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Children and young people's preferences and needs when using health technology to self-manage a long-term condition: a scoping review

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ABSTRACT

Background The use of patient-facing health technologies to manage long-term conditions (LTCs) is increasing; however, children and young people (CYP) may have preferences about health technologies which they interact or engage with, that influence their decision to use these technologies.

Aims To identify CYP's reported preferences about health technologies to self-manage LTCs.

Methods We undertook a scoping review, searching MEDLINE, PsycINFO and CINAHL in July 2021. Searches were limited to papers published between January 2015 and July 2021. We included any health technologies used to manage physical and mental LTCs. Qualitative content analysis of study data was undertaken to categorise data into themes and quantitative data were described and visually represented. We engaged CYP with LTCs to support the review design, interpretation of findings and development of recommendations.

Results 161 journal articles were included, describing preferences of CYP. Most included studies were undertaken in high-income countries. CYP's main preferences and needs were: design and functionality; privacy and sharing; customisation and personalisation of the technology; and interaction options within the technology.

Conclusions This review highlights important preferences and needs that CYP may have before using technologies to self-manage their LTC. These should be considered when developing technology for this population. Future research should involve CYP throughout the development of the technologies, from identifying their unmet needs through to final design, development, evaluation and implementation of the intervention.

BACKGROUND

Healthcare is increasingly incorporating technology into patient care, using telehealth, artificial intelligence (AI), virtual reality (VR), devices and smartphone applications (apps). While technology is also being used by children and young people (CYP) and families, their preferences and what they find appealing about it remain unknown. Our previous

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Healthcare is increasingly incorporating technology to support children and young people (CYP) to self-manage their long-term conditions (LTCs).
- ⇒ Involving CYP meaningfully in all stages of technology development and evaluation is necessary to ensure technologies are appropriate, but this does not always happen.
- ⇒ Our previous review identified key concerns that CYP with LTCs have when using technologies; labelling and identity; accessibility; privacy and reliability; and trustworthiness.

WHAT THIS STUDY ADDS

- ⇒ We have identified key preferences that CYP have about health technologies to self-manage LTCs.
- ⇒ Preferences included design and functionality; being able to balance privacy and sharing; the option to customise and personalise the technology; and interaction options within the technology.
- ⇒ It is important to understand the preferences of CYP to enable engagement with health technologies and enhance end-user experience and acceptability of new devices and digital platforms.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ We report the importance and process of meaningful involvement of CYP in a scoping review to support future teams undertaking reviews about topics that impact CYP.
- ⇒ When developing technologies for CYP to support them in managing their LTCs, CYP's preferences and needs should be considered to help increase CYP engagement with the technologies.
- ⇒ The co-produced recommendations provide clear guidance for technology developers about how to involve CYP; these also build on our previous published recommendations.



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Table 1 Eligibility criteria for studies

Inclusion criteria	Exclusion criteria
<p>Population: CYP with physical and/or mental LTCs aged up to and including 18 years (no lower age limit). LTCs were defined as 'those conditions for which there is currently no cure, and which are managed with drugs and other treatments'.¹⁴⁵</p> <p>Concept: preferences that CYP have about health technologies and any positive elements that they look for when using health technology. Also, any information that CYP want or need to know before using health technology.</p> <p>Context: the focus was on health technologies that CYP engage with or use to manage LTCs. Health technologies included mobile/smartphone apps; virtual reality; telehealth/telemedicine; digital health; medical devices (digitised); gamification/health gaming; augmented reality; receiving health information via SMS (digital health education messages); wearables for monitoring and patient care; remote monitoring; consumer products (eg, FitBits); and social media including patient blogs. All settings (eg, home, hospital and clinic) and all countries were included.</p> <p>Study design: qualitative, surveys, questionnaires, feasibility, acceptability, user testing/usability and mixed methods (including any of these designs undertaken within trials), where data from those 18 years or younger could be extracted.</p>	<p>Studies were excluded if they:</p> <ol style="list-style-type: none"> 1. Did not involve CYP with LTCs 2. Only explored parents' or clinicians' views, experiences, use or preferences about health technology without including CYP's views 3. Explored the use of health technology to manage acute conditions, diagnosis or for a one-off measurement 4. Involved students in a school setting using health technology rather than children or young people with an LTC 5. Included technologies to enhance mobility, senses or provide medications (eg, hearing aids, mobility aids, prostheses) 6. Exclusively included CYP aged over 18 years 7. Were published before 2015 (to ensure we only included technology that is relevant to current technology used) 8. Did not separate CYP's and adults' data within the study 9. Were conference abstracts or protocols 10. Were not written in English.
apps, applications; CYP, children and young people; LTCs, long-term conditions.	

review¹ on CYP's concerns about health technology found many studies overlook CYP in designing, developing, evaluating and implementing health technologies. CYP who were involved in the previously reviewed studies expressed concerns about labelling and stigma, privacy and reliability, accessibility and trustworthiness.⁴ The aim of this current review was to identify studies that included CYP's preferences about health technologies to self-manage long-term health conditions (LTCs), and to co-develop with CYP recommendations for technology development and researchers in consultation with CYP as advisors.

METHODS

We undertook a scoping review in line with guidance by Khalil *et al* 2016, which updated the original scoping review guidance developed by Arksey and O'Malley by incorporating further guidance by Levac *et al* 2010 and the Joanna Briggs Institute.²⁻⁵ We followed guidance to inform data analysis and charting.⁶ Our protocol is available.⁷

Search strategy

We searched Ovid MEDLINE, PsycINFO and CINAHL (July 2021) using a strategy developed with an information specialist, modified for each database (online supplemental file 1). To ensure that the literature reviewed was relevant to current health technologies, searches were limited to papers published in January 2015–July 2021, reflecting the publication of two key documents in 2015.^{8,9}

Eligibility

Table 1 outlines inclusion and exclusion criteria.

Study selection

Records were de-duplicated in EndNote and managed in Rayyan for title and abstract screening. Two searches were undertaken (2019 and 2021). Six reviewers (RJC, IK, KG-B, JML, VS, MP) screened in pairs, independently undertaking title and abstract screening for records in search 1. For search 2, records were categorised by Rayyan in terms of probability of relevance according to decisions made in screening for search 1. Studies with $\leq 30\%$ probability of being relevant were excluded; those with 50% probability were single screened (JM-K) and those with $\geq 70\%$ probability were double-screened (JM-K, IK). Full texts were screened independently in Covidence by two reviewers (JM-K,

SE-Y, RJC, MK or JML). When uncertainty arose, articles were discussed until a consensus was reached.

Data extraction and analysis

Data were extracted by SB, JML, JMK, SE-Y, LPr, FS, LPo, AW, GW, MK, JB with FS checking 10% of studies. Data extracted included: lead author; publication year; country; study participant details (age, number, sex, ethnicity, LTC); study design; technology type; setting; retrospective/prospective use; preferences and needs; whether CYP were involved in the scoping/design of the technology; and quotations to support preferences.

Content analysis was undertaken¹⁰ as recommended.⁶ JM-K read through and coded extracted data (quotations and interpretation from the primary study authors) to categorise data into four overarching themes. Themes were reviewed by VS and discussed with the wider team.

Stakeholder consultation

We convened a Patient and Public Involvement (PPI) Advisory Group of 12 CYP with LTCs in England. Regular 60-minute online workshops, using Zoom and Miro, enabled CYP's contribution to the review's focus, interpretation of findings and co-development of recommendations. We met with the young people at key time points in the study. Five meetings were held at approximately 2-month intervals. Early sessions focused on developing PPI members' understanding of a review process, building skills in critiquing and discussing research findings through exploring recommendations of our previous review.¹ Workshops built upon understanding and ideas generated previously, with members empowered to work with facilitators to draft the review's recommendations. Attendees received a £20 thank-you voucher after each workshop; minutes were distributed to the entire PPI group for further mutual learning, particularly for those who missed a session due to illness or health-care appointments.

RESULTS

Study selection

Electronic searches identified 22 063 unique records. Many excluded papers did not include preferences, did not separate CYP participant responses from those of adults or reported technology outside the review's scope. 161 papers were included

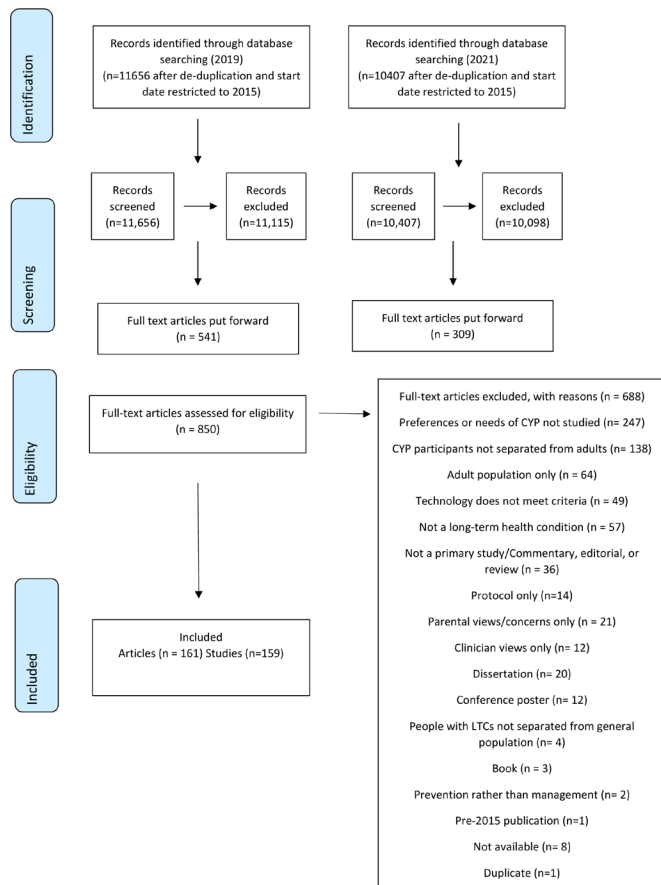


Figure 1 PRISMA flow chart. CYP, children and young people; LTCs, long-term conditions; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

(figure 1) representing 159 studies. Details of the 161 papers are provided (online supplemental file 2).

Characteristics of included studies

Studies were published between 2015 and 2021 (figure 2), undertaken in the USA (n=62), the UK (n=23), Canada (n=18), Australia (n=14), the Netherlands (n=7), Brazil (n=6), New Zealand (n=4), China (n=3), Denmark (n=3), Spain (n=3), Sweden (n=3), Finland (n=2) and Norway (n=2), and one study each in Korea, Estonia, France, Ireland, Japan, Korea, Nigeria, Greece and Turkey.

Studies included CYP with the following LTCs (online supplemental table 1): type 1 diabetes mellitus (n=22); mental health conditions including depression, anxiety, post-traumatic stress disorder, early-onset psychosis and unspecified mental health conditions requiring access to mental health services (n=26); cancer (n=20); asthma (n=17); obesity (n=7); juvenile idiopathic arthritis (n=6); attention deficit hyperactivity disorder (n=4); autism spectrum disorder/conditions (n=4); spina bifida (n=3); cerebral palsy (n=3); cystic fibrosis (n=3) and various other LTCs (n=44). Most studies focused on one LTC without reporting any comorbidities. One study included CYP with concurrent coeliac disease and type 1 diabetes,¹¹ another included CYP with mental health conditions and comorbid symptoms of insomnia and anxiety disorder,¹² and one study included CYP with autism spectrum disorder and depression.¹³ Studies included CYP aged 2–18 years; 62 studies included participants under 11 years.^{11 14–74} Seven studies included

children under 5 years, with parents, caregivers and specialists supporting their preferences.^{23 30 33 34 75–77 99} 99 studies (58%) did not report ethnicity of CYP participants (figure 3A), and of the 133 studies that recorded sex, 65% recorded ≥50% female participants (figure 3B). Two studies included trans and gender-diverse CYP.^{78 79}

Many studies were qualitative (n=74) or mixed methods (n=25). Study designs also included user testing (n=11), pilot/feasibility studies (n=28), co-design (n=9), surveys/questionnaires (n=7), randomised trials (n=2), and one each of participatory action research, single-site cohort and community-based participatory design. Technologies were categorised using a typology⁸⁰: internet (eg, websites, forums) (n=10); social media (eg, Facebook, Instagram) (n=10); mobile health (mHealth, for example, mobile phone apps, text messaging, tablets) (n=72); telehealth (eg, video-conferencing, interactive online treatment programmes) (n=18); devices (eg, wearables) (n=5). An additional category was developed to capture immersive/machine-led technologies comprising gaming, AI and VR (n=18). 26 studies^{17 22 43 48 50 52 62–64 81–97} involved a combination of technologies.

Preferences and needs expressed by CYP

Defining preferences was challenging; we excluded studies that only reported *satisfaction* or *level of acceptability*, to ensure an in-depth approach to understanding preferences. CYP provided detailed accounts of technology features they liked or preferred. Many preferences were similar across studies (online supplemental table 2). There were four overarching themes, summarised with quotations (online supplemental table 3). Many studies did not report the age and/or sex of the participant who reported the preference.

Design and functionality

CYP reported specific preferences about technology design and functionality. They preferred clearly laid out mobile apps and internet sources, divided into subsections, and well labelled.^{20 22–24 37 61 98–104} Ease of use and convenience were important; preferring technology that was ready to use and CYP not needing to search for information.^{20 22–24 52 59 77 89 95 99 101–103 105–109} Bright colours were appealing, making them ‘feel good’ when interacting with the technology.^{64 100 110}

CYP expressed interest in using technologies that were present in their daily lives, for example, digital games accessed through smartphones, tablets and computers. Additionally, they valued apps that were accessible across different platforms/operating systems.^{27 61 102} Some CYP found it easier to record information using technology.⁵² They preferred a balance between technology simplicity and receiving appropriate information enabling them to engage with the technology.^{61 102 111} CYP appreciated technology with clear and uncomplicated language, without ‘doctory’ words or jargon, but not ‘too dumbed down’.^{70 82 95 100 104 112} They also had preferences about images and multimedia, and for programmes and apps with age-appropriate and developmentally appropriate content incorporating images and media that were relatable.^{30 66 69 95 100} Younger children’s preferences included background music, visual graphics and manga (Japanese comic) animations.^{30 34}

Privacy and sharing

CYP need to balance privacy and sharing when using technology. Most CYP preferred to use technology to interact with, and share, information.^{19 20 25 39 52 78 94 99 101 111 113–118} They valued connecting

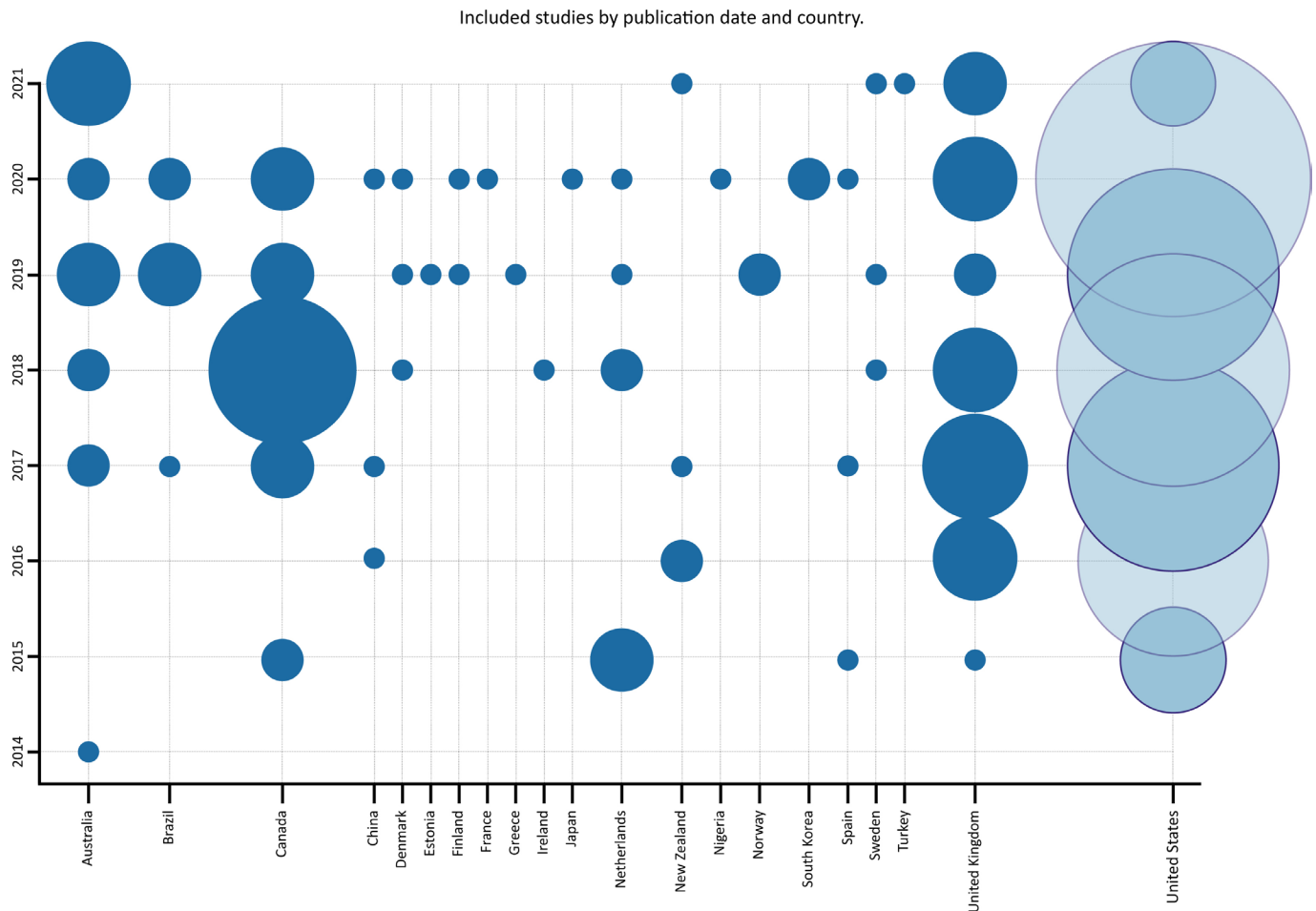


Figure 2 Included studies by publication date and country.

with others with similar conditions or experiences, reducing loneliness and isolation.^{19 21 59 62 63 66 72 79 81 82 85 88 89 93–95 97 104 113 117–125} CYP with cystic fibrosis and type 1 diabetes benefited from chat rooms, breaking their isolation and helping them feel less alone.^{63 99 104} Immediacy of communication with healthcare professionals and assessment via messaging or video was positive for CYP with asthma, facilitating timely and targeted intervention.³⁹ Some CYP preferred using technology to communicate, avoiding embarrassment and maintaining independence.^{12 79 111 113 118 126 127} They expected security functions in healthcare technologies.^{14 66 94 111 124 125 128 129} CYP appreciated technology enabling them autonomy and control over their information.^{20 78 90 102 113 130}

Customisation and personalisation

The functionality to customise and personalise technologies was viewed as positive and important.^{20 21 49 55 66 78 101 102 105 117 131 132} This included personalising frequency (eg, reminders, text messages), content (eg, asthma triggers relevant for the individual), when and how they used the technology, and tracking their conditions and symptoms.^{49 72 77 78 87 88 91 98 105 116 133–140} Being able to set personal goals within the technologies was motivational, providing visual representation of their progress and incentive to achieve.^{37 89 113 114 121 133 135} The preference to personalise the technology was reported by CYP with spina bifida, asthma, cancer, type 1 diabetes, depression, sickle cell anaemia and haemophilia.^{20 49 78 102 105 117} Younger children's views were well represented; CYP aged 6–17 years appreciated creating

their own personalised character.^{20 68 87 141} CYP with LTCs with particularly complex medicine regimens, for example, asthma and cystic fibrosis, considered apps with medication reminder functions to be important.^{96 98 99 101 142 143}

Interaction

Interaction preferences covered a range of features including gamification within the technology, for example, referring to the 'magical' experience of shooting balloons,⁴² noting games within the technology 'provides a distraction and it calms me down'.⁷⁸ CYP of different ages valued games, such as goals to incentivise improving their health, providing motivation.^{14 62 78 89 114 132} CYP valued incentives and rewards, including financial incentives.^{14 54 60} Interestingly, while CYP valued the opportunity to interact with peers with the same condition or with healthcare professionals online, some valued interactive technologies which removed the need for them to speak, viewing communication online as 'less intimidating'.^{12 19 20 117} One study reported the positive of visualising personal experiences using avatars lessened the need to talk.¹³¹

CYP described how interacting with games and customising avatars helped them demonstrate their emotions and express their feelings.^{26 87 131} For example, CYP liked the option to add inner voices and emotions to avatars to express their feelings and interpret situations.¹³¹ Some CYP expressed how interaction with technology gave them greater confidence and better understanding about self-management, enabling independence.^{21 43 130 131} Immersive technologies were described by some

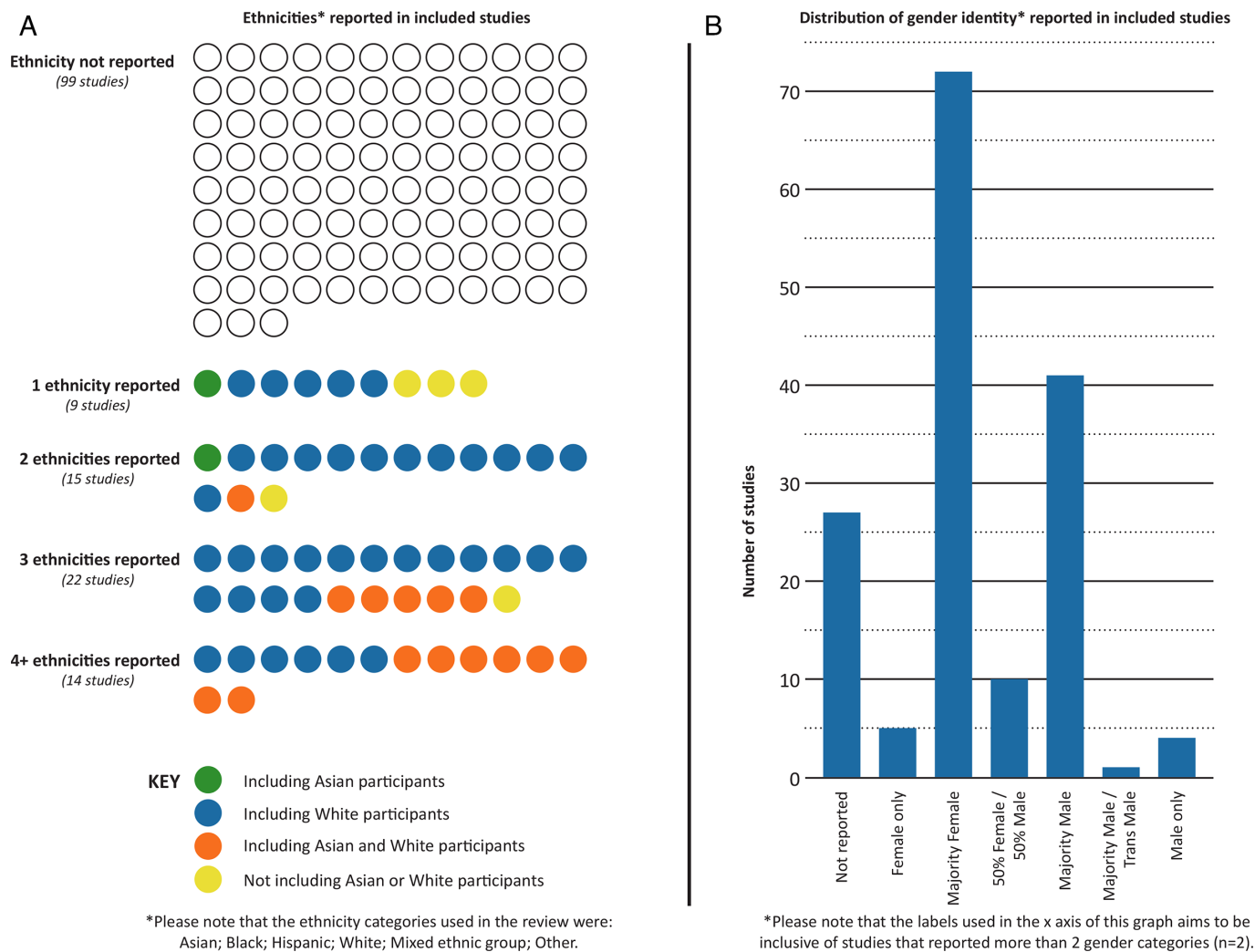


Figure 3 Ethnicities and distribution of gender identity reported in included studies.

as a distraction from what was happening around them,^{64 78 144} with VR games an ‘exciting distraction’ from negative aspects of rehabilitation such as boredom and pain.⁴²

Stakeholder consultation

PPI members believed that it was critical to value CYP’s unique and expert opinions, separate from those of their parents, caregivers and healthcare professionals. This approach differs from studies excluded from this review that consider adults as proxies for CYP. PPI members contributed to the interpretation of findings, exploring early themes with quotations from CYP. They agreed with the initial findings presented, adding further depth to discussions of privacy, customisation and health technologies’ potential impact(s) on the relationship between CYP and their parent/caregiver. The PPI members led the development of the recommendations based on their review of the data and findings. The recommendations were refined over several months between PPI members and the wider team, delivering the final set of recommendations (Box 1).

DISCUSSION

Main findings

This review highlights CYP’s preferences and needs for technology to support them to self-manage LTCs, including design and functionality; privacy and information sharing; customisation

and personalisation; and interaction. Included studies involved CYP aged 2–18 years, with 39% involving CYP under 11 years. Most studies were conducted in high-income countries, focusing on type 1 diabetes, mental health conditions, cancer and asthma. Studies predominantly recruited CYP with a specific LTC and therefore the views of CYP in these studies may not be representative of the wider CYP population with multimorbidity. Ethnic background was not consistently reported, and participants were predominantly female. Although CYP were reported as being involved in the scoping, design and/or evaluation of the technology in many studies (n=105), their involvement was not always defined and engagement methods were not clearly articulated.

Our findings in relation to the literature

There has been a marked increase in the number of studies involving CYP’s use of health technologies to manage an LTC, compared with our previous review.¹ Nonetheless, in the current review, many studies focused on effectiveness of the health technology without asking CYP about their preferences and needs. No review has specifically explored CYP’s preferences when using health technology to manage LTCs. Our review suggests a shift in the focus of technologies investigated with fewer studies focusing on internet sites, but with mHealth remaining the most studied technology.

Box 1 Recommendations

The following recommendations were derived from our findings and co-developed with CYP stakeholders (recommendations that CYP identified as most important are denoted with an asterisk).

The following recommendations were congruent with the recommendations made in our previous scoping review¹:

1. Recognise the importance of CYP having their own, unique, expert opinion that is distinct from those of their parents/caregivers and healthcare professionals.*
2. Ensure any technology for use by CYP is age-appropriate and developmentally-appropriate (in terms of language and style).*
3. When designing and developing technology for CYP to manage LTCs, consider the value CYP place on customising/personalising aspects such as characters, reminders and when they choose to use the technology.*

The following recommendations are new and based on this review's findings:

4. When developing and testing technology for CYP, include research that captures in-depth, detailed understanding of what CYP think about the technology (rather than satisfaction or simple acceptability scales).*
5. When undertaking research about CYP's use of technology, consider whether your study participants represent the target end-users of the technology (for example, consider ethnic background, age and other characteristics of CYP participants). Report the characteristics clearly but do not use them to generalise results to specific populations unless appropriate.
6. Carefully consider the appearance of the technology as CYP have particular preferences including it being aesthetically pleasing and user-friendly.*
7. Consider that CYP need a balance between sharing information with peers, but not wanting to share with others (eg, their parents or other CYP). The option of sharing ultimately needs to rest with the individual and the option of anonymity may be preferred by some. Consider that some CYP may prefer the opportunity to interact through technology rather than verbally (eg, in appointments with clinicians).
8. Consider the positive value that CYP place on gamification aspects and incentives when using technology and include this as an option to encourage them to use the technology. CYP, children and young people; LTCs, long-term conditions.

We developed a new category for this review to encapsulate newer immersive technologies of AI, VR and chatbots which were not included in our previous review; this category now represents approximately 13% of included studies. CYP's preferences appear consistent across all technologies and not specific to a particular technology. Preferences reported by CYP using the newer technologies however did focus on personalisation opportunities within the technology.

We identified a range of preferences and needs of CYP when using health technologies to self-manage an LTC. As in our previous review,¹ we found that CYP wanted to achieve a balance between sharing information with others, for example, CYP with the same LTC, while still ensuring their privacy was maintained and that the technology securely

dealt with their information. This is an important consideration for technology developers and researchers and is highlighted in recommendation 7.

Interestingly, CYP reported that using technologies with chat functionality removed the pressure on them to speak (eg, at clinical appointments), which CYP appreciated.^{20 39 126} CYP also wanted a balance between clear and colourful websites, with enough well-written and accessible information. Some CYP indicated that independence from parents and technology that was targeted solely at CYP was important.¹¹³

Strengths and limitations of the review

A strength of this review is its broad focus on technologies and LTCs. We used a recognised methodology,^{2 6} ensuring rigour, and worked with CYP throughout the review. We co-developed recommendations based on the review's findings which are important for future development of health technologies for CYP with LTCs. The PPI group have led the focus and outputs of the review which has made the research meaningful and relevant to young people, and the recommendations represent their voice.

A limitation of the primary studies included was lack of diversity. Ethnicity was reported in less than half of studies and the most represented ethnic group was 'white', with Asian CYP particularly under-represented. Sex was not reported in all studies, but where sex was reported, more than half of studies recorded a majority of female participants. Sex was reported as male or female; and only two studies^{78 79} reported preferences of trans and gender-diverse CYP. Many excluded studies only explored acceptability/satisfaction with the technology. Meaningful understanding of CYP's preferences is important as these will influence whether CYP use technologies.

Future research

Based on the findings from our review and the recommendations developed with our PPI members, we believe further research should focus on the co-development of a framework to support consistent and appropriate involvement of CYP when new health technology is designed, developed and tested.

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