



Self-care and Independence in Children with Long Term Conditions

SBRI Healthcare NHS England competition for development contracts

May 2016

Summary

A new national Small Business Research Initiative (SBRI) Healthcare competition is being launched by NHS England in partnership with the Academic Health Science Networks (AHSN's) to find innovative new products and services. The projects will be selected primarily on their potential value to the health service and on the improved outcomes delivered for patients.

The competition is open to single companies or organisations from the private, public and third sectors, including charities. The competition will run in two phases:

- Phase 1 is intended to show the technical feasibility of the proposed concept. The development contracts placed will be for a maximum of 6 months and up to £100,000 (inc. VAT) per project
- Phase 2 contracts are intended to develop and evaluate prototypes or demonstration units from the more promising technologies in Phase 1. Only those projects that have completed Phase 1 successfully will be eligible for Phase 2.

Developments will be 100% funded and suppliers for each project will be selected by an open competition process and retain the intellectual property rights (IPR) generated from the project, with certain rights of use retained by the NHS.

The competition opens on 8 June 2016. The deadline for applications is 1200hrs on 28 July 2016.

Background

What happens during childhood affects health and wellbeing in later life. It is important to ensure that all children and young people (CYP), including those with health problems and long term conditions, have the best start in life and are well equipped to deal with life's challenges. Currently, CYP with long term-conditions spend a lot of their lives interacting with the health service. Hospital admissions for CYP with multiple co-morbidities and long term conditions have increased significantly in the last decade as these children undergo investigations, monitoring, and treatment including rehabilitation. In addition, they have an increased number of out-patient hospital appointments with multiple professionals.

Key impacts of this burden of time spent engaging with the health service includes missed time from education, and social integration with peers both inside and outside of school. In 2012, 31% of school pupils aged 11–15 who reported having a long-term illness, disability or medical condition felt it impacted negatively on their ability to participate in education ¹. Conversely, as long term conditions can impact on education, there is also clear evidence that lack of education can have negative impact on health².

The higher use of health services by this population and the subsequent potential negative effect on education and future prospects has an obvious economic burden. Thus there is a growing economic and social need to improve the health and the lives of children and young people (CYP). Thus realigning the social and environmental context by which health is delivered i.e. in the home environment, has the potential not only

¹ Brooks F, Magnusson J, Klemmera E, Spencer N, Morgan A. HBSC England National Report: World Health Organization Collaborative Cross National Study. Hat eld: CRIPACC, 2011.

² Durlak JA, Weissberg RP, Dymnicki AB, Taylor RD, Schellinger KB. The impact of enhancing students' social and emotional learning: a meta-analysis of school-based universal interventions. *Child Dev.* 2011 Jan- Feb;82(1):405-32.

to improve quality of life and promote independence but also serves to facilitate the long term societal contribution that young people make after leaving school.

Challenges

How many children and young people require help and support?

There are multiple long-term conditions in childhood that could benefit from a reduction in hospital admissions and improved care and monitoring in the home environment. These even include rare diseases which individually have a very low prevalence but collectively are common and will have common issues requiring attention.

0.8 million disabled CYP aged 0–18 in the UK are disabled which accounts for 6% of all children. The most common functional limitations concern mobility (18%), communication (22%) and memory, concentration or learning (24%)³.

There are a significant number of CYP with common long term conditions such as diabetes and asthma. The prevalence of type 1 and 2 diabetes among CYP in the UK is increasing. Treadgold ⁴ estimates that at least 29,000 CYP in the UK have diabetes. 26,500 CYP have Type 1 diabetes while 500 have Type 2 diabetes. A further 2,000 CYP are estimated to have diabetes, but have not been diagnosed. The peak age for diagnosis is 10 and 14 years of age.

Asthma is the most commonly diagnosed long term condition among CYP. Asthma UK ⁵ estimates that 1.1 million CYP in the UK (1 in 11) have asthma, and the UK has one of the highest prevalence rates of asthma symptoms for children worldwide. Asthma accounts for a higher number of emergency bed-days and emergency admissions to hospital for children and young people than any other paediatric long term condition.

The number of hospital admissions in England for asthma has increased by 27% since 2002/3 to just under 8,600 in 2009/10 ⁴. An estimated 75% of hospital admissions for asthma are preventable. Whilst relatively small in number compared to the adult population, children with cancer have significantly better survival outcomes in the last decade, but as a result, have multiple co-morbidities and disabilities as a result of their disease or treatment known as the late effects of cancer.

Why do we need to improve the level of support?

It is recognised that key elements of development, particularly emotional development, continue until the early 20s, and will have a permanent effect on life skills in adulthood. Improving self-care and independence in children with disability and long term conditions and reducing hospital admissions through appropriate self-management of conditions and remote monitoring in the community is key. Improvement in self-care has the potential to lead to better compliance with investigations and treatments, a reduction in hospital admissions and thus better integration within peer groups in the short and long term, which has the potential to improve emotional wellbeing and confidence.

³ Department for Work and Pensions (2012) Family Resources Survey 2010/11.

⁴ Treadgold, P., 2012, Long-term conditions – Association for Young People’s Health, Research Summary

⁵ Asthma UK., 2015 – Asthma Facts and Statistics

In early and mid-adolescence, individuals often take over management of their chronic conditions from their parents, and there is strong evidence that self-management behaviours initiated in adolescence remain with them throughout life ⁶. Adolescence therefore provides an important window of opportunity to influence outcomes in adulthood.

CYP using specialist health services perceive themselves as experts on their own conditions and health status, and want those with non-specialist knowledge to acknowledge this expertise and specialists to recognise them as partners in their care⁷. Moreover, young people have repeatedly commented that they want improved co-ordination, communication and integration between health workers and health provision, so that they do not have to keep repeating their experiences to different professionals ⁸ and wish services to be easy to access at convenient, non-stigmatising locations, close to home ⁹.

Ultimately, this requires a shift change in the way in which long term conditions are managed and health care is delivered for CYP. This provides an opportunity to improve the management of long term conditions in the community environment, particularly in the home.

Challenges

Through the work of The Technology Innovation Transforming Child Health (TITCH) Network and consultation involving a broad range of health care professionals and families, a number of priority unmet health needs have been identified for children and young people, which require innovative solutions.

We are inviting applications to support self-care and independence in children with long term conditions in two key categories:

- Category 1: Assisting or restoring function
- Category 2: Self-care & remote monitoring

One of the key challenges in developing technology for children and young people in this area, is that solutions must either be age specific and appropriate, or instead be versatile and adaptable to meet the physiological and anatomical changes aligned with growth and development.

Moreover, in the child health setting, the family unit must also be considered, particularly in relation to young children, whilst facilitating independence and self-care as children develop and move into adolescence. As part of this challenge, applicants must consider how the technology or innovation may reduce the number of hospital admissions and facilitate independence that may ultimately support better participation in home and school activities and lead to improved social independence in adulthood.

⁶ Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: challenges living, challenges treating. *Lancet* 2007; 369(9571): 1481–9.

⁷ Franklin A, Sloper P. Listening and responding? Children's participation in health care within England. *The International Journal of Children's Rights*. 2005 Mar 1;13(1):11–30.

⁸ Allard A. *Managing my way*. Council for Disabled Children. 2011.

⁹ Mainey A, Ellis A, Lewis J. *Children's views of services: A rapid review*. National Children's Bureau. 2009.

Category 1: Assisting or restoring function

According to the UK Equality Act 2010, a person is disabled if they have a physical or mental impairment that has a substantial and long term effect on their ability to carry out normal day-to-day activities. Technology can play an important role in enabling a young person's independence. The following "what if" are some examples of scenarios that have the potential to assist or restore function:



Almost half of disabled children and young people, as compared with a fifth of non-disabled children and young people, live with a parent who is also disabled. Therefore, technologies that can be used to aid limb rehabilitation in children and young people must also be usable by parents.

Category 2: Self-care & Remote Patient Monitoring (RPM)

There are a significant number of long term conditions, both common (e.g. asthma) and rare, that affect children. The development of RPM to support children with long term conditions (including children with neurodisabilities) could be disease specific, relating to a particular condition, or may be generic, to measure signs or detect symptoms that are attributable or common to a number of long term conditions. The following "what if" are some examples of scenarios that have the potential to aid self-care and remote monitoring:

What if there was better remote monitoring in the home environment?

More accessible self-management of health?

Preventing health issues from arising?

Recording self-management technique to improve self-management skill/accuracy?

Detection of issues in relation to management of the long-term condition?

Detection of abnormal signs/changes in physiological parameters to facilitate early diagnosis?

Facilitate communication between patients, families and health professionals

Documenting treatment regimes and physiological/cognitive responses to treatment?

Early detection of deterioration/exacerbation leading to more rapid intervention?

Applicants must consider how data from RPM can be communicated/relayed rapidly or in real-time to health professionals, and the storage of information derived from monitoring. In addition, applicants may wish to consider means by which parents and young people can communicate easily with clinicians, either directly or through remote monitoring, to reduce the number hospital attendances. RPM must also be considered within the context of age and development.

What if innovative solutions could reduce journeys to a healthcare setting?

Technology to facilitate investigations in the home?

Reduce the number of hospital visits/administrations?

Easy & remote communication with clinicians?

Relay of real time data for rapid response during remote investigation/consultation?

Technology is breaking down the traditional NHS barriers of monitoring and delivering care. Remote patient monitoring of patients outside of conventional clinical settings (e.g. in the home), may increase access to care and decrease healthcare delivery costs. In chronic disease management in CYP, technology can significantly

improve an individual's quality of life and provide independence, prevent complications, and minimise personal costs ¹⁰.

RPM can also be used to facilitate communication between families and health professionals, whilst rapidly transmitting real time data to allow patient monitoring and diagnosis. The implementation of RPM is in line with the NHS Five Year Forward View, which supports the use of technology to help deliver appropriate intervention and care in the home and community, with services integrated around the patient and to reduce the number of hospital admissions.

Application process

This competition is part of the Small Business Research Initiative (SBRI) programme which aims to bring novel solutions to Government departments' issues by engaging with innovative companies that would not be reached in other ways:

- It enables Government departments and public sector agencies to procure new technologies faster and with managed risk;
- It provides vital funding for a critical stage of technology development through demonstration and trial – especially for early-stage companies.

The SBRI scheme is particularly suited to small and medium-sized businesses, as the contracts are of relatively small value and operate on short timescales for Government departments.

It is an opportunity for new companies to engage a public sector customer pre-procurement. The intellectual property rights are retained by the company, with certain rights of use retained by the NHS and Department of Health.

The competition is designed to show the technical feasibility of the proposed concept, and the development contracts placed will be for a maximum of 6 months and up to £100,000 (incl. VAT) per project.

The application process is managed on behalf of NHS England by the Eastern Academic Health Science Network. All applications should be made using the application forms which can be accessed through the website www.sbrihealthcare.co.uk.

Briefing events for businesses interested in finding out more about these competitions will be held on the 21st June in London and 22nd June in Leeds and. Please check the [SBRI Healthcare Website](#) for confirmation of dates and venues, information on how to register and details of the challenges that will be presented at each event.

Please complete your application using the online portal and submit all relevant forms by 1200hrs on the 28th July 2016.

¹⁰ Bayliss, E., Steiner, J.F., Fernald, D.H., Crane, L.A., & Main, D.S. 2003. Descriptions of barriers to self-care by persons with comorbid chronic diseases. *Ann Fam Med*, 1(1), 15-21

Key dates

Competition launch	8 June 2016
Briefing events	21 June 2016, London 22 June 2016, Leeds
Deadline for applications	28 July 2016
Assessment	September 2016 / October 2016
Contracts awarded	November 2016
Feedback provided by	December 2016

More information

For more information on this competition, visit:

www.sbrihealthcare.co.uk

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For more information about the SBRI programme, visit:

www.innovateuk.org/SBRI