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Stones, SR, Swallow, V, Majeed-Aris, R et al. (1 more author) (2015) OP0243-PARE Involvement of Children and Young People with Long-Term Conditions in the Development of Mobile APP Technology to Promote Disease Self-Management. In: EULAR (European League Against Rheumatism) 2015, 10-13 Jun 2015, Rome, Italy.


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Background: The use of mobile devices is commonplace among young people. There is scope to develop this technology to support the needs of those with long-term health conditions (LTCs). Young people need support to become independent and be 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 equal partners.

Objectives: To establish a Manchester-based research team, consisting of young people with LTCs, parents, researchers, technologists and healthcare professionals (HCPs) as equal partners. The team will develop a plan of work that focuses on the use of mobile technologies for children and young people with LTCs, using the design and methods of our previous National Institute for Health Research, Research for Patient Benefit funded project.

Methods: A group involving a patient with juvenile idiopathic arthritis (JIA), a parent, HCPs and researchers have established a Manchester-based research and development programme on mobile technologies for young people with LTCs. We have fostered strong partnerships with other national groups to help us agree on research priorities in this important area, and a plan of work to help us achieve these. Qualitative research was carried out in the form of an electronic survey, completed by a small population of 14 young people with JIA.

Results: 86% of young people living with JIA felt there was a need for the mobile app, with 14% unsure about the benefit. Children and young people felt that they would use the app most at home or at the hospital. There was an observable lack of interest to use the app whilst at school, with friends or when shopping. Young people suggested that the app should be a tool to improve skills in disease self-management, as well as providing a safe and secure environment for social interaction and mutualistic data collection with HCPs.

Conclusions: The development of mobile app technology for supporting disease self-management is important in an environment driven by technology and innovation. However, such tools must be developed, for and with, children, young people and their families, in order to be effective and promote long-term retention of such software. Following a
systematic review of the literature regarding mobile apps in health, the project will continue to work with young people, parents and HCPs to produce a detailed software specification for a prototype application to test with young people.


**Acknowledgements:** MobAPP Steering Group, The University of Manchester

**Disclosure of Interest:** None declared