



mHealth for chronic disease management:

Experiences of young people
and professionals

"I always have my own phone, my phone is – this is my life"

¹This quotation is taken from a participant in one of the studies included in this systematic review:

1. Rhee H, Allen J, Mammen J, Swift M. Mobile phone-based asthma self-management aid for adolescents (mASMAA): a feasibility study. *Patient Prefer Adherence* 2014; **8**: 63-72.

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Glossary, acronyms and abbreviations

App: is an abbreviation for ‘application’. Apps are typically software that runs on the internet, computer or a mobile device.

Best practice care: Approaches that are available to identify, implement and monitor the available evidence in health care.

Chronic Disease: conditions of long duration and generally slow progression, lasting 3 months or more.

Co-care: refers to a co-operative approach to care delivery and evaluation undertaken between a health professional(s) and the consumer of the care, together with their family or guardians.

Comorbidity: the presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder.

Consumer: any actual or potential recipient of healthcare (e.g. patient in hospital, client in a health centre, person seeking health information via the internet). In this context, the term ‘consumer’ does not relate solely to a monetary transaction for a health service.

Cost effectiveness: analysis that compares the relative costs and outcomes of different Models of Care. In this way, cost is balanced against health outcomes.

Digital health: the use of digital, mobile and wireless technologies to support the achievement of health objectives. Digital health describes the general use of information and communications technologies (ICT) for health and is inclusive of both mHealth and eHealth.

eHealth: the use of computer technology and telecommunications to deliver health information and services more effectively and efficiently.

Enabling environment: the attitudes, actions, policies and practices that stimulate and support effective and efficient functioning of organisations, individuals, and programmes or projects².

End-users: an ultimate user of a product or technology³ defined in this study, as young people with chronic non-communicable diseases who interact directly with mHealth technology⁴.

Formative evaluation: a method for judging the worth of a program, while the program activities are forming (in progress). Formative evaluation assesses program design, early implementation and associated outcomes and is generally undertaken before a program is implemented across a system and continuously or over the course of time, especially in the context of digital health³.

Holistic Framework: this is a framework to guide the design and implementation of eHealth technologies in chronic health condition management⁵.

Implementers: individuals that are involved in the development and deployment of an mHealth product² defined in this study as including health professionals, mHealth designers, policy makers, and researchers⁴.

Information and communication technology (ICT): the integration of information systems, telecommunications systems, and components of a system related to the capture, storage, retrieval and transmission of data.

Interoperability: the ability of different information technology systems and software applications to communicate, exchange data and use the information that has been exchanged. Interoperability is enabled by the use of common data standards².

mHealth: is an abbreviation for 'mobile health'. It is defined in this study as including any mobile device or service, such as mobile phones, SMS, smartphones, personal digital assistants, and devices that work on wireless technology or Bluetooth-compatible devices; criteria consistent with a recent systematic review of mHealth to support chronic disease management⁶. In this study, interventions delivered using a Web-based platform were included, only if it was specified that the user accessed the service via a mobile phone, or other mobile device.

mHealth strategy: the application of a technology for a defined health purpose (e.g. text message to deliver messages for antenatal care follow-up) in order to address specific health system challenges².

Macro level factors: these factors consider the functionality and scope of health systems or organisations; health policy; infrastructure and resource allocation; and socioeconomic factors⁷.

Meso level factors: these factors consider health services; the clinical workforce volume and competencies; health professional and student/trainee education; service delivery systems; funding models; and clinical infrastructure⁷.

Micro level factors: these factors refer to the participation of the person in his/her care, including clinical interactions⁷.

Models of Care: An MoC is an evidence-informed policy or framework that outlines the optimal manner in which condition-specific care should be made available and delivered to consumers at a system level. An MoC aims to describe the principles of care for a given condition (the 'what') as well as guidance on how those principles could be implemented in a local setting (the 'how')⁷.

Multimorbidity: the presence of two or more chronic medical conditions.

Musculoskeletal: refers to conditions involving muscles, joints, bones and associated tissues such as ligaments and tendons.

Non-communicable disease (NCD): condition or disease that is non-infectious or non-transmissible. NCDs usually refer to chronic diseases that last for long periods of time and progress slowly. In this study, chronic NCDs, were defined as conditions of long duration and generally slow progression, lasting 3 months or more and included, but were not limited to, musculoskeletal conditions, diabetes, respiratory conditions (such as asthma), cardiovascular diseases, mental health disorders and cancer⁸.

Person-centred: an outcome relevant to a consumer/patient/person of a health service or resource. Person centred outcomes typically reflect outcomes that are meaningful or important to a person and most often include function, quality of life and satisfaction with health services.

Practice enablers: tools, strategies, resources or systems that equip providers to deliver best practice care.

Qualitative methods: a research approach that aims to explore in detail an audience's range of behaviours and the perceptions that drive them, with reference to specific topics or issues. A range of methods can be undertaken to collect qualitative data, such as interviews and focus groups.

Systematic review: a thorough, standardised and documented approach to synthesising relevant literature with the aim of informing a specific research question.

System outcome: an outcome relevant to the health system function or governance. The outcomes generally relate to service use, service funding and workforce.

About this report

This report seeks to inform key agencies and stakeholders such as consumer organisations, government and health agencies about the experiences of users in engaging with mobile health (mHealth) technologies for non-communicable chronic disease (NCD) management in young adults.

This report represents a collaborative initiative between MOVE muscle, bone & joint health, Arthritis and Osteoporosis Western Australia and the School of Physiotherapy and Exercise Science, Curtin University, Perth, Western Australia. Other partner organisations included The Joanna Briggs Institute, University of Adelaide; Government of Western Australia; and the Department of Health and Child Health Evaluative Sciences, The Hospital for Sick Children, Toronto, Canada.

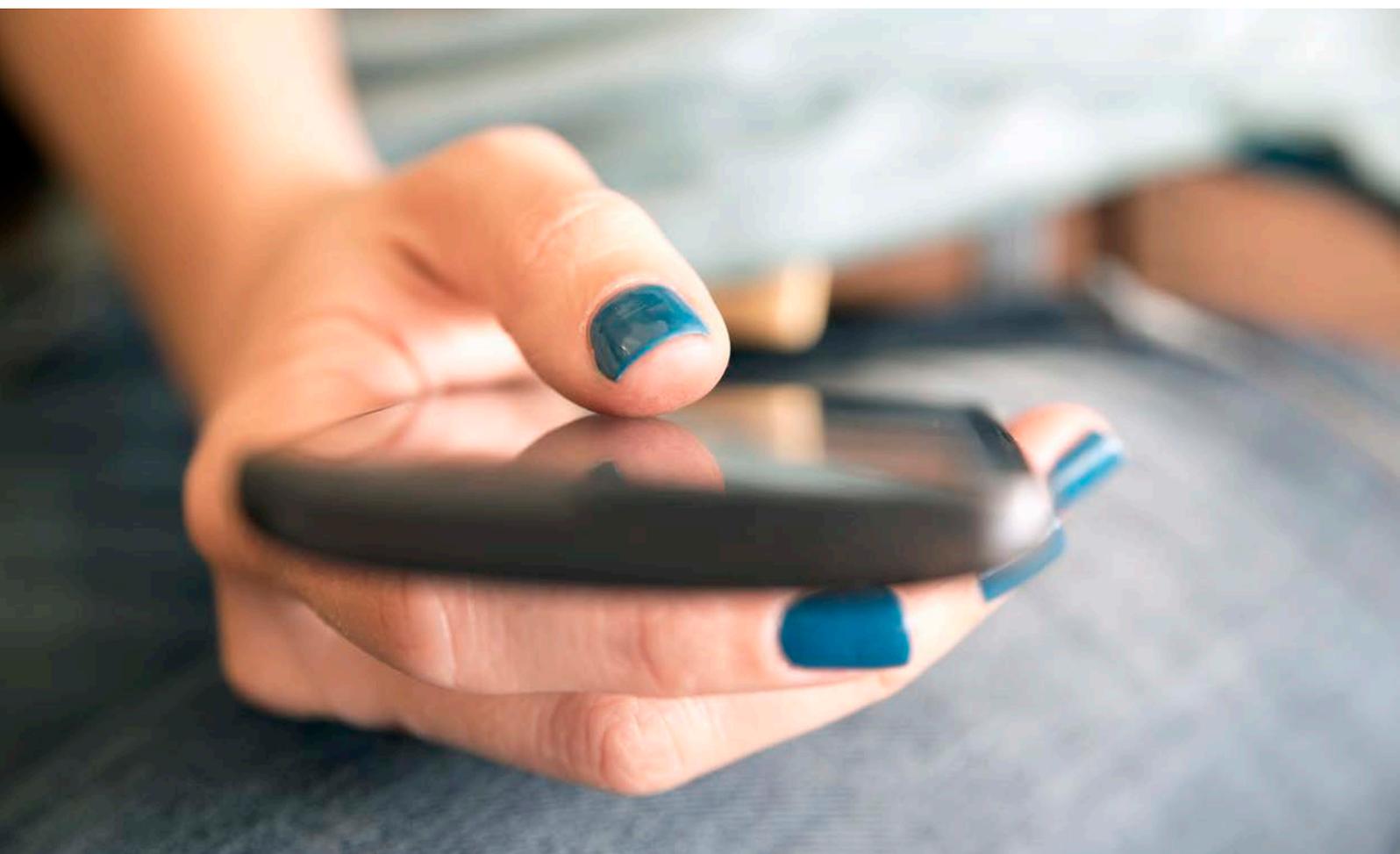
The aim of this project was to identify, appraise and synthesise insights from users (collectively referring to both end-users and implementers) about the characteristics of acceptable and useful mHealth technologies for young people's management of their chronic non-communicable diseases (NCDs). This report provides a user-friendly summary of the results of this project. Readers are referred to the full original version of the systematic review for a comprehensive analysis and interpretation of the study findings⁹.

A systematic review method was adopted to ensure that all relevant evidence was identified and analysed in a rigorous and reproducible manner. Importantly, this approach allows for updates of the review in later years as more evidence in this rapidly evolving area emerges.

This review builds on previous collaborative work^{10,11} and was primarily undertaken to inform the future design and implementation of mHealth technologies specifically targeted for young people with persistent musculoskeletal pain, consistent with the current evidence^{7,12-14}. However, for this review the experience of young people with chronic NCDs was considered more broadly, given that the self-management of chronic health conditions frequently overlaps, is associated with chronic comorbidities and multimorbidities¹⁵, and requires similar core management skills¹⁶.

This systematic review had two key aims:

- i) to identify users' (end-user and implementers) experiences with mHealth technologies to support the self-management of young people with chronic NCDs; and
- ii) to identify facilitators or barriers to the uptake and/or implementation of mHealth technologies for young people with chronic NCDs.



What do we currently know about young people and use of mHealth technologies for health care?

Young people are clear about wanting a health system which puts people first and has improved access to digital health services^{12,17}. Here, the portability and capabilities of mobile digital devices can act as a key lever to connect young people with health systems and their clinicians; thus supporting their chronic disease self management¹⁸. Exploring how mHealth technologies can support management for young people with NCDs is imperative as chronic conditions such as asthma, diabetes, cancer and persistent musculoskeletal pain impose an escalating and unsustainable burden on young people, their families and society¹¹.

The use of mHealth technologies as a health enabler is intuitive, given the high rates of internet usage globally, with rates nearing 100% for the Millennial generation in many of the world's largest economies¹⁹. Further, as digital natives, young people are also more likely than older generations to own a smartphone in virtually every country¹⁹. In some economies, this translates to upwards

of 95% of users connecting daily and using this technology as their main source of information including health and mental health information²⁰. Digital technologies also provide a potential mechanism to mitigate care disparities reaching across high, middle and low-income economies;¹² thus enabling the delivery of integrated and holistic information about chronic NCD management for young people²¹.

While the use of mHealth apps to support ready access to health resources for young people has grown substantially in recent times²², the evaluation of the quality and quantity of health information delivered through these apps remains limited^{23,24}. In particular, significant design limitations have been identified where complex health messages need to be conveyed to users²⁵. Further, many of these mHealth technologies have not been robustly tested for implementation in real world settings. Therefore, barriers and enablers to successful implementation remain unclear.

How does this systematic review contribute to existing knowledge?

Digital strategies can help transform health and ensure quality and sustainability of care^{9,17}. Transformation is critical if we are to meet the escalating burden-service gap imposed by musculoskeletal and other NCDs^{12,13}. In Australia, the lack of accessible, reliable and sustainable resources to address persistent musculoskeletal pain is widely acknowledged,²⁶ while health services and digital resources oriented to the specific needs and preferences of young Australians are largely absent¹⁰. Furthermore, available apps developed specifically for pain management, have been reported as simplistic and typically have not been rigorously tested for pain-related health outcomes²⁷.

Overall while this technology appears promising, the evidence of benefit for the use of mHealth technologies by young people with chronic NCDs, often fails to translate into real world settings²⁸.

This systematic review helps to identify the enablers and barriers to implementation and explores users' experiences of mHealth, providing valuable insights into how we can apply mHealth technologies to better support young people's management of their chronic NCDs⁹.

What is a systematic literature review?

A systematic review is a formal research study which follows a clear, predefined structure to find, assess, and analyse studies that have answered a similar question. The results of a systematic review can provide a reliable picture of what we know and what remains uncertain.

A protocol was developed by the project team to ensure that the results were reproducible and that the review could be updated at a later stage⁴.

In our review, a rigorous systematic approach was undertaken using standardised critical appraisal instruments from the Joanna Briggs Institute (<http://joannabriggs.org/>), specifically the Meta-Analysis of Statistics Assessment and Review Instrument (JBI-QARI)²⁹.

What types of studies were included in the review?

Participants

This review considered all qualitative studies on young people (aged 15 to 24 years) with chronic NCD's (end-users). Additionally, the experience and perspectives of implementers which support young people with chronic NCDs were also considered (such as health service delivery providers, administrators, researchers, clinicians and policy makers).

Chronic non-communicable conditions (NCDs), were defined as conditions of long duration and generally slow progression, lasting 3 months or more, including but not be limited to musculoskeletal conditions, diabetes, respiratory conditions, cardiovascular diseases, mental health disorders and cancer⁴.

Types of studies

This review included full reports published in peer-reviewed journals from January 2007 to December 2016, searched across databases including Embase, MEDLINE (PubMed), Scopus and PsycINFO.

Studies collecting and analysing data using qualitative methods (including but not limited to phenomenology, grounded theory, ethnography, critical enquiry, participatory action research, and descriptive qualitative) were considered. The qualitative components of mixed-methods studies were also included.

mHealth strategies

In this review, mHealth was defined as any mobile device or service, such as mobile phones, SMS, smartphones, personal digital assistants, and devices that work on wireless technology or Bluetooth-compatible devices.

Screening and selection of studies

Two independent reviewers identified eligible reports and conducted critical appraisals—based on the Joanna Briggs Institute, Meta-Analysis of Statistics Assessment and Review Instrument (JBI-QARI)²⁹. One reviewer (JC) was responsible for data extraction and a second reviewer (HS) extracted data for a subset of studies to ensure reliability in data extraction processes. Three reviewers (JC, HS, AMB) independently, then collaboratively, synthesised and interpreted the extracted data through an inductive and iterative process to derive emergent themes across the extracted data. External construct validity checking of the emergent themes was undertaken by an expert clinical researcher (JS) and for relevant content, a health policy expert (MB). The final set of themes were subsequently subjected to a meta-synthesis with findings compared and contrasted between user groups. The project team then derived policy and practice recommendations.

What the systematic review shows

Twelve studies were identified for inclusion in the review⁹:

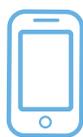
- seven studies on end-users which investigated mHealth technologies in young people with diabetes, cancer and asthma^{1,30-35} and
- five studies for implementers investigating mHealth technologies for young people with cognitive and communicative disabilities, asthma, chronic self-harm and attention deficit hyperactivity disorder³⁶⁻⁴⁰.

No relevant studies were identified for persistent musculoskeletal pain.

Quality ratings were higher for 'implementer' compared with 'end-user' studies.

End users' experiences and perspectives

A number of themes were identified among the studies investigating end-users of mHealth⁹. These included:



Theme 1: Functionality of mHealth technology

Functionality that supported self-management

End-users identified that mHealth technologies could support self-regulation, monitoring health status, reminders for medication adherence, safety, and communication with health professionals.

Enhancing clinical encounters

mHealth technologies were perceived to enable accurate and immediately available clinically-relevant personal data at a consultation to facilitate communication with health professionals.



Theme 2: Acceptance of mHealth technologies (technical usability and feasibility)

Technical usability

End-users reported usability as a key perceived capability including the capacity to optimise the technology to meet their requirements. Users also made suggestions for optimisation or improvement such as bypassing the need for accessing SMS text messaging via an internet browser on their mobile phone and having a download of the software for use directly on their own mobile phones.

Perceptions of experiences around acceptability and feasibility

End-users preferred apps that were intuitive, self-explanatory, simple to understand and that provided practical self-management information.



Theme 3: Importance of co-design

End-users identified the critical importance of co-design of mHealth technologies, including the importance of:

Intra-personal factors

End-users identified considerations that were important in the co-design of mHealth technologies including competing time constraints, understanding disease triggers and addressing preconceived beliefs (e.g. that they were already adequately self-managing their condition).

Extra-personal factors

Included the capacity for tailoring design and making mHealth technologies more broadly acceptable for end-users by understanding disease-specific requirements and meeting young people's needs around the use of technology for self-management, and peer and social settings.



Theme 4: Perceptions of benefit (self-efficacy and empowerment)

Self-efficacy

End-users indicated that mHealth technologies were beneficial and positively influenced their internal sense of control, consistent with improved self-efficacy.

Empowerment

End-users perceived mHealth technologies as empowering their NCD self-management resulting in increased confidence and more positive perceptions about their ability to better manage their lives.

Implementers' experiences and perspectives



Theme 1: Characteristics that supported self-management (functional, technical and behavior change)

Implementers identified multiple components of young people's NCD management that can be supported by mHealth technologies.

Functional aspects of design that support end-users' management

These included tracking of disease symptoms and progress, medication safety and adherence, communication, and focusing the clinical encounter.

Technical characteristics that support clinicians' delivery of clinical care

This included perceptions and experiences that assisted their delivery of clinical care and promoted effective engagement with end-users. Communication reminders regarding clinical management also supported clinical care and assisted in focusing clinical encounters through pre-planning.

How mHealth can support positive health behavior change

mHealth technologies were perceived by implementers as positively influencing end-users to independently manage their condition. This facilitated positive health behavior change through providing positive feedback to end-users and enhancing communication and engagement through age-appropriate appeal.



Theme 2: Implementation challenges (systems level, service delivery level and clinical level)

Important challenges to implementation of mHealth technologies were experienced or perceived by implementers as extending across multiple levels of the health care system including:

Challenges at the clinical level/micro level

These challenges included the accuracy of health indicator monitoring (lack of feedback and long-term monitoring capabilities) and a limitation of task-specific capability for specific health conditions.

Challenges at the service delivery/meso level

Factors that posed challenges and barriers to implementation for service delivery included the regulatory environment of organisations, competing resource allocation (remuneration and funding); issues with integration into the current work flow; organisational climate and readiness for change; and a lack of interoperability with existing information and technology infrastructures.

Challenges at a systems/macro level

These included the need to meet health information security requirements and alignment with national or jurisdictional eHealth regulatory frameworks.



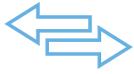
Theme 3: Adoption considerations for specific populations (training end-users; specific design requirements)

The need for training of end-users

Specific training was perceived as facilitating better uptake or adoption of mHealth technologies in specific populations where independent use of mHealth technologies is difficult (for example, those with cognitive impairments).

The need for design to facilitate uptake and match social context or peer expectations

Factors included design that encouraged adoption by end-users and allowed end-users to ‘blend in’. Further, implementers highlighted the need for capabilities to streamline functionality with end-users existing technology (efficient) and adopt technologies that align with their daily habits.



Theme 4: Co-design and tailoring to facilitate uptake and person-centred care

Implementers perceived specific characteristics of mHealth technologies that they considered important to support end-users’ management of NCDs.

The importance of co-design

Implementers highlighted the importance and value of working collaboratively with end-users to optimise functional requirements of mHealth technologies in the early phase of mHealth development.

Tailoring to end-user needs

Implementers identified the need for mHealth technologies to be adaptable, providing for tailored age-relevant design, content and functionality and meeting condition-specific requirements.

Both complementary and unique user themes emerged as components aligned with an existing Holistic Framework model (Figure 1). The Holistic Framework was developed by van Gemert-Pijnen and colleagues⁵ to guide the design and implementation of eHealth technologies in chronic health condition management. The framework allows for an inherently fluid, iterative and cyclical nature of design, implementation and evaluation of digital technologies.

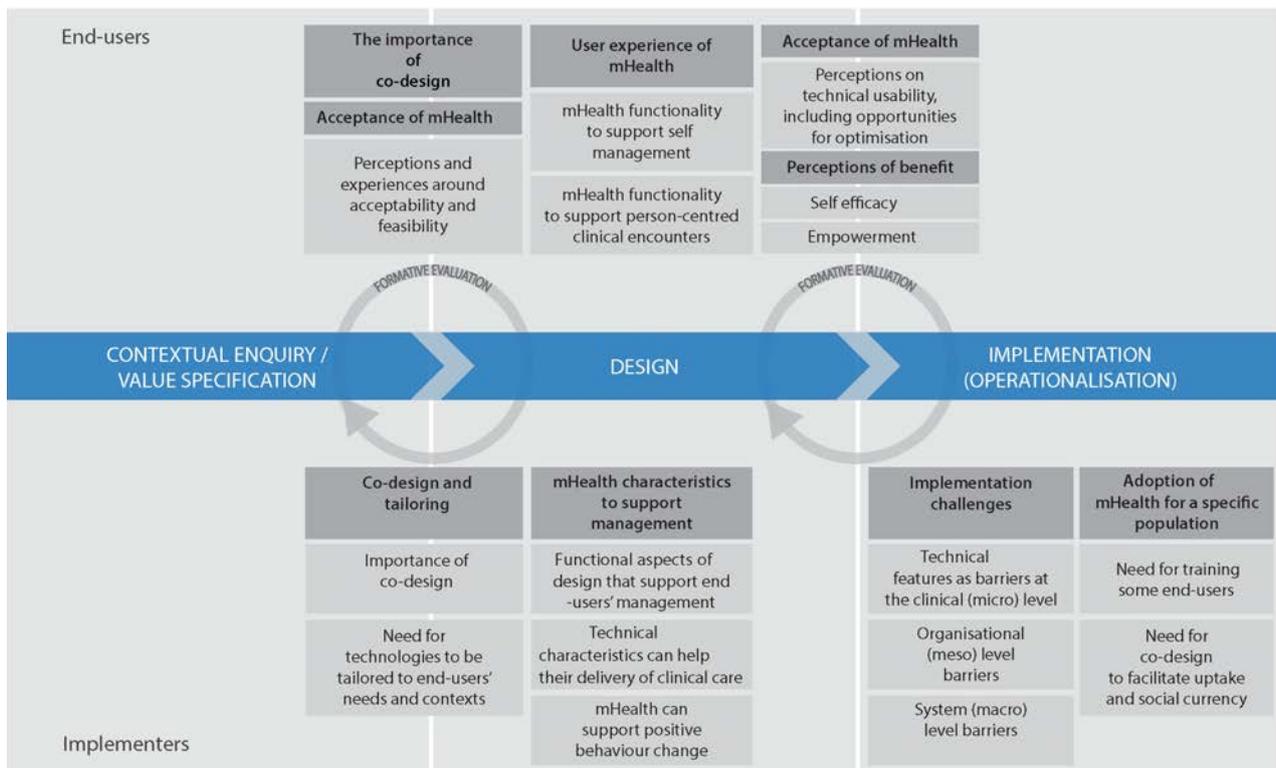


Figure 1. A representation of the review findings are mapped against elements of the Holistic Framework⁵. Both complementary and unique user perspectives are evident: themes (dark grey) and subthemes (light grey) for ‘end-users’ are represented above the blue line and for ‘implementers’, are shown below the blue line. The central blue line indicates a left to right movement showing the continuous and iterative cycles of mHealth design, development and implementation. This figure is adapted from Slater et al 2017⁹.

Key insights

The key findings from this systematic evidence synthesis indicate both shared and unique user perspectives on the use of mHealth for NCD management in young people⁹.

- mHealth technologies were perceived by users (young people and implementers) as supporting young people's self-management across a range of chronic NCDs including diabetes, cancer, asthma, communicative disabilities, chronic self-harm and attention deficit hyperactivity disorder. No relevant studies were identified that specifically examined persistent musculoskeletal pain.
- Complementary perspectives were shared by both user groups on the use of mHealth technologies to enable young people's management of NCDs. These perspectives included the co-design of mHealth technologies; functional and technical aspects of mHealth technologies that were person-centred and which aligned with young people's current technology use (habits, routines and preferences); and those which supported the delivery of clinical care and positive behaviour change.
- As end-users, young people perceived the benefits of mHealth technologies as empowering them to more independently manage their chronic health conditions.
- Implementers (specifically clinicians) perceived a great benefit in mHealth providing ready access to clinical data during consultations and as an enabler to support person-centred clinical encounters.
- Implementers identified barriers to the uptake or adoption of mHealth technologies as representing 'whole of system' (multi-level) factors, including at the clinical level (micro factors), at the organisational level (meso factors) and at the systems level (macro factors). Implementers also identified the need for specific design considerations for mHealth applications for vulnerable populations such as those with cognitive impairments.

These complementary and unique perspectives highlight both the interdependencies and complexities encountered by different users interacting with a rapidly evolving digital health ecosystem. The findings are likely to be transferable across all NCDs.

Policy and practice recommendations and implications

mHealth can support self-management of young people with chronic NCDs and drive meaningful change in contemporary health ecosystems⁹. Young people with chronic NCDs want to be part of any mHealth solution to improved care. However, identifying and resolving implementation challenges are critical to enabling co-designed mHealth solutions that are engaging for young people as well as sustainable and scalable.

Based on this systematic review, we have derived five key recommendations and described the associated policy and practice implications (Table 1). These recommendations should help to inform appropriate resource design, evaluation and implementation in a manner that all users will find acceptable and that health systems will find sustainable.

Non-governmental organisations such as MOVE muscle, bone & joint health, and Arthritis and Osteoporosis Western Australia can play leadership roles in assisting the implementation of these recommendations. In particular, leadership that focuses on advocacy, resource development, and partnership approaches to research, policy and education about the critical role for mHealth design, development and implementation to support young people better manage their health.

Table 1. Recommendations

RECOMMENDATION 1



Mobile health (mHealth) technologies should be considered as a potential strategy or solution to enable self-management, to improve clinical encounters, and to encourage positive health behaviors in young people with chronic non-communicable diseases (NCDs).

Implications

- mHealth should be considered by consumers and stakeholders involved in the delivery of care as a complement to existing health care options, as a means to enhance care delivery and efficiency and to integrate into care pathways.
- To achieve this outcome, it is important to clearly identify end users' needs and also to identify where and when in a young person's care pathway mHealth technologies could meaningfully affect capacity for self-management, improve clinical encounters and influence positive health behaviour.
- Policy makers need to respond to the momentum around mHealth by considering current care pathways and support systems and identifying opportunities for integration of mHealth technologies to optimise co-care; to facilitate location-based care; and drive quality, safety, and efficiency in care delivery.

RECOMMENDATION 2



Design of mHealth technologies for young people with chronic NCDs should be a collaborative process involving partnerships with multi-stakeholders (e.g. young people, health professionals, digital technology designers, service delivery, and policy makers) to achieve meaningful co-design and to inform appropriate implementation approaches.

Implications

- A collaboration of relevant stakeholders needs to be engaged from inception and at all stages through planning, developing, testing, implementing and through continuous cycles of improvement (formative evaluation) for mHealth technologies.
- Importantly, different stakeholders may be needed at different stages and these stakeholders should be explicitly identified to align with requirements at each stage.
- From inception, processes should be informed by contemporary evidence and an appropriate implementation science framework.
- The outcome of this collaborative and evidence-informed approach should ensure that mHealth technologies have social currency and are contemporary, relevant and useful to young people.

RECOMMENDATION 3



mHealth technologies for chronic NCD management in young people need to have functional capabilities that allow for tailoring to end users' preferences and person-centered needs.

Implications

- Implementers need to undertake formative evaluations of mHealth technologies across the development and implementation stages in partnership with young people to ensure that functionality is responsive to their end user needs, including changing developmental and NCD needs.
- These formative evaluation outcomes need to direct iterations of mHealth technologies.

RECOMMENDATION 4



Implementation initiatives must consider whole-of-system readiness to adopt mHealth technologies. The use of contemporary mHealth toolkits for planning and scale is advisable².

Implications

- At a health systems (macro) level, it is necessary to consider system readiness to support implementation and adherence. This requires identifying gaps and opportunities across the system to support implementation, including
 - > current policy or strategy platforms
 - > workforce capacity building initiatives and priorities
 - > infrastructure and human resourcing
 - > strategic cross-sector partnerships
 - > alignment with existing policy, technological, legal, and regulatory frameworks. Compliance with information and communication technology regulatory frameworks is imperative.
- At the service delivery (meso) level it is necessary to consider:
 - > organisational readiness for change (eg, culture, change management leadership, executive support, and technophobia)
 - > seamless integration of mHealth into existing and planned workflow
 - > business modeling to capture value, cost effectiveness, and sustainability
 - > interoperability with existing information and technology systems.
- At the clinical (micro) level, implementers need to jointly assess, in partnership with health providers and end-users, the desired functionality, required accuracy of data capture and security associated with the use of proposed mHealth technologies.



Implementers of mHealth technologies must undertake continuous cycles of improvement to maintain technical and functional optimisation. The use of contemporary digital health monitoring and evaluation guidance is advisable³.

Implications

- Given the rapidly changing landscape of mHealth technologies, continuous technical updates are needed to address changes (to maintain platform compliance and security).
- Planned review cycles are necessary to allow for iteration and optimisation of content and functionality based on analytics data.
- A governance framework needs to be developed in advance of implementation, with the aim of addressing project management and guiding these review cycles.
- Dedicated resourcing is required to implement such a framework.



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