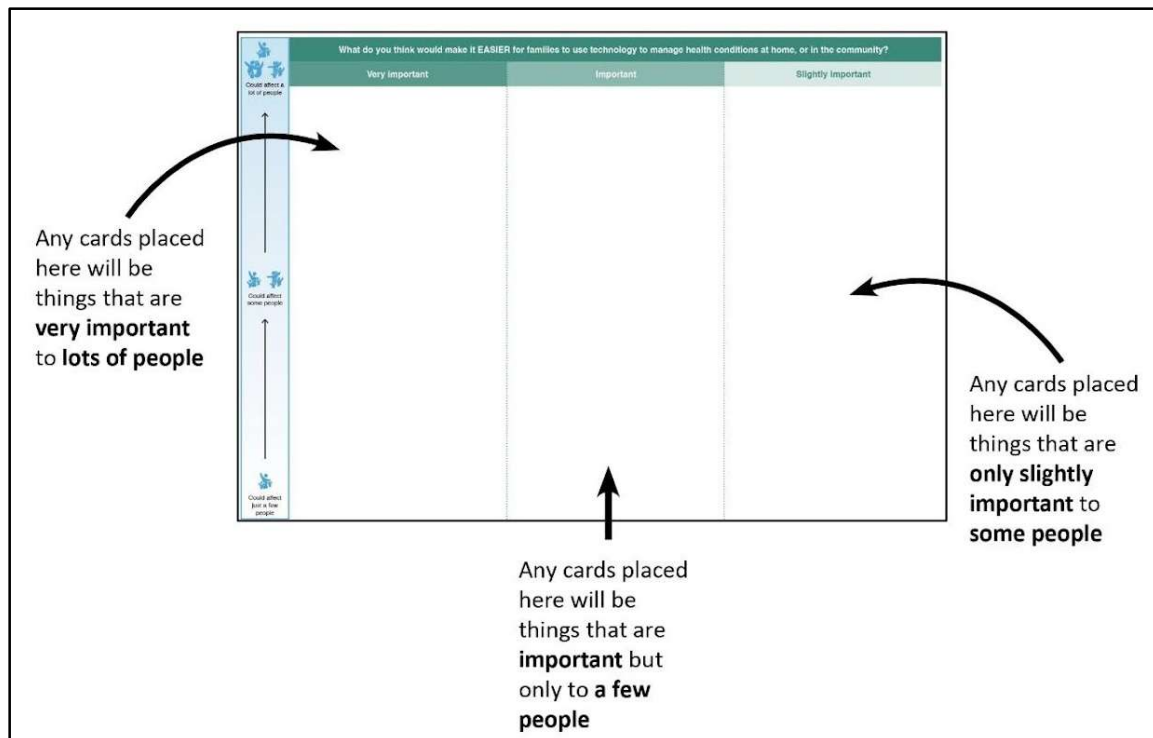


Figure 7: An explanation of how the cards could be placed on the board.

Participants were reminded that there were no right or wrong answers, and that differences of opinion were constructive. A facilitator was available on each table to support and take notes of the discussions. If needed, each “kit” contained some blank cards, for participants to add new ideas as they emerged.

6.3.3 How to conduct board game 2: “What do you think would make things **harder** for families to use technology to manage health conditions at home, or in the community?”

Once the first board games were completed, each table was invited to share 2-3 key points from their discussions with the rest of the group, so that participants were able to learn from others outside of their working group.

Next, participants were asked to complete a similar board game, but this time looking at the factors that would make it harder for families to use health technologies at home, as shown in Figures 8 and 9.

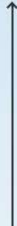
 Could affect a lot of people   Could affect some people   Could affect just a few people	What do you think would make it HARDER for families to use technology to manage health conditions at home, or in the community?		
	Very important	Important	Slightly important

Figure 8: The board used to support participants in considering “What do you think would make things harder for families to use technology to manage health conditions at home, or in the community?”



Figure 9: Examples of cards used in the second board game activity.

6.3.4 Reflecting on answers

Next, participants were invited to reflect on their answers so far from the perspectives of other people (i.e., by adding “new players” to their game). To support this, each table was given some additional materials to help them consider families from different backgrounds and circumstances, as well as the multiple areas of a child’s life that are important to them, as shown in Figures 10 and 11 respectively. These materials added further depth to the discussions on each table, and in some cases the moving and/or adding of new tiles to the boards.

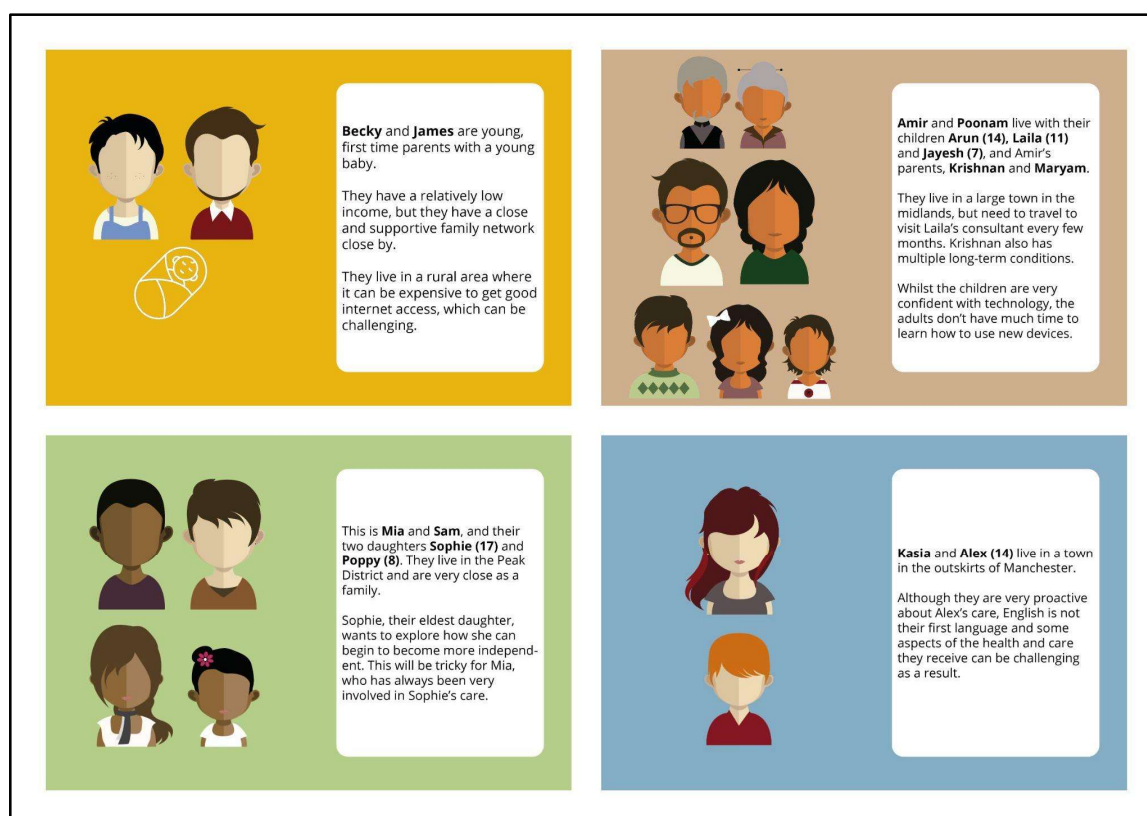


Figure 10: Personas of fictional families, to support workshop participants in considering the needs and preferences of others.

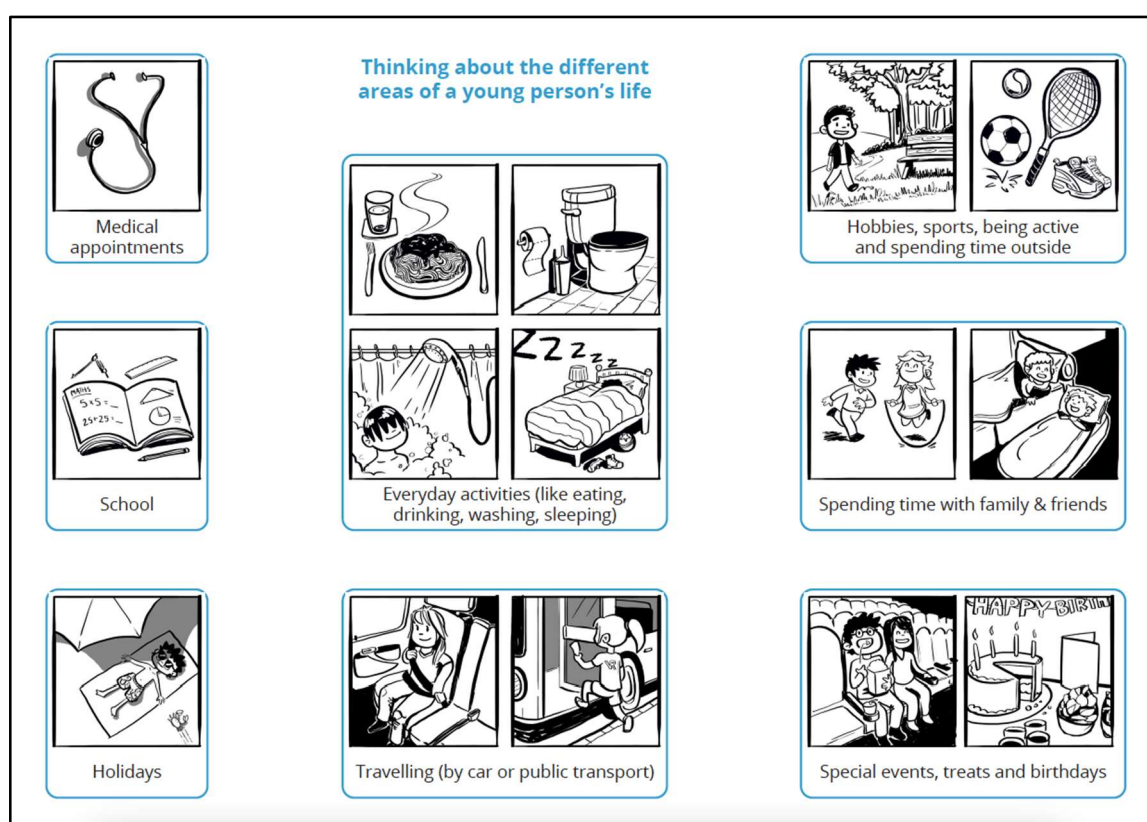


Figure 11: An illustration of the multiple areas of a child's life that may be affected by their long-term condition and/or health technologies.

6.3.5 Ideation

After a break, participants were guided through some creative warm up activities, then invited to generate as many ideas as they could related to the four PhD topics. Each participant was then given a strip of five gold star stickers, which they could use to 'vote' on their favourite ideas. These top scoring ideas were then shared with the wider group.



Figure 12: Participants voting on their favourite ideas.

6.4 Workshop plan: Online

Unfortunately, on the day of the in-person workshops, some participants were unable to attend. One family who was unable to attend due to illness expressed a strong interest in participating in the project another way, if possible. As such, the workshop plan was adapted to accommodate an individual online session at a later date with this family.

To support the online workshop, a postal pack of the two board game activities was sent to the family. This included an introductory letter explaining the context of the project, a “kit” for both board games, and step-by-step instructions of how to complete them.

After the family had time to complete the board games together at home, a one-hour online workshop was arranged with one NIHR HRC in Paediatrics and Child Health facilitator to discuss the factors they had identified as important. It was also a chance to share the results of the workshops with this family, to support mutual learning from other families and healthcare professionals.

6.5 Summary of workshop findings

The workshop activities were understood and successfully completed at all workshops, and conversations were not hindered by hierarchies or disciplinary boundaries. Indeed, in many cases the young people led the discussions within their small groups.

Participants engaged well with the “board game” activity, which stimulated lively discussions, identifying differing perspectives and the reasons behind them. Some examples of the completed boards are shown in Figure 13, with the full set available in Appendix 3. An overview of the results of the board games are given in the following section, followed by a summary of the key new insights in the discussions during these activities. A more detailed description of these discussions is provided in Appendix 4.



Figure 13: Several examples of the board games used to prioritise factors that can support or challenge uptake and efficacy of health technologies. Full scans of the completed board games are available in Appendix 3.

6.5.1 Board game results: “What do you think would make things **easier** for families to use technology to manage health conditions at home, or in the community?”

As can be seen in the examples above, participants did not choose to rate many factors in the low importance, low impact section of the board.

The factors identified in the high priority, high impact, section of the board (the top left corner) are listed below, with the number of times that factor was prioritised by different working groups across the three workshops given in brackets.

- Making sure the technology is easy to use (7)
- Knowing that any information it provides is reliable (6)
- Good training on how to use the technology (5)

- *Training that is fast for teachers, etc* (1)
- The technology is available in lots of languages (5)
- Involving families in the design of the technology (5)
- Being able to see if using it is having a good effect or not (4)
- Using age-appropriate language (3)
 - *Using developmentally appropriate language* (1)
- Managing expectations of what the technology can do (2)
- Make it “fool-proof” so you can’t use it incorrectly (2)
 - *Doesn’t add additional burden to families (e.g., time consuming, large and clunky, etc)* (1)
 - *Must be safe* (1)
 - *Help and support system* (1)
- Being able to personalise how the technology looks or how it works (1)
- Reminders to use the technology (1)

6.5.2 Board game results: “What do you think would make things **harder** for families to use technology to manage health conditions at home, or in the community?”

The following factors were identified as having the potential to have a large impact on a large population when introducing new health technologies:

- It’s unreliable (8)
- It’s expensive (8)
- It feels like too much pressure to get it right (3)
- Young people might want more privacy about their health condition as they get older, which might be hard if parents/carers can still see and use the technology (3)
- Not wanting other people to know about the technology (e.g., school friends) (3)
- Not having enough internet data to use the technology (3)
- Managing expectations of what the technology can do (2)
- It’s boring to use after a while (2)
- Is it long-lasting, or does it create waste? (2)
- The technology “taking over” the house (e.g., if it was too big, or too loud) (1)
- Having to charge the technology (1)

6.5.3 Summary of new insights from workshops discussion

The workshop format, with a range of creative tools and multidisciplinary groups, allowed for more nuanced discussion that considered multiple perspectives together. For example, rather than saying certain topics were all important, the card-sorting format scaffolded detailed conversations about how important each topic was in relation to the others, for who, in what circumstances, and why. The format also allowed answers to change (i.e., the cards could be moved around easily, or stacked, or edited) and did not infer a “correct” answer, supporting honest, equal reflection in group discussions.

Some of the previous findings were corroborated by workshop participants. For example the importance of issues such as ease of use, providing reliable information, providing good training, involving families in the design of the technology, and keeping costs low. However, through the workshop discussions, a better understanding of why these factors are important, and how they may impact families in real life, was developed. For instance, “ease of use” may also be linked to the time it takes to use the technology, as well as portability (to fit in with school, holidays, etc). Good training may also need to include education on the benefits of use, or in other words, including the *why* as well as the *how* to use the technology. Information provided by the technology should be reliable *and* developmentally appropriate.

Workshop participants were concerned about ensuring equal access to high-quality care, and that the technology used to support this did not put users at risk or take advantage of them. The risks of digital exclusion were discussed in relation to cost (both for the families and NHS providers), and avoiding the assumptions that everyone has access to a reliable internet connection, unlimited data transfer, and smartphones that have adequate processing power and storage for new apps, or the assumption that they can afford to keep technology charged consistently. Accessibility was also discussed in terms of providing multiple language support (and how this could also improve the quantity and range of user feedback), including new use cases, such as different language proficiencies in multi-generational households. Whilst safety was discussed in terms of functionality (i.e., ensuring the technology cannot be used incorrectly, or in a way that could cause harm), the topic of digital safety was a very high priority for workshop participants, particularly around the risks of misinformation, transparency, and control over how their data was stored and who had access.

Within the discussions, it was also helpful to consider the wider contexts of using child health technologies. Workshop participants highlighted that some families may live in busy or crowded home environments where it would be difficult to introduce larger technologies (particularly if there are stairs but no lifts). Families may also have competing demands on their time and cognitive load. For example, concurrent mental health challenges may make it more difficult for children, young people, and/or their parents/caregivers to use new technologies. The lifespan of the technology is also important to consider. For example, who is responsible for updating the device, maintaining it, and any waste management required. It was highlighted that sustainability is core to many young people's values, but that safety (i.e., infection control) must always come first.

An interesting theme that emerged from the workshop discussions was the notion of health technologies as mediators of relationships, on multiple levels. On an individual level, it was suggested that the personalisation of how a health technology looks and operates could support young people in developing a sense of ownership of, and a more positive relationship with, their long-term condition. If a technology is designed to be discreet, the young person retains control over if, when and how they choose to disclose information about their long-term condition to their friends. Technology could also be used to leverage and engage with their wider support networks (i.e., friends, teachers, siblings, and other family members additional to their parent/caregivers), as well as develop new support networks with their peers (i.e., connecting or learning from other young people with the same long-term condition).

Perhaps the most complex element to these discussions, though, was how the technology could support, or challenge, the relationship between the young person with a long-term condition, and their parent/caregiver. Throughout the workshops, technology was seen as having strong potential in the areas of symptom tracking and monitoring management of a long-term condition. When the child is younger, this responsibility falls to the parent/caregiver, but technology could be adaptable over time, allowing young people to gradually learn the skills to take ownership of their long-term condition management. The timing and types of these adaptations would depend on the age and developmental stage of the young person, as well as the condition itself. Parents/caregivers were anxious that young people learn how to advocate for themselves through this process, supported by the technology, and young people felt that technology could reassure them that they are able to give accurate data to their clinicians as they start to lead their own appointments. However, this transition of ownership could be difficult. Some young people may begin to want more privacy, and some workshop participants described a sense of vulnerability around recording data about their daily life (i.e., symptom/treatment tracking apps), and having that data visible to parents/caregivers carries a risk of judgement. Moreover, if this visibility affects how they are able to socialise with their peers, they may choose to disengage from using the technology. On the other hand, parents/caregivers described how their continued involvement could act as a 'safety net' as their

child learns how to self-manage their condition. As such, new technologies in this area will need to support families in finding a balance between parental supervision and young people's independence as they transition from paediatric into adult health services, and beyond.

Please see Appendix 4 for more details on these workshop discussions.

6.6 Idea generation

Despite having a relatively short time to generate 'blue sky' ideas related to the four PhD topics, participants were enthusiastic and created a broad range of creative solutions. Some examples are shown in Figure 14, with the full set of ideas available in Appendix 5, and a list of the highest-voted ideas given below.



Figure 14: Examples of the blue sky ideas generated in the in-person workshops.

6.6.1 Ideas related to PhD topic 1: New technologies to monitor breathing problems during sleep at home

- Sleep bear (10 votes)
 - This intervention uses sensors embedded into a soft toy that can monitor breathing problems during sleep at home
- Sleep tent with personalisable themes - fun camping! (Space, cinema, etc) (6 votes)
- "Smart" cot (safe, cost, easily cleaned, universal sizes, low energy usage) (3 votes)
- Soft toy with sleep sensors [a separate idea note from "sleep bear"] (2 votes)
 - This intervention uses sensors embedded into a soft toy that can monitor breathing problems during sleep at home.
- Motion tracking video stream for sleep - sent to clinician (2 votes)
- IR (infrared) camera that calculates volume of child's breathing (1 vote)
- Make the hospital room you sleep in like home/cool theme (1 vote)
- Special toys to measure output (1 vote)

- Accelerometer on chest (1 vote)

6.6.2 Ideas related to PhD topic 2: Developing virtual reality for paediatric neurorehabilitation following cancer treatment

- Augmented reality avatar on iPad while doing physio (5 votes)
- Social activities challenge tracker (e.g., park walk challenge) (4 votes)
- Build a narrative or format that keeps people coming back = increased compliance (2 votes)
- Virtual reality online classes with physios and other patients, like exercise classes. Has peer support and online gaming experience (1 vote)
- Mini indoor park (1 vote)
- Home exercise programme, app for continuity, gamification “wii fitness” (1 vote)

6.6.3 Ideas related to PhD topic 3: Technologies to support lifestyle behavioural changes in children and young people attending clinical settings

- Virtual reality to show the future after surgery (8 votes)
- Healthy habits app that has peer support and gamification (6 votes)
 - This app would be similar to a ‘Strava’ for healthy habits and would encourage (in an anonymous way) young people to compete against their peers to develop healthy habits
- Virtual pet to look after (4 votes)
- Smart watch - rewards for activity meeting set parameters (cinema tickets / bowling, etc) (4 votes)
- TikTok cooking videos made by kids, for kids (3 votes)
- Games around routine (e.g., eating slowly, setting snack times) (2 votes)
- Blood sugar monitoring (2 votes)
- Health app to set a goal every day (2 votes)
- App that gamifies healthy habits. Peer competition, kudos, positive reinforcement (1 vote)
- Gamification of physical activity (1 vote)
- If a mood ring actually worked. A device that can assess changes in mood/behaviour and collect the data to support services (1 vote)
- Teach a new sport (1 vote)
- Multiple ideas on one post-it (5 votes)
 - Psychology - smaller plates
 - Gamifying healthy lifestyle (“Pokémon Go” and walking to school)
 - Reminders to move
 - Dancing game
 - Meal planning

6.6.4 Ideas related to PhD topic 4: Improving oxygen monitoring technology for infants and young children to reduce A&E attendances

- “Smart onesie” - Babygrows with technology which can monitor their oxygen, discreet not big, can wear everyday and collects data, links to an app (7 votes)
- Sock or glove that measures oxygen levels (6 votes)
- Measure chest movement amount/type of noise/sound of chest (5 votes)
- Make monitor into car/barbie/toy to hold (3 votes)
- Smart glasses measures eye movements for oxygen [sic] (3 votes)
- Oxygen; a special ring [sic] (2 votes)
- Wristband for O2 monitoring (2 votes)
- Ankle band oxygen monitor (2 votes)
- A patch for continuous monitoring similar to diabetes patch on arm (can scan with phone) (2 votes)

- Contactless tech (1 vote)
- Adapts for skin colour (1 vote)

07 Conclusion

Throughout this report, it is clear that the inclusion of children, young people, and their families is crucial if we are to develop effective and sustainable technologies for paediatrics and child health.

Through a process of literature review, online surveys, and in-person and online workshops, a series of key priorities have emerged, including: usability, reliability of the technology and any information it provides, feedback on whether using the technology is having a positive effect or not, data privacy and security, involving families in the design of the technology, sustainability, accessibility, digital exclusion, supporting the child-parent/caregiver relationship, and considering how the technology fits into the wider healthcare system and/or home environment.

Moving forwards, the four PhD students supported by the NIHR Great Ormond Street Hospital BRC, the Insigneo Institute, and the NIHR HRC in Paediatrics and Child Health, will be developing health technologies that have the potential to transform the way we care for our young people, both now and in the future.

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09 Appendices

9.1 Appendix 1: Bibliography of literature review

1. Moving from exclusion to inclusion in digital health and care

Item Type: Web Page

Moving from exclusion to inclusion in digital health and care

Publication Year: 2023

Abstract: Digital exclusion in health and care often overlaps with other forms of social exclusion and disadvantage. In this long read we explore what digital exclusion is, who is commonly assumed to be excluded, and what can be done to mitigate digital exclusion.

URL: <https://www.kingsfund.org.uk/publications/exclusion-inclusion-digital-health-care>

3. Problems and Barriers Related to the Use of Digital Health Applications: Scoping Review

Item Type: Journal Article

Authors: Giebel, Godwin Denk;Speckemeier, Christian;Abels, Carina;Plescher, Felix;Börchers, Kirstin;Wasem, **Publication Date:** 2023

Journal: Journal of Medical Internet Research 25, pp. e43808

Abstract: Background The digitization of health care led to a steady increase in the adoption and use of mobile health (mHealth) apps. Germany is the first country in the world to cover the costs of mHealth apps through statutory health insurance. Although the benefits of mHealth apps are discussed in detail, aspects of problems and barriers are rarely studied. Objective This scoping review aimed to map and categorize the evidence on problems and barriers related to the use of mHealth apps. Methods Systematic searches were conducted in the MEDLINE, Embase, and PsycINFO databases. Additional searches were conducted on JMIR Publications and on websites of relevant international organizations. The inclusion criteria were publications dealing with apps similar to those approved in the German health care system, publications addressing problems and barriers related to the use of mHealth apps, and articles published between January 1, 2015, and June 8, 2021. Study selection was performed by 2 reviewers. The manuscript was drafted according to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist. The analysis of the included publications and categorization of problems and hurdles were performed using MAXQDA (VERBI Software GmbH). Results The database search identified 1479 publications. Of the 1479 publications, 21 (1.42%) met the inclusion criteria. A further 8 publications were included from citation searching and searching in JMIR Publications. The identified publications were analyzed for problems and barriers. Problems and barriers were classified into 10 categories ("validity," "usability," "technology," "use and adherence," "data privacy and security," "patient-physician relationship," "knowledge and skills," "individuality," "implementation," and "costs"). The most frequently mentioned categories were use and adherence (eg, incorporating the app into daily life or dropouts from use; n=22) and usability (eg, ease of use and design; n=19). Conclusions The search identified various problems and barriers in the context of mHealth apps. Although problems at the app level (such as usability) are studied frequently, problems at the system level are addressed rather vaguely. To ensure optimal use of and care with mHealth apps, it is essential to consider all types of problems and barriers. Therefore, researchers and policy makers should have a special focus on this issue to identify the needs for quality assurance. International Registered Report Identifier (IRRID) RR2-10.2196/32702

DOI: 10.2196/43808

URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10221513/> <https://www.jmir.org/2023/1/e43808/PDF>

4. Caring for children with new medical technology at home: parental perspectives

Item Type: Journal Article

Authors: Pitch, Natalie;Shahil, Anam;Mekhuri, Samantha;Ambreen, Munazzah;Chu, Stephanie;Keilty,

Publication Date: 2023

Journal: BMJ Paediatrics Open 7(1), pp. e002062

Abstract: Objectives This qualitative descriptive study explores the experiences of family caregivers (FCs) of children with medical complexity who are initiated on new medical technology in the hospital and transition to new daily life at home. The study aims to investigate FCs' response and readiness for medical technology use, the value of education and transition support and the challenges associated with managing new medical technology in the home. Study design A qualitative descriptive approach was used to conduct and analyse 14 semistructured interviews with a group of FCs composed of 11 mothers and 3 fathers. Content analysis was used to analyse transcripts of the caregiver interviews. The study was conducted at a tertiary paediatric hospital in Toronto, Canada. Results Our study revealed three main themes: FC's response and readiness for medical technology use, the value of education and transition support for initiation of new medical technology and the challenges associated with managing new medical technology in the home. FCs expressed emotional distress related to coping with the realisation that their child required medical technology. Although the theoretical and hands-on practice training instilled confidence in families, FCs reported feeling overwhelmed when they transitioned home with new medical technology. Finally, FCs reported significant psychological, emotional and financial challenges while caring for their technology-dependent child. Conclusions Our study reveals the unique challenges faced by FCs who care for technology-dependent children. These findings highlight the need to implement a comprehensive education and transition programme that provides longitudinal support for all aspects of care.

DOI: 10.1136/bmjpo-2023-002062

URL: <https://bmjpaedsopen.bmj.com/content/7/1/e002062> <https://bmjpaedsopen.bmj.com/content/bmjpo/7/1/e002062.full.pdf>

5. 'It doesn't feel like our house anymore': The impact of medical technology upon life at home for families with a medically complex, technology-dependent child

Item Type: Journal Article

Authors: Mitchell, Tracy Karen;Bray, Lucy;Blake, Lucy;Dickinson, Annette and Carter, Bernie

Journal: Health & Place 74, pp. 102768 **Publication Date:** 2022

Abstract: The study aimed to identify how medical technology impacts upon the home and life at home. Inductive auto-driven photo-elicitation or semi-structured interviews were conducted with technology-dependent children/young people (n = 2) and their family members (n = 15) from 10 families. Thematic analysis generated three themes: Altered physicality and look of the home; Altered sounds in the home; and 'It's worth it! Technology enables us to stay as a family'. Fundamentally, the detrimental impacts of living with medical technology were perceived as worth it as these enabled their child to be at home. Home was not home, and families were incomplete without their child at home.

DOI: 10.1016/j.healthplace.2022.102768

URL: <https://www.sciencedirect.com/science/article/pii/S1353829222000296> <https://www.sciencedirect.com/science/article/pii/S1353829222000296/pdf?md5=2037e4efbfc45acfc2970b90394c39f&pid=1-s2.0-S1353829222000296-main.pdf&isDTMRedir=Y>

7. Digital Technologies for Children and Parents Sharing Self-Management in Childhood Chronic or Long-Term Conditions: A Scoping Review

Item Type: Journal Article

Authors: Edwards, Jill;Waite-Jones, Jenny;Schwarz, Toni and Swallow, Veronica

Publication Date: 2021

Journal: Children 8(12), pp. 1203

Abstract: Worldwide, the prevalence of chronic (or long-term) conditions in children and young people from birth to 18 years (children) is increasing. Promoting competent and effective self-management skills early in the trajectory is important to improve adherence to treatment and optimise quality of life. Successful self-management, therefore, requires parents and children who are developmentally able to develop a range of complex skills, including the use of digital technologies. This scoping review aimed to identify primary research investigating digital technologies for children and parents sharing self-management in childhood chronic illnesses. A comprehensive search of electronic databases was conducted. Nineteen papers were included, assessed for quality and methodological rigour using the Hawker tool and thematically analysed. Three themes were identified: (i) the feasibility and acceptability of using technology, (ii) the usability of technologies and (iii) the effect of technologies on adherence and self-management skills. The results indicate that technologies such as mobile apps and websites can assist the management of long-term conditions, are an acceptable method of delivering information and can promote the development of effective self-management skills by parents and children. However, future technology design must include children and parents in all stages of development.

DOI: 10.3390/children8121203

URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8700031/> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8700031/pdf/children-08-01203.pdf>

9. Children and young people's concerns and needs relating to their use of health technology to self-manage long-term conditions: a scoping review

Item Type: Journal Article

Authors: Blower, Sarah;Swallow, Veronica;Maturana, Camila;Stones, Simon;Phillips, Robert;Dimitri,

Publication Date: 2020

Journal: Archives of Disease in Childhood 105(11), pp. 1093-1104

Abstract: BACKGROUND: The use of patient-facing health technologies to manage long-term conditions is increasing; however, children and young people may have particular concerns or needs before deciding to use different health technologies. AIMS: To identify children and young people's reported concerns or needs in relation to using health technologies to self-manage long-term conditions. METHODS: A scoping review was conducted. We searched MEDLINE, PsycINFO and CINAHL in February 2019. Searches were limited to papers published between January 2008 and February 2019. We included any health technology used to manage long-term conditions. A thematic synthesis of the data from the included studies was undertaken. We engaged children with long-term conditions (and parents) to support review design, interpretation of findings and development of recommendations. RESULTS: Thirty-eight journal articles were included, describing concerns or needs expressed by n=970 children and/or young people aged 5-18 years. Most included studies were undertaken in high-income countries with children aged 11 years and older. Studies examined concerns with mobile applications (n=14), internet (n=9), social media (n=3), interactive online treatment programmes (n=3), telehealth (n=1), devices (n=3) or a combination (n=5). Children and young people's main concerns were labelling and identity; accessibility; privacy and reliability; and trustworthiness of information. DISCUSSION: This review highlights important concerns that children and young people may have before using technology to self-manage their long-term condition. In future, research should involve children and young people throughout the development of technology, from identifying their unmet needs through to design and evaluation of interventions.

DOI: 10.1136/archdischild-2020-319103

URL: <https://adc.bmj.com/content/archdischild/105/11/1093.full.pdf> <http://www.ncbi.nlm.nih.gov/pubmed/32444448>

11. Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study

Item Type: Journal Article

Authors: Waite-Jones, Jennifer;Majeed-Ariss, Rabiya;Smith, Joanna;Stones, Simon R.;Van Rooyen, Vanessa

Publication Date: 2018

Journal: JMIR mHealth and uHealth 6(1), pp. e25

Abstract: BACKGROUND: There is growing evidence that supporting self-management of Juvenile Arthritis can benefit both patients and professionals. Young people with Juvenile Arthritis and their healthy peers increasingly use mobile technologies to access information and support in day-to-day life. Therefore, a user-led, rigorously developed and evaluated mobile app could be valuable for facilitating young people's self-management of Juvenile Arthritis. OBJECTIVE: The objective of this study was to seek the views of young people with Juvenile Arthritis, their parents or carers, and health care professionals (HCPs) as to what should be included in a mobile app to facilitate young people's self-management of chronic Juvenile Arthritis. METHODS: A qualitative approach was adopted with a purposeful sample of 9 young people aged 10-18 years with Juvenile Arthritis, 8 parents or carers, and 8 HCPs involved in their care. Data were gathered through semi-structured focus group and individual interviews with young people and their parents or carers and HCPs. Interview discussion was facilitated through demonstration of four existing health apps to explore participants' views on strengths and limitations of these, barriers and facilitators to mobile app use, preferred designs, functionality, levels of interaction, and data sharing arrangements. Data were analyzed using the framework approach. RESULTS: Analysis revealed three interlinked, overarching themes: (1) purpose, (2) components and content, and (3) social support. Despite some differences in emphasis on essential content, general agreement was found between young people with Juvenile Arthritis their parents or carers, and professionals that a mobile app to aid self-management would be useful. Underpinning the themes was a prerequisite that young people are enabled to feel a sense of ownership and control of the app, and that it be an interactive, engaging resource that offers developmentally appropriate information and reminders, as well as enabling them to monitor their symptoms and access social support. CONCLUSIONS: Findings justify and pave the way for a future feasibility study into the production and preliminary testing of such an app. This would consider issues such as compatibility with existing technologies, costs, age, and cross-gender appeal as well as resource implications.

DOI: 10.2196/mhealth.9179

URL: <https://mhealth.jmir.org/2018/1/e25/PDF> <http://www.ncbi.nlm.nih.gov/pubmed/29351898>

13. The Effect of Medical Technology on a Concept of Home

Item Type: Web Page

The Effect of Medical Technology on a Concept of Home

Publication Year: 2015

Abstract: Homecare—the provision of personal, often sophisticated, medical care in the home—has been promoted as an attractive alternative to a lengthy hospitalization for patients. Homecare is further advanced as providing patients greater independence and more control over their care and as financially preferable to in-patient hospitalization.

URL: <https://www.psgh.com/analysis/the-effect-of-medical-technology-on-a-concept-of-home/>

9.2 Appendix 2: Summary of family survey results

The results listed below demonstrate the most selected answers to the survey questions for each of the four demographic groups, and where appropriate, free text responses to the survey questions. Highlighted responses represent the most selected responses in each demographic:

Why do you think families might like to be able to manage the health conditions of children and young people at home?

- 1) Parent/carer of a child with a long-term health condition
 - They don't miss as much school/work
 - Children/young people might be more involved in managing their health condition
 - They don't have to spend as much money travelling to the hospital
 - They might learn more about the health condition and how to manage it
- 2) Parent of a child who does not have a long-term health condition
 - They might learn more about the health condition and how to manage it
 - They don't miss as much school/work
- 3) Young person with a long-term health condition
 - They might learn more about the health condition and how to manage it
 - Children/young people might be more involved in managing their health condition
 - They can spend more time as a family at home
 - They don't have to spend as much money travelling to the hospital
 - They don't miss as much school/work
- 4) Young person who does not have a long-term health condition
 - They can spend more time as a family at home
 - Children/young people might be more involved in managing their health condition
 - They don't have to spend as much money travelling to the hospital
 - They might learn more about the health condition and how to manage it
 - They don't miss as much school/work

What do you think would make it easier for families to use technology to manage health conditions of children and young people at home?

- 1) Parent/carer of a child with a long-term health condition
 - Being able to personalise how the technology looks or how it works
 - Involving families in the design of the technology
 - Good training on how to use the technology
 - The technology is available in lots of languages
 - Being able to see if using it is having a good effect or not
 - Making sure the technology is easy to use
 - Reminders to use the technology
- 2) Parent of a child who does not have a long-term health condition
 - Good training on how to use the technology
 - Involving families in the design of the technology
 - Making sure the technology is easy to use
- 3) Young person with a long-term health condition
 - Good training on how to use the technology
 - Making sure the technology is easy to use
 - Involving families in the design of the technology
 - Reminders to use the technology
 - Being able to personalise how the technology looks or how it works

- Knowing that you can trust any information it gives (for example, it comes from the NHS)
- The technology is available in lots of languages
- Being able to see if using it is having a good effect or not
- 4) Young person who does not have a long-term health condition
 - **Making sure the technology is easy to use**
 - Good training on how to use the technology
 - Being able to personalise how the technology looks or how it works
 - Knowing that you can trust any information it gives (for example, it comes from the NHS)
 - Involving families in the design of the technology
 - The technology is available in lots of languages
 - Being able to see if using it is having a good effect or not

What do you think would make it harder for families to use technology to manage health conditions of children and young people at home?

- 1) Parent/carer of a child with a long-term health condition
 - **Not having enough internet data to use the technology**
 - It's unreliable
 - It's expensive
 - Young people might want more privacy about their health condition as they get older
 - The technology "taking over" the house (for example, if it was too big, or too loud)
 - It feels like too much pressure to get it right
- 2) Parent of a child who does not have a long-term health condition
 - **Not having enough internet data to use the technology**
 - Having to use a phone to access the technology (for example, an app)
 -
- 3) Young person with a long-term health condition
 - **Not having enough internet data to use the technology**
 - It's expensive
 - Young people might want more privacy about their health condition as they get older, which might be hard if parents/carers can still see and use the technology.
 - It feels like too much pressure to get it right
- 4) Young person who does not have a long-term health condition
 - **It's expensive**
 - It feels like too much pressure to get it right
 - Not having enough internet data to use the technology
 - Having to charge the technology
 - Young people might want more privacy about their health condition as they get older, which might be hard if parents/carers can still see and use the technology.
 - Having to use your phone to access the technology (for example, an app)
 - The technology "taking over" the house (for example, if it was too big, or too loud)
 - It's unreliable

Is there anything that might stop you from trying a new technology to manage a child's health condition at home?

- 1) Parent/carer of a child with a long-term health condition

- How does it store the data it collects?
- Will it mean we can't see doctors in person as often?
- Who has access to the data it collects?
- If I use it wrong, will it affect my child's health?
- 2) Parent of a child who does not have a long-term health condition
 - Will it mean we can't see doctors in person as often?
 - If I use it wrong, will it affect my child's health?
- 3) Young person with a long-term health condition
 - Who has access to the data it collects?
 - If I use it wrong, will it affect my health?
 - Will it mean I can't see doctors in person as often?
 - How does it store the data it collects?
- 4) Young person who does not have a long-term health condition
 - If I use it wrong, will it affect my health?
 - Who has access to the data it collects?
 - How does it store the data it collects?
 - Will it mean I can't see doctors in person as often?

How important do you think it is that young people can learn to use the technology by themselves as they get older? Give a reason for your answer

- 1) Parent/carer of a child with a long-term health condition
 - Average score: 5/5 (Very important)
 - Respondents stressed the need for young people to have some independence and empowered control over their condition. They stated that as young people grow it is inevitable that they will need to advocate for themselves so learning to use the technology would be a very important step.
 - One respondent stated they did not like the use of artificial intelligence as this may reduce the young person's interpersonal skills - they stressed the need for relationships with medical teams.
- 2) Parent of a child who does not have a long-term health condition
 - Average score: 5/5 (Very important)
 - Respondents stated that young people will need to become independent at some point, and it would be beneficial to prepare early in case anything happens to their carers and they must take more responsibility unexpectedly.
- 3) Young person with a long-term health condition
 - Average score: 4.71/5 (Very important)
 - Respondents stressed that responsibility is an important part of growing up and living with their health conditions.
 - One respondent stressed that managing their own health conditions would be important in achieving a successful transition from paediatric to adult healthcare services. They elaborated that having a reporting tool would help them track their own condition and give accurate information to their clinical team.
- 4) Young person who does not have a long-term health condition
 - Average score: 4.43/5 (Very important)
 - Respondents stressed that it is important to become more independent with age and that they must be prepared for when they must take responsibility (e.g., moving out)
 - Young people spend more time away from parents when they get older and will likely live away from their parents before completing transition
 - One participant stated that not all people with long term conditions will move out of their family home, and therefore it is less important for these individuals.

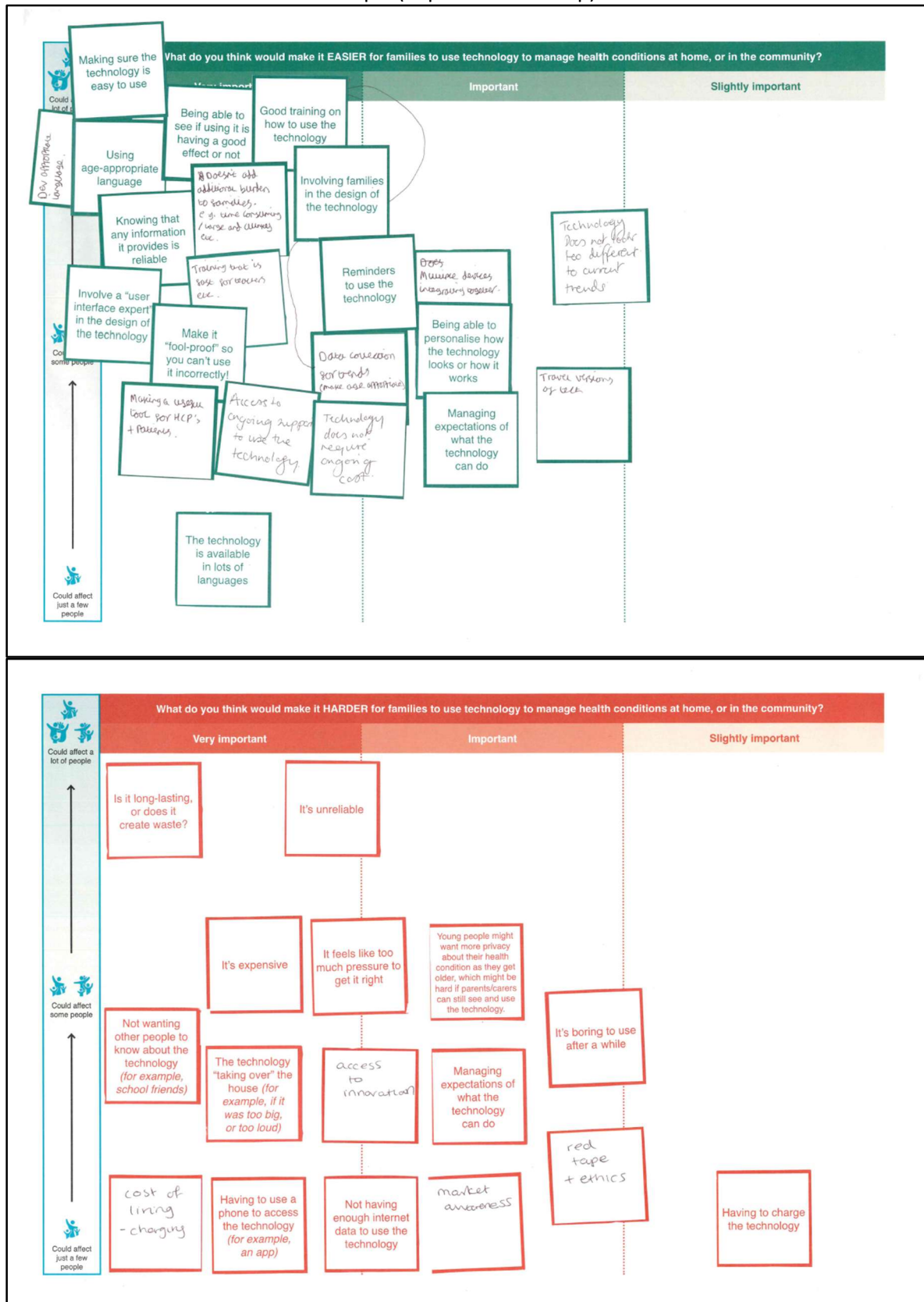
- Important as young people begin to go on holiday independently from their parents.
- It is important to not feel reliant on other people as the young person grows up. This is also important for the wellbeing of the carer, and the mental health of the young person.

Is there anything else you'd like to share with us about using technology to manage the health conditions of children and young people at home?

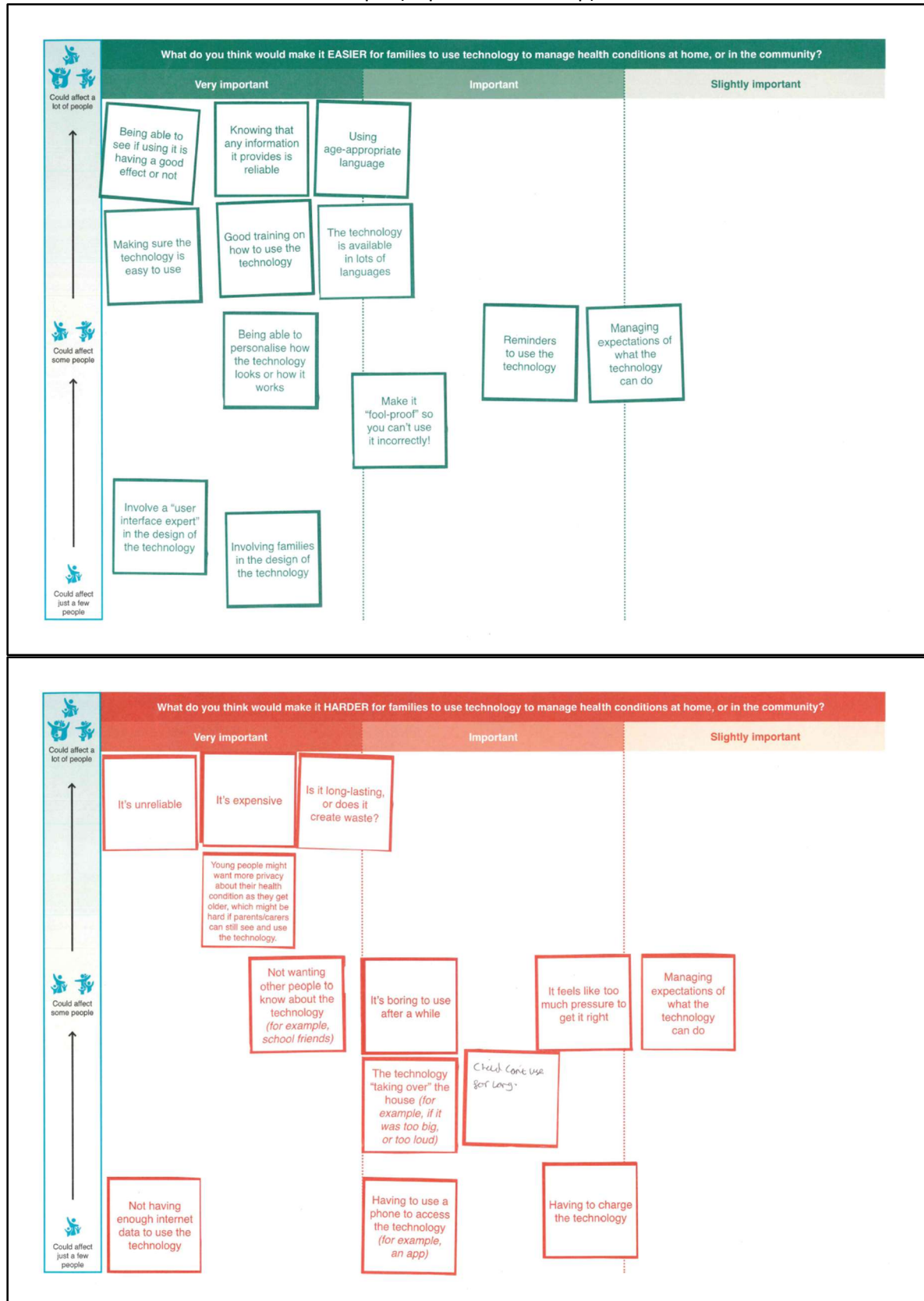
- 1) Parent/carers of a child with a long-term health condition
 - Respondents stated that using technology to manage health conditions is important as technology is and will continue to be a big part of the lives of young people.
 - One respondent stated the need for a helpline for people to seek advice if people are having difficulty or encounter problems using the technology at home
 - One respondent has concerns around staff entering inaccurate information/not using the systems properly. Technology if not easy to use and accompanied with the correct training for staff can cause serious problems and burdened the workforce further.
- 2) Parent of a child who does not have a long-term health condition
 - One respondent stated that it would definitely save time if you manage a health condition from home (no travelling to appointments / no time off school / work / more comfortable in your own home).
- 3) Young person with a long-term health condition
 - One respondent stated the following:
 - It's important to make sure the technology is accessible for people who have blindness, hearing loss/ deafness, ADHD, or dyslexia etc.
 - Suggest making the technology adaptable so someone with dyslexia can change the background so they can read the text easier, for example.
 - Suggest making it free (if possible) for those who need the help but can't afford it if it costs money. Adding it into a care plan, maybe with specialists, so they can use it to communicate issues if needed.
 - If it is phone based, suggest making sure it is available on all phone types (e.g., Apple, Samsung, Lenovo)
- 4) Young person who does not have a long-term health condition
 - Respondents stated the need for the technology to be easy to use and that training is offered for those who need it.
 - Respondents feel technology needs to be implemented.
 - One respondent stated that technology must be available in multiple languages.
 - Another respondent stated that it is important to personalise the depth/complexity of the information given based on the age group of the patient. For those too young to understand, there should be a parent account.
 - One respondent stressed that technology must be affordable to everyone who needs it.
 - One respondent stated that any technology must be checked for choking hazards.

9.3 Appendix 3: Complete “board game” activities

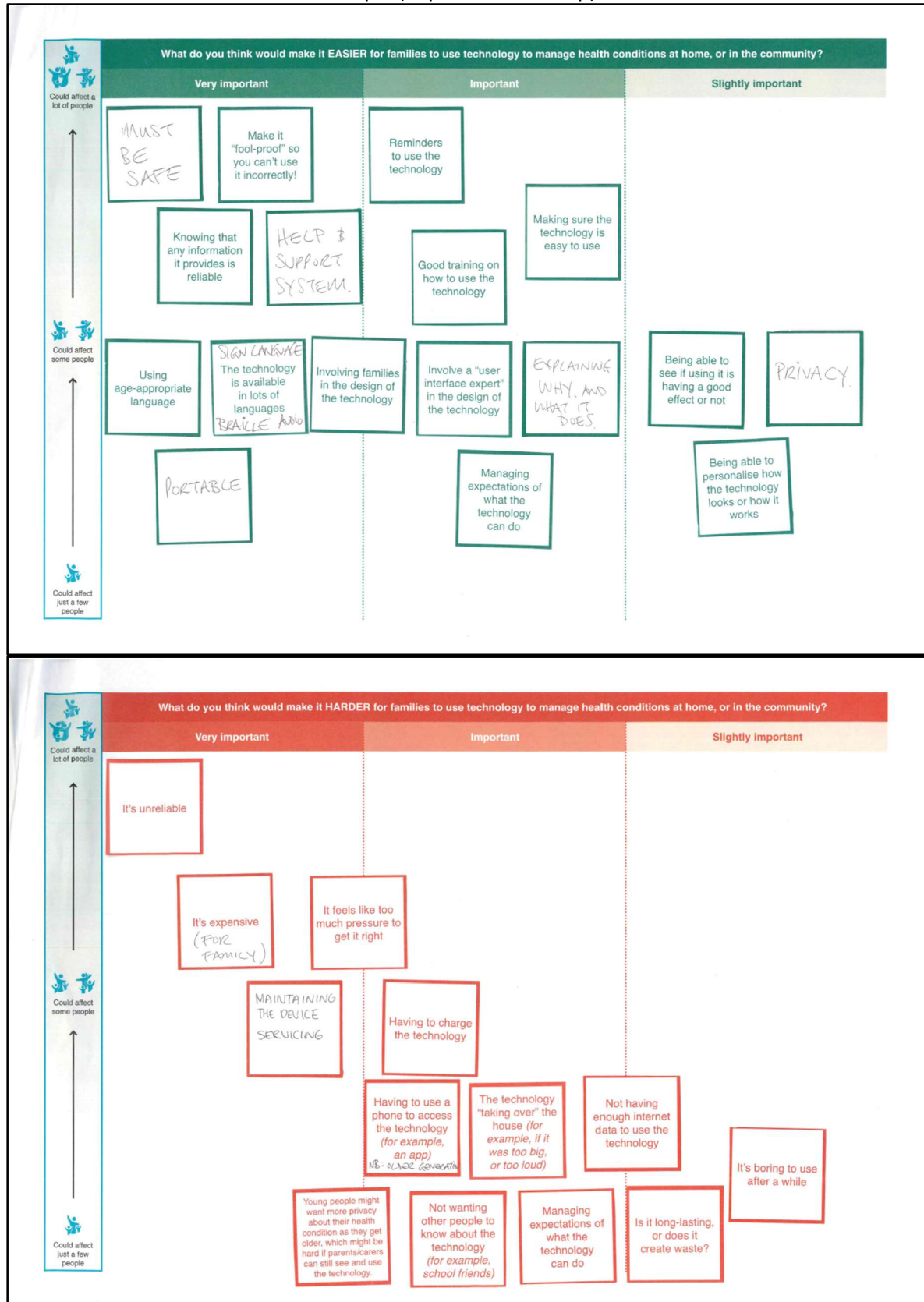
9.3.1: Enablers and Barriers from Group 1 (In person workshop)



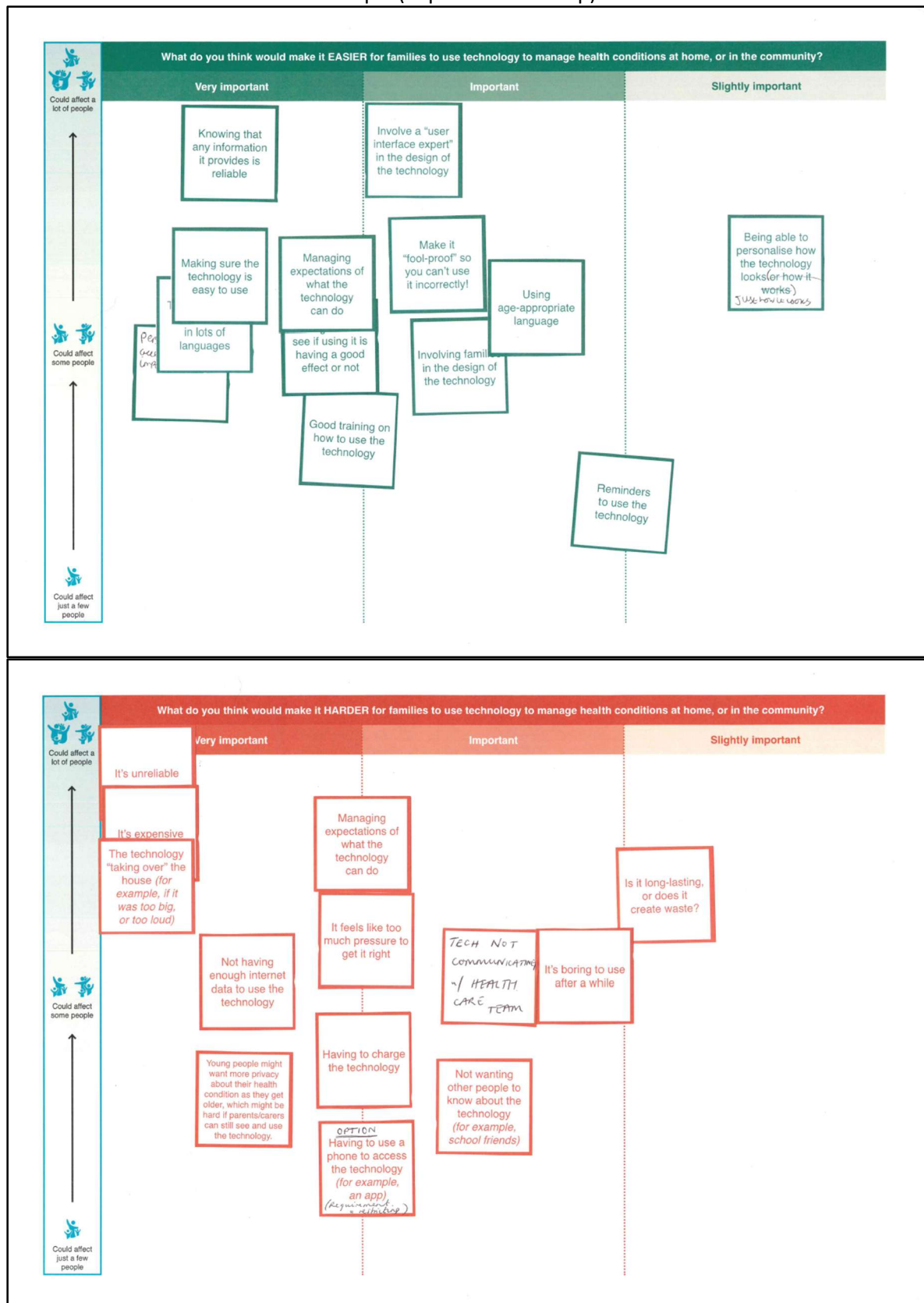
9.3.2: Enablers and Barriers from Group 2 (In person workshop)



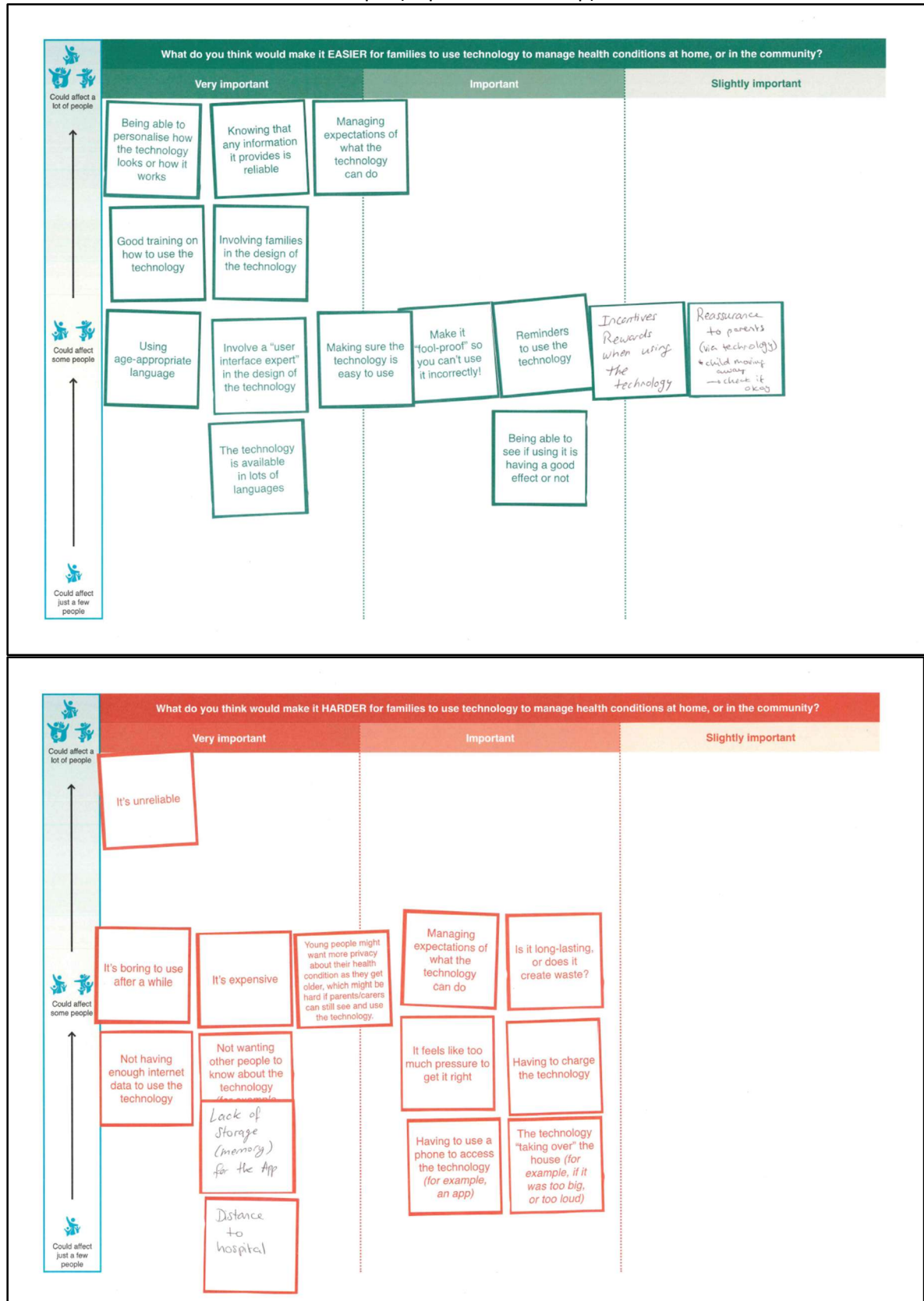
9.3.3: Enablers and Barriers from Group 3 (In person workshop)



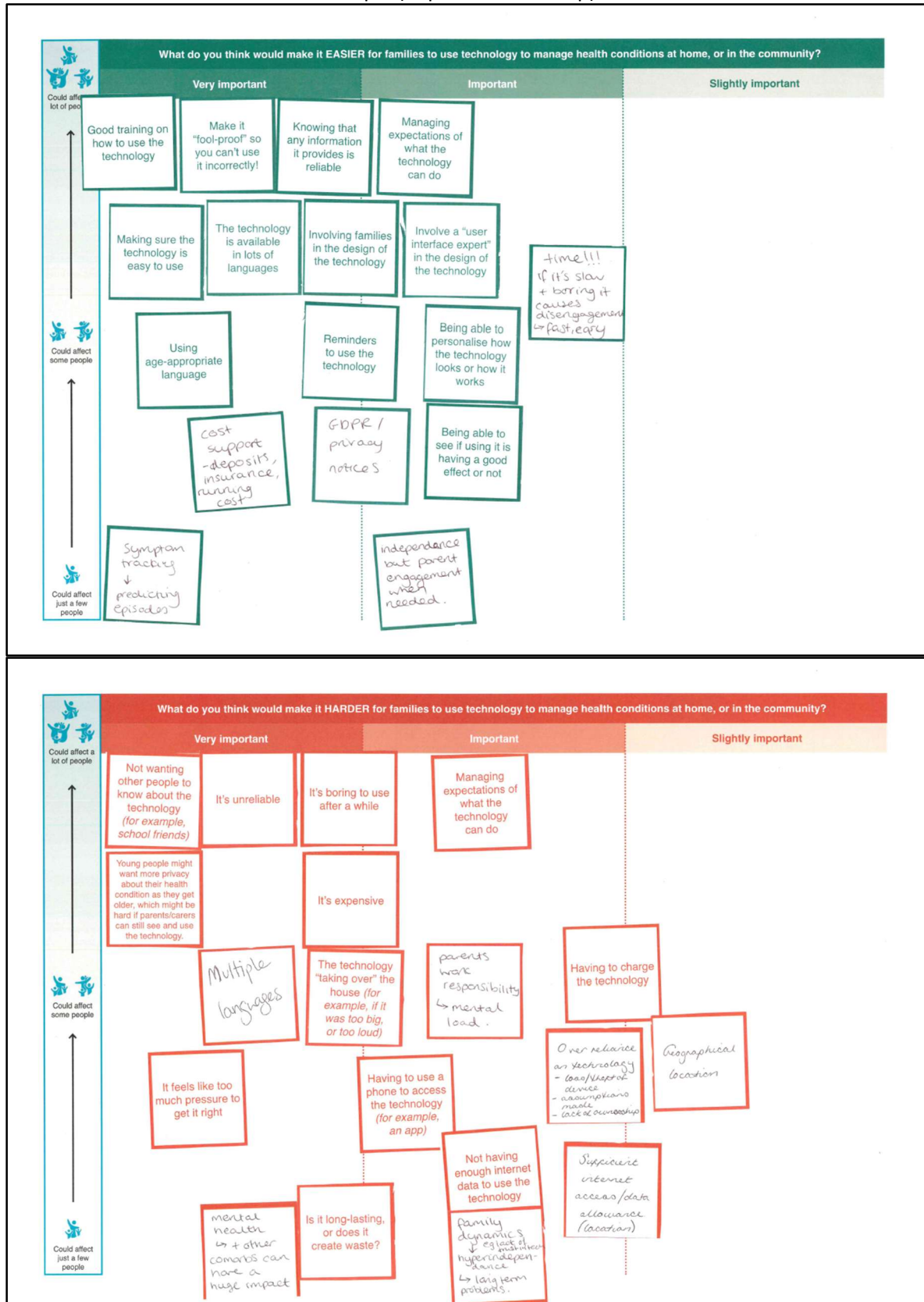
9.3.4: Enablers and Barriers from Group 4 (In person workshop)



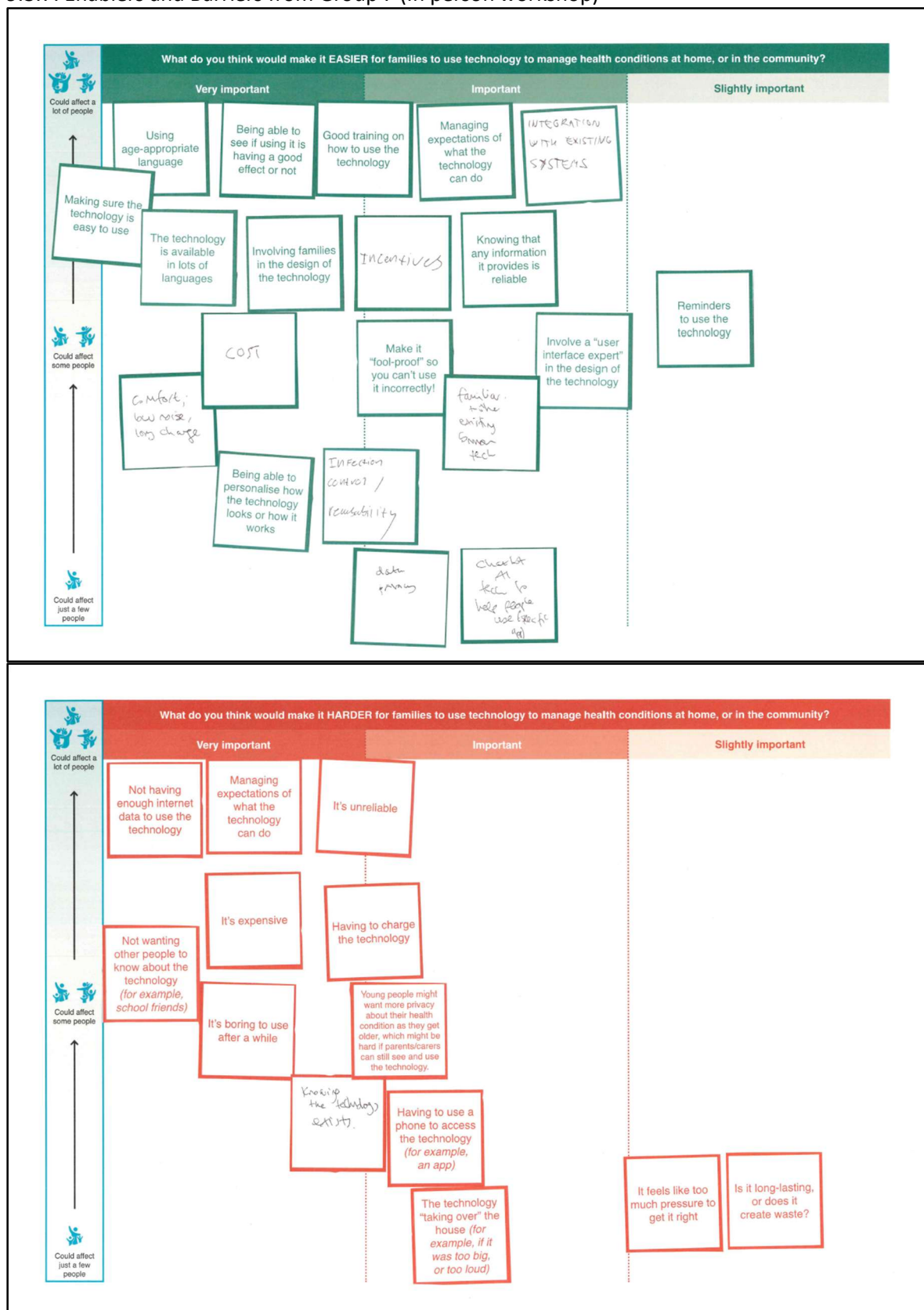
9.3.5: Enablers and Barriers from Group 5 (In person workshop)



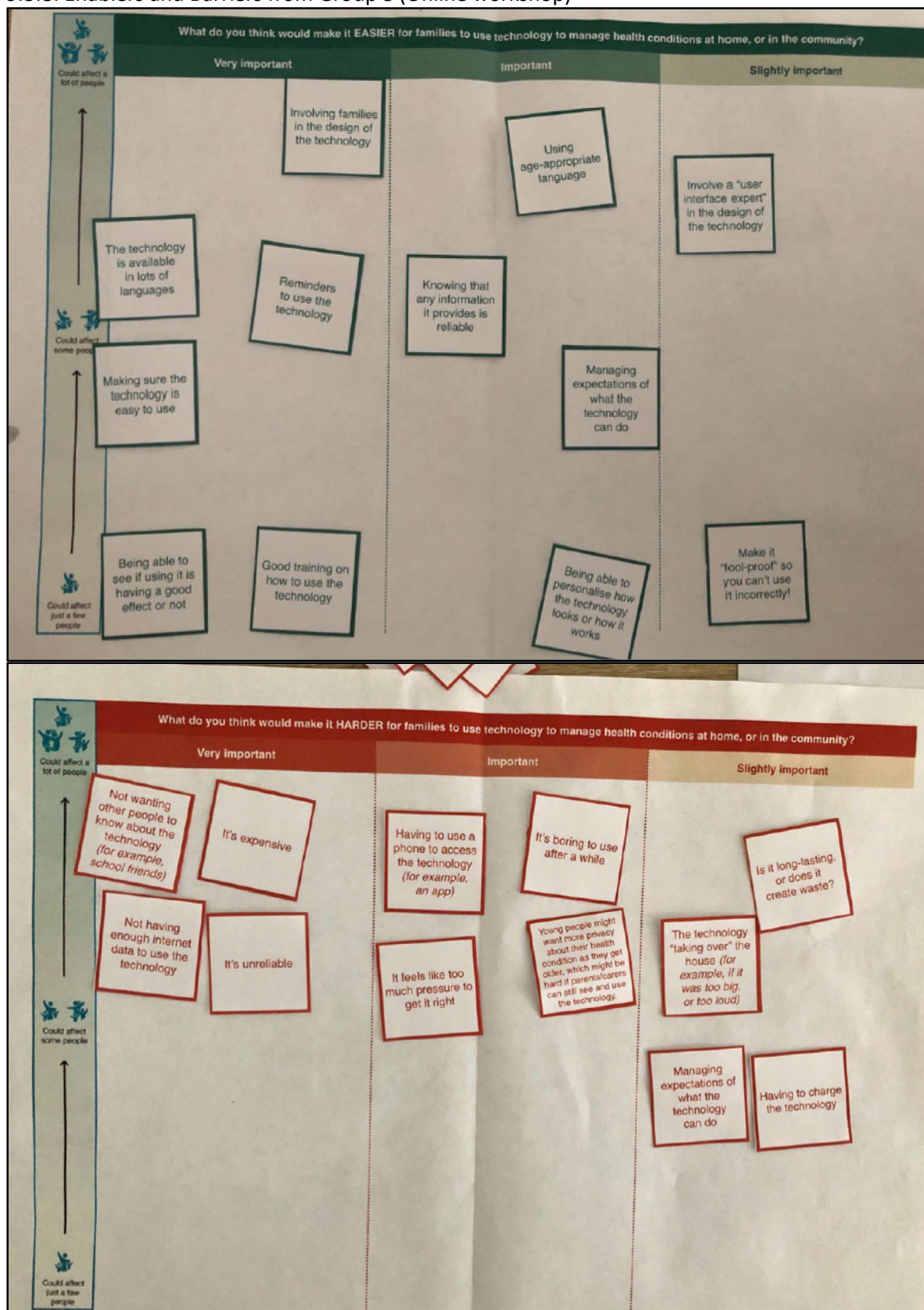
9.3.6: Enablers and Barriers from Group 6 (In person workshop)



9.3.7: Enablers and Barriers from Group 7 (In person workshop)



9.3.8: Enablers and Barriers from Group 8 (Online workshop)



9.4 Appendix 4: Full description of workshop discussions

9.4.1 Results: “What do you think would make things easier for families to use technology to manage health conditions at home, or in the community?”

Participants engaged well with the “board game” activity, which stimulated lively discussions, identifying differing perspectives and the reasons behind them.

9.4.1.1 Board game results

Participants did not choose to rate many factors in the low importance, low impact section of the board.

The factors identified in the high priority, high impact, section of the board (the top left corner) are listed below, with the number of times that factor was prioritised by different working groups across the three workshops given in brackets.

- Making sure the technology is easy to use (7)
- Knowing that any information it provides is reliable (6)
- Good training on how to use the technology (5)
 - *Training that is fast for teachers, etc* (1)
- The technology is available in lots of languages (5)
- Being able to see if using it is having a good effect or not (4)
- Involving families in the design of the technology (5)
- Using age-appropriate language (3)
 - *Using developmentally appropriate language* (1)
- Managing expectations of what the technology can do (2)
- Make it “fool-proof” so you can’t use it incorrectly (2)
 - *Doesn’t add additional burden to families (e.g., time consuming, large and clunky, etc)* (1)
 - *Must be safe* (1)
 - *Help and support system* (1)
- Being able to personalise how the technology looks or how it works (1)
- Reminders to use the technology (1)

9.4.1.2 Facilitator-led discussion of enablers to using health technologies

Usability

Ease of use

Participants felt very strongly, in both in-person workshops, that it was vital to make the technology as easy and “smooth” to use as possible, to not make it inconvenient, and avoid taking too much of families’ time who may already have a high burden of care. The size of the technology was also discussed, both in terms of fitting into small and/or crowded houses, but also in terms of portability (i.e., can the family or young person easily bring the technology to school, appointments, on holiday, etc), especially for those living in rural areas. Participants felt that the user interface was important, as small things can make a big difference, impacting on ease of use and engagement.

Making it foolproof

Although some participants felt “making it foolproof” was linked with “ease of use,” others felt that there were important safety elements to this, particularly if the technology is essential for caring for a condition where mistakes could be harmful. It was acknowledged it can be hard to think of all situations, but a model of continuous improvement of the design, which welcomes input from the families using it, could support this. A live chat functionality could help to mitigate some issues as they occur “in the wild,” but having the knowledge that it can *only* be used correctly (i.e. the users

can't make a mistake in how they use it and accidentally cause harm) would help to reduce anxiety over the responsibility of using the technology correctly and collecting the right data. Similarly, it should be very clear if the technology should not be used (i.e., if it is damaged) with clear warnings.

Reliability

Reliability was discussed both in terms of functionality and in relation to information provision. Functional reliability was strongly linked to whether or not a family chooses to continue using it, and the families' focus on providing trustworthy information was much stronger than that suggested in the literature, perhaps suggesting a growing awareness of the risks in this area. Young people in the workshops described how there is a lot of misinformation online that can be very damaging, and that this can cause anxiety when managing a health condition, and have "knock on" effects on the people around them. They felt that verification is important; if the technology and/or the information provided has variable reliability, everyone involved will lose faith in the device and will stop using it.

Many of the discussions above, related to usability, reliability, and safety were linked to credibility and trust, and a need to cultivate good first impressions in order to foster long-term engagement with new health technologies. A clear plan for how technologies are maintained long term, and by who (i.e., GP, hospital, school, etc) is also important.

Personalisation

The age, maturity, and developmental stage of the child/young person all play a factor in the types of personalisation that might be appropriate and/or increase engagement. As found in the responses to the previous survey (see section 5), it was suggested that the complexity of information provision should be personalisable, with workshop participants suggesting that parents/caregivers would be best placed to make these decisions during set up of a technology. Previous project experiences of the NIHR HRC in Paediatrics and Child Health have also shown the importance of personalisation, and whilst workshop participants suggested that too much choice could be overwhelming, personalisation options could help young people feel a sense of ownership of their condition. That being said, other participants suggested that the aesthetics of the technology are not as important as it being easy to use.

Language

Participants highlighted that, even if it does not affect the majority of people in the UK, providing access to technology through a range of languages is important to avoid deepening health inequalities. They suggested that, if more people are able to use the technology, more feedback could be gathered to improve it.

Several additional use cases were also raised during the workshops: 1) the use of the technology by healthcare professionals and families overseas; 2) UK-based families who have multidisciplinary teams including overseas healthcare professionals; and 3) UK-based families where the children/young people have a stronger English language proficiency than their parents and/or grandparents. In the latter case, it is important to avoid further burdening the child/young person with translation responsibilities around using the technology correctly, or interpreting the data/information it provides. In addition, in some families, children/young people may be able to understand their parents'/grandparents' native language when heard, but may find it difficult to read, which may have implications on the language support offered (i.e., including options to "speak aloud" instructions).

Training

Whilst “ease of use” was seen as a factor that could reduce the need for in-depth training, “training” was seen as an important resource for children/young people, parents/carers, families, and healthcare professionals. It was acknowledged that this would be more important for some technologies than others, and that some families may need more support than others. For example, first-time parents of newborns that need to use healthcare technologies may feel additional pressures and anxiety than others. As such, training may need to be tailored, and may need to include explanation of the benefits of using the technology (i.e., reducing the need to travel to hospital appointments) to encourage uptake and consistent use.

Encouraging uptake and consistent use

Make it engaging

Whilst younger children may enjoy colourful graphics and storytelling, participants suggested that teenagers would need different styles (and “not baby stuff”). Gamification was suggested as a potentially useful mechanic for most ages (if age and developmentally appropriate to each user), but that the concept/use of rewards or incentives would need careful consideration. It was also suggested that interventions, games and stories included in the technology should be gender neutral.

Reminders

Participants suggested that it can be easy to forget to engage with apps, healthcare technologies, and/or health condition management alongside a busy lifestyle (i.e., school, hobbies, part time work, etc), so inbuilt reminders or alarms might be helpful. It was highlighted that, depending on the context, reminders might not just be limited to app usage, and that incentives could be considered (i.e., stickers, badges, etc) to reward positive behaviours and responding to the reminders. An ability to create custom reminders might be helpful for some families, but the language and tone must be carefully considered and care should be taken to avoid them becoming a ‘nuisance.’ It was felt that reminders may be best suited to time-sensitive situations (i.e., when medication is carefully scheduled throughout the day).

Support in understanding if using the technology is having a positive effect

Participants felt that depending on the technology, being able to see a good effect of the technology was important, however it is not essential as some technology takes a long time to take effect. Setting realistic expectations was seen as important, as well as making a clear link between the data collected, what that means, and any changes in quality of life or in care/treatment decision-making as a result.

Managing expectations

Participants felt it was important to be clear from the beginning about appropriate usage conditions, potential benefits, and the limitations of the technology to avoid misuse and/or disengagement. They did, however, feel that if expectations were made too low, users may not see the point in using the technology.

Reflect the reality of living with long-term conditions

Workshop participants highlighted that young people can have a wider support network beyond their parents/caregivers, including siblings, friends, wider family members, and that technologies should support this network as well.

Clear data privacy agreements

Many of the participants were concerned that any new health technologies were fully GDPR compliant, and suggested that some younger parents (i.e. in their 20’s) may not like to give away their data or their child’s data.

Involving families in the design and development of new healthcare technologies

Ease of use has been previously highlighted as a key factor in developing new health technologies, and many workshop participants highlighted that involving families in technology design is key to achieving this. Participants also suggested that other specialisms were equally important, such as user interface design experts, and that it is important to set realistic expectations of what can be achieved when involving families in the design process.

9.4.2 Results: “What do you think would make things harder for families to use technology to manage health conditions at home, or in the community?”

Participants continued to engage well with the board game activity when discussing and prioritising potential barriers to using health technologies.

9.4.2.1 Board game results

The following factors were identified as having the potential to have a large impact on a large population when introducing new health technologies:

- It's unreliable (8)
- It's expensive (8)
- It feels like too much pressure to get it right (3)
- Young people might want more privacy about their health condition as they get older, which might be hard if parents/carers can still see and use the technology (3)
- Not wanting other people to know about the technology (e.g., school friends) (3)
- Not having enough internet data to use the technology (3)
- Managing expectations of what the technology can do (2)
- It's boring to use after a while (2)
- Is it long-lasting or does it create waste? (2)
- The technology “taking over” the house (e.g., if it was too big, or too loud) (1)
- Having to charge the technology (1)

9.4.2.2 Facilitator-led discussion of barriers to using health technologies

Cost

Participants felt that expensive technology will be a big barrier for a lot of people. It may deter some NHS service providers from providing the intervention, thus widening health inequalities based on income and location. In addition, participants highlighted that some apps are free to use initially, then introduce charges for certain features or after an introductory period, which should be avoided where possible in health apps.

Charging

Across the workshops, participants had a range of views on the impact of health technologies that require charging. Some participants felt that needing to charge the technology was not a huge problem, as many people are familiar with charging devices everyday, such as smartphones. They felt that issues may arise if the device takes a long time to charge, has poor battery life, is used in a situation where running out of charge could cause harm, and/or requires cumbersome charging equipment when travelling.

However, other participants argued that the cost of charging additional devices, such as health technologies, has implications for providing equitable care. Some families may choose to have treatment/monitoring interventions in hospital if they cannot take on the burden of powering new

devices at home, or may not be able to use the devices regularly if they are only able to charge them at off-peak times. Moreover, others suggested that a reliance on having a smartphone to access the technology also risks excluding those who cannot afford one, and/or cannot afford to use (and charge) the phone frequently.

Digital exclusion

Many workshop participants discussed the need to consider if, or to what extent, families might have reliable access to the internet in order to use some medical technologies. Some families may also have restrictions on how much data they are able to upload/download when using health technologies, which may also be in competition with other needs of the family (i.e., for school homework, for working from home, for access to utilities and bank services, speaking with family members who live in another country, social media use or gaming with friends, etc). In rural areas, there may be limited internet connectivity, and some companies may have a monopoly on internet service provision.

There were mixed opinions on whether we can assume most families have access to a smartphone. However, even if a family does own a smartphone, some participants felt that using a phone to access the technology had some issues. For example, small screens that do not give all functionalities that you may have on larger appliances, older phones that do not have the required compatibility for some apps or devices, and some phones that may have limited memory (to install apps and/or store data locally). Participants did stress that if the technology was to become available on a mobile phone, it must be available on all platforms e.g., Apple and Android.

Impact on the family home environment

Participants agreed with previous findings (from the literature review and survey), and felt that technology taking over the home could make the home experience difficult and so the smaller the technology the better for the overall family. Large appliances could make the home feel like a hospital, impacting the user experience, and frequent maintenance could impact the feeling of personal space in the home.

In addition, participants highlighted that some housing situations may not have lifts, or accessible routes into the home, which may impact on health technology design.

Technology can become boring after a while

Participants felt that if the technology was boring to use after a while, it may be an issue for some, especially if the technology is an educational tool. They argued that this may depend on how the technology is used and if it is designed to be used daily. A “boring” technology that is not essential to care but that is designed to be used daily, could lead to a drop in user engagement.

This corroborates the experiences of some of the projects in the NIHR HRC in Paediatrics and Child Health, and is especially important in interventions that use gamification (i.e., virtual reality-assisted therapeutic gaming).

Workshop participants advised against stagnant content that does not consider user engagement, and to consider communities of users (and how they may interact with each other) rather than single-user focussed interventions.

Mental health

Concurrent mental health issues can make it harder for young people and/or parents/caregivers to use health technologies, so some workshop participants raised the important question of, “How can we ensure the technology does not cause additional burden or anxiety?”

Sustainability

Workshop participants suggested that there are different sustainability concerns for production and for users, and that whilst medical waste is a widespread issue, the impact this might have on uptake and use depends on the context and the technology in question.

All participants agreed that if it is possible to take a sustainable approach, then designers and producers of health technologies should do so, but safety (i.e., infection control) must come first. This also includes issues around whether the technology creates waste, where to store the waste, and if the waste needs collecting. In addition, if the technology is one that needs to be replaced or reinstalled at times, this could also be disruptive to family life. Some participants encouraged consideration of the multiple ways that resources could be recycled (i.e., using Fitbits across multiple projects, designing for multiple users, etc).

Some participants suggested that, even if a technology does create waste, families may still be happy to use it if it is important to care. Others highlighted that children and young people are becoming increasingly interested in the green credentials of products they use, and so using technologies that generate a lot of waste may go against their values. In addition, research grant applications are also beginning to ask for details on how applicants are reducing the carbon footprint of their proposals.

Existing attitudes towards technology

The attitudes of children, young people, and their family members (including parents/caregivers, grandparents, siblings, etc) can all play a role in how well a new technology can integrate into home life.

Some workshop participants suggested that parents/caregivers may be concerned about their (particularly younger) children using technology, such as smartphones, too much, which may impact on the uptake of health technologies. Others suggested that a perceived over-reliance of any technology can be de-skilling, which may have impacts on health technologies too (particularly those that aim to support self-management of long-term health conditions).

As in the survey responses, some workshop participants also suggested that families may have concerns that technology is being introduced into a child’s care in order to free up clinician’s time only, and that using the technology would reduce their ‘rights’ to access appointments with healthcare teams (in-person or otherwise).

9.4.2.3 Other key considerations

Symptom tracking

Across all workshops, participants discussed the potential benefits of using technology to support symptom tracking, and how this could help to predict “episodes” of certain long-term health conditions (i.e., fits, migraines, etc). However, participants also highlighted the need to consider if the data provided by technology could also be overwhelming, confusing, prompt obsessive

behaviours, and/or add additional pressure to the decisions needed to be made related to living well with their condition(s).

Discretion - How does the technology support, or interrupt, young people's social lives?

For some children and young people, it is very important that they are able to control who knows about their health condition, and who does not. This is related to the physicality of any healthcare technology (i.e., how noticeable is a wearable device? Will it prompt unwanted or awkward discussions for the young person?), but also to the digital footprint (i.e., is it able to send notifications to a user's phone, and how "medical" do they look?). Participants discussed how some conditions may come with some stigma, and that technologies could exacerbate this stigma, or reduce the control a user has on how and when they talk to their friends about it (if at all).

A child/young persons' preferences around discretion may be age dependent, and may be particularly important at certain milestones, for example when making new friends in a new school, or if they move into university accommodation with shared bathrooms and kitchens. Young people may be particularly anxious immediately after diagnosis of a new long-term health condition, so discretion could be important here too.

Balancing parental involvement, privacy and independence

The role of parental involvement in child health technology, and how this may need to be flexible/adaptable over time as the child gets older and may want more independence, was one of the most discussed topics at the workshops. It was clear that technology has the potential to significantly impact on the relationship between a young person and their parent/caregiver, as well as with the young person's relationship with their long-term health condition, and its management, as they become young adults.

The young people involved gave insights into how there is a sense of vulnerability to recording data about your daily life (such as in symptom tracking apps), and having that data visible to parents/caregivers does carry a risk of judgement. When most young people are able to socialise with their friends without constant oversight from their parents, young people with long-term health conditions may not experience their teenage years, or university years, in the same way as their peers, and technology could exacerbate this. Some young people in the workshops felt that parents/caregivers should not automatically have access to health technologies, but this is currently the more prevalent model. They added that some young people may not use a certain technology if their parents/caregivers can see all of the data and trends gathered by it.

Participants suggested that the way in which technology is used (i.e., whether the parent/caregiver or young person is the main user) should be adjustable over time, as needed. They explained that this might be at different stages for different families, and may also depend on the health condition, age of the child, and their developmental stage.

The process by which parents/caregivers and children/young people find a balance between privacy and independence can be challenging for many parents. Participants discussed how technology could provide reassurance to a parent/caregiver during that transitional period, by giving them an overview of the child's health and management so they could act as a "safety net" until the young person is confident. Related to this, it was suggested that some technologies could have different interfaces for the young person and for their parent/caregiver.

9.5 Appendix 5: Idea generation activities

Lifestyle
Healthy habits, app that
has peer support and
motivation.

VR for exercise (rehab or weight management)

Virtual elastic band as centre of a VR game to practice certain motor skills (transfer to real world)

VR. Online classes with Physios + other patients. Like exercise classes. Has peer support and online gaming element.

VR to show the long term effects of obesity

games around routine eg eating slowly, sitting snack times.

O₂ - better fixation of the monitor - skin patches (not clips)

online cook-a-longs

Apps to track progress → customisable with own clinic goals.

light weight VR headset for younger children + poor muscle stability

"Food Tracker App WHERE YOU JUST NEED TO UPLOAD A PHOTO & IT RECOGNISES THE FOOD RATHER THAN A NORMAL APP WHERE YOU HAVE TO SPEND AGES ENTERING EACH INDIVIDUAL COMPONENT OF THE FOOD. GET DAILY/WEEKLY FEEDBACK ABOUT BALANCE (G) COULD BENEFIT FROM EXTRA DAIRY OR USE EAT WELL GUIDE SECTIONS TO GIVE FEEDBACK

infants baby grow with technology which can monitor their oxygen, direct not big can wear everyday and collect data - is an app.

sock or glove that measures oxygen levels

O₂ monitoring
A patch for continuous monitoring similar to the diabetes patch on arm (on skin not bone)

Virtual pet to look after

Breathing sleep
camera that (worn) that can be used to measure volume of air when breathing out. Use more here?

teddy bear that has tech in it to monitor sleep

signal in O₂ monitoring to overcome pick-up, race with skin colour.

VR to show the future after surgery

Exercise camps to encourage children to keep fit

Wristband for O₂ monitoring

if mood ring was actually worn would be a device that can assess changes in mood/behaviour and collect the data to support services.

Family weight loss therapies/technologies



Technologies to monitor breathing problems during sleep at home

Sleeping and monitoring how you breathe while you're asleep can be challenging while at home. Current equipment isn't always designed with children and young people in mind, especially for those that have one or more long-term health conditions. This project aims to work with healthcare professionals and families to build tools to make it easier to monitor breathing quality accurately during sleep at home.

- > Sleep in a tent (at home) - PFW caping
- > Sleep -> cinema theme
- > Astronaut theme
- > Space pool
- > 3D face mask
- > bed sensors
- > play board



Quality for

Having an exercise program at home can help people with severe long-term health conditions, such as cancer, to access to paediatric services. The NHS is very keen to develop novel technologies as virtual reality, which is an alternative to traditional therapy by enabling patients to access engaging neurorehabilitation from home.

- > have exercise program
- > App for community
- > gamification, "win friends"



Psychology

Using psychology to help children and young people with long-term health conditions to manage their weight before surgery, to reduce risks and improve outcomes. This project aims to create new tools to support these services.

- > stop one but stop early
- > avoid junk food at home
- > gamifying healthy lifestyle
- > Pokemon Go + walk school
- > reminders to move
- > Dancing Game
- > cooking workshop
- > meal planning app



Improving oxygen monitoring technology for infants

Measuring oxygen levels in infants with a hospital is crucial for their wellbeing but it can be challenging. This project aims to create new tools to support these services.

- > Smart natches
- > Smart glasses measures eyes
- > more accurate oxygen



Oxygen: A special ring

A special ring that light up cord



Clearing

Using a device to clear the airways of children with long-term health conditions. This project aims to create new tools to support these services.

- > use device into glove
- > growth
- > climate
- > seasonal

Health App

A health app to help children and young people with long-term health conditions to manage their weight before surgery, to reduce risks and improve outcomes. This project aims to create new tools to support these services.

- > to put and set a goal
- > feedback



Improving oxygen monitoring technology for infants

Measuring oxygen levels in infants with a hospital is crucial for their wellbeing but it can be challenging. This project aims to create new tools to support these services.

- > smart natches
- > smart glasses measures eyes
- > more accurate oxygen



Young people

Using psychology to help children and young people with long-term health conditions to manage their weight before surgery, to reduce risks and improve outcomes. This project aims to create new tools to support these services.

- > stop one but stop early
- > avoid junk food at home
- > gamifying healthy lifestyle
- > Pokemon Go + walk school
- > reminders to move
- > Dancing Game
- > cooking workshop
- > meal planning app



Developing virtual reality for

Having an exercise program at home can help people with severe long-term health conditions, such as cancer, to access to paediatric services. The NHS is very keen to develop novel technologies as virtual reality, which is an alternative to traditional therapy by enabling patients to access engaging neurorehabilitation from home.

- > have exercise program
- > App for community
- > gamification, "win friends"



Problems during sleep at home

Sleeping and monitoring how you breathe while you're asleep can be challenging while at home. Current equipment isn't always designed with children and young people in mind, especially for those that have one or more long-term health conditions. This project aims to work with healthcare professionals and families to build tools to make it easier to monitor breathing quality accurately during sleep at home.

- > Sleep in a tent (at home) - PFW caping
- > Sleep -> cinema theme
- > Astronaut theme
- > Space pool
- > 3D face mask
- > bed sensors
- > play board



