Clinical advisor to lead evaluation and identification of a patient passport for children and young people with long term conditions (asthma, diabetes and epilepsy)

Expressions of Interest

October 2018
Introduction

In May 2018 the Greater Manchester Health and Care Board approved the Greater Manchester Children and Young People Health and Wellbeing Framework for 2018-2022. At a meeting of the Greater Manchester Children and Young People Health and Wellbeing Board in May 2017 the benefits that a passport could give to young people and their families were identified and a mandate to implement a passport for young people with long term conditions was given. From this work and as part of the delivery of the framework to support the objective aiming to prevent hospital attendances and admissions for children with long-term conditions such as asthma, epilepsy and diabetes, the Greater Manchester and Eastern Cheshire (GMEC) Strategic Clinical Network (SCN) has committed to deliver a project in financial year 2018/19 under the title:

**GM Young People’s Long Term Condition Passport: Determine a recommended passport**

To achieve this we are looking for a clinical advisor:

1. to evaluate existing passports against the requirements of children and young people from Greater Manchester who have been diagnosed with asthma, diabetes and or epilepsy

2. make recommendations as to the best type of passport for them to use.

GM has been identified as an outlier with significantly higher hospital admissions for asthma, diabetes and epilepsy compared to the England average and so for this project the passport will be used for patients with a diagnosis for those three conditions only. If a patient has multiple or complex needs that include asthma, diabetes and epilepsy then the passport will likely be used by the person and their family to provide information on their additional conditions and needs. This work which focuses on the 3 long term conditions, asthma, diabetes and epilepsy, will potentially act as a pilot for a wider roll out in future years to children and young people with other long term conditions and their families.

It is essential that the children and young people of Greater Manchester, particularly if they have one of the 3 conditions, are involved in design and development of the passport.

The passport may also be used by the families of children and young people without the capacity to express or represent themselves and must take account of data protection and confidentiality requirements. It is desirable to have one single solution for the passport which covers a range of aspects such as these.

The aim of this project is NOT to design and produce a new passport but rather to recommend the use of an existing product, particularly if there is evidence for its success. The passport can then be rolled out across GM with the smallest possible cost and product maintenance and support requirement.
Outline of work envisaged for LTC Passport

1. Identify existing passports used by children and young people with long term conditions and their families and carers.

2. Engage with children and young people and their families in GM with long term conditions to better understand and identify their requirements from a passport.

3. Assess the requirements from young people and their families alongside the functionality of existing passport system or applications to produce a recommendation for a single preferred passport.

Role of the Clinical Advisor (Oct 2018-March 2019)

- Engage with local representatives of children and young people to produce a list of user requirements for a young people’s long term condition passport
- Identify and review existing digital resources, systems or applications that may serve as the GM young people’s long term condition passport against the user requirements from young people and their families
- Identify appropriate mechanisms to launch the recommended passport to the public and GM system leaders
- Link with other geographical areas and national teams to identify best practice in young people passports
- Produce an updated plan for delivery of the project with delivery milestones
- Provide a monthly highlight (update) report outlining progress on delivery

Role of the Strategic Clinical Network (SCN)

- Provide a one off (non-recurrent) payment of £5,000 to the person selected as clinical advisor
- Provide project management support for the work
- Link the clinical advisor with existing children and young people and family groups
- Connect the clinical advisor with wider clinical networks to establish clinical consensus

How to express an interest in being the clinical advisor

Anyone who would like to express an interest in leading the work on the long-term conditions passport for children and young people in Greater Manchester should contact:

sam.bolton1@nhs.net

Expressions of interest (totalling no more than 1500 words) should detail:
- How the clinical advisor plans to deliver the project based on the outline of work for the project (above)
- Their personal and professional experience that would demonstrate their suitability for the role, specifically:
  - Awareness of the clinical, emotional and social problems faced by children and young people with long term conditions, and when they go through transition from paediatric to adult services
    - any experience of IT projects within GM and the healthcare sector
    - any experience of engagement with young people and their families
    - any experience of raising awareness of initiatives and changes within the GM healthcare and widest possible public sectors
- How they will work engage with young people and their families to understand user requirements

The deadline for expressions of interest is: FRIDAY 19th OCTOBER

The selection process will be undertaken the week commencing Monday 22nd October with confirmation of appointment made shortly thereafter.