Scoping review protocol: Identifying and understanding positive elements of health technology, according to children and young people with long-term health conditions

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Background:

The use of technology in healthcare is rapidly expanding, encompassing interventions such as telehealth, artificial intelligence, virtual reality, augmented reality, medical devices, and those delivered by smartphone applications. People of all ages with long-term health conditions increasingly rely on health technology for self-management, with remote clinical support and monitoring becoming the norm, particularly during the COVID-19 pandemic. Consequently, more children, young people and families rely on health technology to manage their long-term conditions.

However, our recent scoping review exploring children and young people's needs and concerns about health technology use (1), found that many studies do not involve children and young people in health technology design, development, evaluation, and implementation. Studies that involved children and young people reported their concerns as: labelling and stigma associated with using technology for long-term health conditions; privacy and reliability; accessibility; and trustworthiness. We know that children and young people also have unique or particular preferences, and thus may be drawn to different positive elements, when using health technology. Further work is needed to scope the associated evidence to inform future technology development research. The findings from this scoping review will inform the larger White Rose Collaboration funded project to help us identify the positive elements that children and young people identify in health technology, in order to use health technology to more effectively and appropriately manage a long-term health condition.

Review team members:

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Patient and Public Involvement and Engagement (PPIE)

Throughout the project, we will engage with children and young people with a long-term health condition, and their parents. We will do this to validate our interpretation of the data and to assist with development of recommendations from the review. PPIE members will have the opportunity to take part in other ways in the review if they would like to (e.g., screening, data extraction), and will be supported by the team in doing this.

Objectives of the scoping review

To identify children and young people's preferences, and the positive elements they look for, when using health technology to manage a long-term health condition. These objectives were developed after consultation with children and young people. Specifically:

- their preferences about using health technology interventions and which positive elements of health technology are important for children and young people to enable use, and
- what information they need/want to know before using health technology interventions.

Methods

This scoping review will be undertaken using the methodology described by Arksey and O'Malley framework (2) with enhancements reported by Levac et al. in 2010 (3).

Search strategy

To identify relevant published literature key health care databases have been used, including: Ovid MEDLINE, PsycINFO, CINAHL. A systematic and comprehensive search strategy was developed with an information specialist (MH). This included both MeSH subject headings and free-text terms relating to the main concepts identified in the review question:

- children and young people with long-term health conditions;
- health technology that children and young people engage with and use;
- engagement/ views/ preferences/ attitudes etc.

The search strategy was used for a previous review about children and young people's concerns with using technology to manage long-term health conditions (1). Searches were undertaken in July 2021 limited to English language papers published between January 2008 and July 2021. As this search brought over 28,000 records, we have restricted the search to all studies published from January 2015 onwards, irrespective of study data collection period. This decision reflects the date of Ofcom's 2015 Communications Market Report, (4) that found 33% of internet users see their smartphone as the most important device for going online, compared with 30% who only use their laptop. The rise in smartphone use marks a clear shift after 2014 – in 2014 only 22% turned to their phone first with 40% preferring to use their laptop. Smartphones have become the hub of our daily lives and are now in the pockets of two thirds (66%) of UK adults, up from 39% in 2012. The vast majority (90%) of 16-24 year old owned a smartphone. In addition, the draft consultation for NICE guidelines "Transition from children's to adults' services for young people using health or social care services" was also published in 2015.

We will also search for pre-prints using MedRxiv (https://www.medrxiv.org/) so that we can identify relevant contemporary studies that have not yet been published. A search strategy will be developed for use in MedRxiv.

There will be no lower age limit of children within the studies but only studies that report the views of children and young people will be included. For this review we will include children and young people as being aged up to and including 18 years. Studies that only report parents' views of health technology will be excluded.

The strategy was modified for each database used. In addition to the search in electronic databases, complementary searching will be completed, including forward and backward citation tracking; author searching and hand searching of relevant journals. Relevant studies from systematic reviews and other reviews will be identified and included.

Study selection

Search results will be organised and managed using Endnote, SR Accelerator and Rayyan. Following deduplication using Deduplicator on SR Accelerator and Endnote, a two-stage screening process of published literature will be undertaken. Following deduplication, the total will be divided into 3 in Endnote, and screening of title and abstracts will be undertaken by three pairs of reviewers (KG-B and JML; IK and RC; and VS and MP). We have made this decision to reflect that it may be difficult to identify relevant studies based on the abstract and title and we want to ensure that we do not exclude relevant papers at this stage. Each record will be reviewed by a pair and where a decision about inclusion/exclusion is not agreed between the two reviewers, a third person will review the record (JMK).

Stage two involves assessing full paper texts. This will be undertaken in duplicate independently by up to four reviewers, dependent on the number of included studies (SY; LP; other members TBC).

Consultation and discussion will take place throughout with review team members until a consensus is reached if there is uncertainty about whether a paper should be included or excluded in the review.

Inclusion criteria

Population

Children and young people with a long-term health condition (physical and/or mental). Children and young people are aged up to, and including, 18 years (no lower age limit), worldwide. We will include studies where a wider age range of participants is reported if data for children and young people (up to and including age 18 years) are reported separately.

Concept

Preferences that children and young people have about health technology and any positive elements that they look for when using health technology. Also, any information that children and young people want or need to know before using health technology will be captured.

Context

Health technology that children and young people engage or interact with and use to manage a long-term health condition*.

Health technology includes any technology used to manage a long-term health condition: mobile/smartphone apps; virtual reality; telehealth/telemedicine; digital health; medical devices (digitised); gamification/health gaming; augmented reality; receiving health information via text message (digital health education messages); wearables for monitoring and patient care; remote monitoring; consumer products (e.g. FitBits); and social media including patient blogs.

All settings will be included (e.g. home, hospital, clinic) and all countries world-wide will be included.

* Long-term health conditions include diabetes; arthritis; cancer; genetic conditions such as muscular dystrophy; mental health (e.g., depression, anxiety); chronic kidney disease, respiratory conditions such as asthma; long-term eye conditions; epilepsy. This list is not exhaustive but highlights some examples of long-term health conditions that affect children and young people.

Study design

Study design will include primary research including qualitative, surveys, questionnaires, feasibility, and mixed methods including these designs undertaken within trials. Protocols and reviews will be tagged and reference lists reviewed for additional studies. Conference abstracts will also be tagged to see if associated full texts can be identified.

Exclusion criteria:

The following studies will be excluded:

- Studies which only explore parents' views, experiences, use or preferences about health technology without including children or young people's views.
- Studies which explore the use of health technology for acute conditions* or for a one off measurement.
- Studies which involve students in a school setting using health technology rather than children or young people with a long-term health condition.
- Studies which use technology for reasons other than managing a long-term health condition.
- Studies which involve the use of technology to enhance mobility, senses or provide medications such as hearing aids, mobility aids, prosthesis, where the child or young person will not be engaging and interacting with the technology.
- Studies which only include young people aged over 18 years.
- Studies published before 2015 to ensure we only include technology that is relevant to current technology used.
- Protocols or reviews. These will be tagged and we can search to see if primary studies from the protocols are published and look at relevant reviews for possibly primary studies of relevance.
- Conference abstracts as these are unlikely to include sufficient detail for extraction. These will be tagged to see if we can identify associated full texts.

* Acute conditions include colds, influenza, measles, tonsillitis, appendicitis. Studies involving vaccinations would also not be included under long-term conditions. Smoking cessation, self-harm, immunisation studies, prevention interventions and sexual health related use of technology are excluded.

Data extraction

Each included paper will have data extracted independently by two review members. A template will be developed and piloted ahead of data extraction.

Extraction will include:

- Authors
- Year of study
- Country where study was conducted/location
- Study population (age, number, gender, sex, ethnicity, education level and long-term health condition)
- Study design (qualitative, surveys/questionnaires, feasibility, acceptability, user-testing/usability and mixed methods)
- Setting where technology was used
- Type of technology
- Retrospective or prospective use of technology
- Preferences/positive elements/needs/information needed
- Limitations reported by each study.

Data synthesis

We will follow the methodology described by Arskey and O'Malley (2) and Levac et al (3) and map the findings. We anticipate a narrative synthesis will be undertaken and gaps identified. Thematic analysis of each of the included studies will also be undertaken. This will involve reading through extracted qualitative (quotations and interpretation from the primary study authors) and quantitative data to identify preferences and assign themes. Bubble plots will be used to show key features of the included studies, e.g. locations and publication dates; or types of technology.

Dissemination

We will write up the review and publish it in a peer-reviewed open access journal. We will also aim to present the findings at relevant conferences and meetings. We will also develop a video about the main findings.

Funding

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References

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2. Arskey H & O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 2015; 8:1, 19-32, https://doi.org/10.1080/1364557032000119616

3. Levac, D., Colquhoun, H. & O'Brien, K.K. Scoping studies: advancing the methodology.*Implementation Sci* **5,** 69 (2010). https://doi.org/10.1186/1748-5908-5-69

4. The Communications Market Report 2015 - Ofcom

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