UNIVERSITY OF LEEDS

This is a repository copy of *Developing mobile applications for and with young people with long-term conditions learning to share their healthcare with professionals: a young person and family-led approach*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/119461/

Version: Published Version

Conference or Workshop Item:

This is an author produced version of "Developing mobile applications for and with young people with long-term conditions" Presented at INVOLVE 2014.

White Rose
university consortium
Universities of Leeds, Sheffield & York

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

Developing mobile applications for and with young people with long-term conditions

Simon R. Stones[1, 10]; Rabiya Majeed-Aris[2, 7]; Andrew Hall[2]; Wendy Thomson[2]; Helen Foster[3, 8]; Eileen Baildam[4,9]; Janet McDonagh[5]; Sharon Douglas[6, 10]; Debbie Fallon[2]; Alice Chieng[7] and Veronica Swallow[2, 7]

[1]Faculty of Life Sciences, The University of Manchester, [2]Faculty of Medical and Human Sciences, The University of Manchester, [3]Musculoskeletal Research Group, Institute of Cellular Medicine, Newcastle University, [4]Alder Hey Children's NHS Foundation Trust, [5]School of Immunity and Infection, University of Birmingham, [6]Scottish Network for Arthritis in Children, [7]Cental Manchester University Hospitals NHS Foundation Trust, [8]Great North Children's Hospital, [9]The University of Liverpool, [10]NIHR CRN: Children/Arthritis Research UK Paediatric Rheumatology Clinical Studies Group
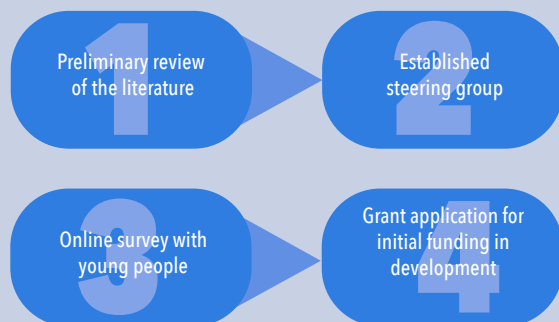
Introduction

- The use of mobile devices is commonplace among young people.[1]
- There is scope to develop this technology to support the needs of those with long-term health conditions.
- Young people need support to become independent and able to self-manage their condition. The mobile app would be a valuable tool in this process.
- However, there is little reliable research on the development or evaluation of this technology that actively involves young people as partners.
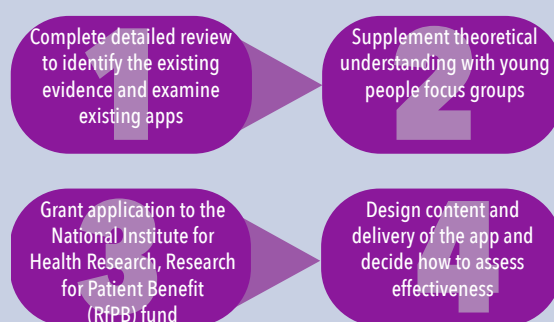
Aims

- To establish a Manchester-based research team.
- To include young people with long-term conditions, parents, researchers, technologists, and healthcare professionals as equal partners.
- To develop a plan of work that focuses on the use of mobile technologies for young people with long-term conditions.[2]
- To use the design and methods of our previous National Institute for Health Research, Research for Patient Benefit funded project as a platform to inform development of this work.[3]

Timeline

Where we have been:

1. Preliminary review of the literature
2. Established steering group
3. Online survey with young people
4. Grant application for initial funding in development

Where we are going: (based on Medical Research Council framework)

1. Complete detailed review to identify the existing evidence and examine existing apps
2. Supplement theoretical understanding with young people focus groups
3. Grant application to the National Institute for Health Research, Research for Patient Benefit (RfPB) fund
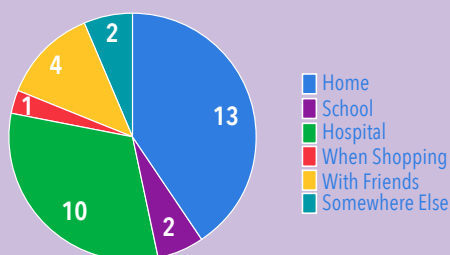4. Design content and delivery of the app and decide how to assess effectiveness

Online Survey Results

Is there a need to develop an app?

12 out of 14 young people living with juvenile idiopathic arthritis (JIA) felt there was a need for the mobile app, and 2 were unsure.

Where would young people use the app?

- Home — 13
- School — 2
- Hospital — 10
- When Shopping — 1
- With Friends — 4
- Somewhere Else — 2

What do young people want from the app?

- Goal setting
- Frequently asked questions
- Keeping track of the past
- Progress reviews
- To share experiences
- Treatment reminders
- Data records e.g. bloods
- Instruction guides
- Appointment reminders
- Social Media element

"The app needs to be password protected and secure for me to use it."

"The app would be good because I don't like asking people for advice, I like to look for it myself."

References

1. Ofcom. (2014). The communications market. Available from http://stakeholders.ofcom.org.uk/binaries/research/cmr/cmr14/2014_UK_CMR.pdf. [Accessed August 2014].
2. Dennison L, Morrison L, Conway G, Yardley L. (2013). Opportunities and Challenges for Smartphone Apps in Supporting Health Behaviour Change: Qualitative Study. J Med Internet Res. 15(4).
3. Swallow V, Carolan I, Hall A et al. (2014). A novel Interactive Health Communication Application (IHCA) for parents of children with long term conditions: Development, implementation, feasibility assessment. Informatics for Health & Social Care. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25119067. [Accessed 19 October 2014].

MANCHESTER 1824 — The University of Manchester

Newcastle University

Alder Hey Childrens' NHS Foundation Trust

UNIVERSITY OF BIRMINGHAM

snac — scottish network for arthritis in children

Central Manchester University Hospitals NHS Foundation Trust

The Newcastle upon Tyne Hospitals NHS Foundation Trust

THE UNIVERSITY of LIVERPOOL

NHS National Institute for Health Research