

Proposal for establishment of congenital heart disease Patient Reported Experience Measures (PREMS)

Background

The national NHS survey programme includes a number of surveys designed to capture patient reported experience measures (PREMS) including some condition specific surveys such as the cancer survey. However, there has not been a drive to develop condition specific PREMS across specialist services. As result of this there are no identified resources to develop condition specific PREMS nor is there funding available for their development.

Within congenital heart disease services there is a real desire for PREMS to be developed and used across the specialist centres and as a result of this the Somerville Foundation developed and Adult Patient Experience Survey with MSB consultancy collating and reporting on the results. The ongoing arrangements for running and reporting on this survey had not been established and as such the Somerville Foundation is keen to establish a way of running this survey going forward.

Across the NHS there is a lack of appropriate mechanisms for hearing of children and young people's experience of care. For example patient feedback surveys, as a mechanism for children's participation, are nearly non-existent. A review of national surveys undertaken between 2001 and 2011 showed that fewer than 3% included the views of under-16s.¹ In response to this the first national children's survey was conducted by CQC in 2014. This represented the experiences of almost 19000 children and young people but cannot be used to report on specific conditions or services.²

Rationale

The NHS Constitution for England, 26 March 2013

'The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be co-ordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.'³

Metrics on patient experience represent a key part of putting patients at the heart of the services the NHS provides. PREMS can be used to drive improvement within centres and networks and identify areas of good practice and poor performance.

¹ Annual report of the Chief Medical Officer 2012. Our Children Deserve Better: Prevention Pays Chapter 4 page 3

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf

² <http://www.cqc.org.uk/content/children-and-young-peoples-survey-2014>

³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf

The standards for paediatric and adult congenital heart disease both include standards requiring centres to provide the opportunity for the experience of services to be reported and acted upon.⁴ The Quality Dashboards were also designed to highlight and share key aspects of patient safety, clinical outcomes and patient experience.⁵ The establishment of PREMS will provide a consistent and robust process through which centres can meet the new standards for congenital heart services and the requirements of NHS England's Quality Dashboard initiative.

The service specifications for paediatric congenital heart services state that the service aims to:

- provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home;
- systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist

The service specifications for adult congenital heart disease state that the service aims to:

- Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home; and

that one of the ways of achieving the objectives of the service is by:

- Systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist (e.g. Somerville Foundation Patient Experience Questionnaire)

Whilst there are other ways of collecting information on patient experience, the geographical spread of the patients receiving care from a specialist centre makes PREMS a more effective way of collecting information from people with congenital

⁴ Paediatric - H10 (L1) – Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service.

Specialist Children's Surgical Centres must make this feedback openly available, to children, young people, families/carers and the general public, together with outcome of relevant local and national audits.

Specialist Children's Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services.

Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made.

Adult – H10 (L1) – Specialist Children's Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.

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⁵ <http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-5/d5-cs/>

heart disease than other approaches. For example, running patient voice workshops or events is less likely to reach a representative sample of patients and increases the likelihood of issues relating to experiences of receiving care from a centre further away from home failing to be heard.

In addition to the benefits for congenital heart services this also provides the opportunity for valuable learning regarding the use of PREMS survey within other specialised services. There are four key areas of learning which could be gained from the establishment of this survey:

- The process for establishing the survey – The process of both procuring an appropriate service and then creating surveys in an affordable way could provide valuable learning for other specialised services interested in capturing information on patient reported experiences.
- The survey – The survey could provide a useful template for other specialties looking to establish an appropriate survey for their users.
- The running of the survey – This would provide learning on how surveys can be hosted and the mechanisms of informing patients of the ability to participate in a survey in a cost effective manner.
- The information provided by the survey – This would provide key learning on whether this way of collecting PREMS actually provides useful information. For example, are the response rates high enough to allow meaningful comparison between sites and is the information provided able to drive improvement within centres and networks? Low response rates may provide useful learning on the limitations of online only surveys or on the use of surveys in general.

What is being proposed?

The proposal is for a digital only survey which would be accessed via links/QR codes and can be completed by families/carers, children and young people and adults. The survey would be promoted through:

- publicity within the specialist centres;
- the activities of patient and public groups;
- links established on key websites (e.g. NHS England, the National Congenital Heart Disease Audit, the National Congenital Anomaly and Rare Disease Registration Service)

Digital only is being proposed due to the widespread availability of mobile technology which makes online surveys the easiest way for the majority of people to complete surveys. This approach also reduces the costs associated with developing a paper version of the questionnaire, printing of the questionnaires, distribution of the survey, returning the survey and entering the information from returned surveys into the database.

Surveys are to include sections for both inpatients and outpatients to ensure that anyone receiving care is able to report their experiences of the service they access. The surveys will be hosted on an easily accessible website which is optimised for mobile devices. The user will be able to decide from three options of surveys:

- Families and Carers
- Children and Young People

- Adults

Development of a parent congenital heart disease patient experience survey. (aimed at families and carers of children aged 0-15)

This will include:

- focus groups;
- review of existing questions and literature;
- development of draft questions;
- consultation with stakeholders;
- testing of the draft questionnaire on stakeholders;
- a Report on the process; and
- production of the final survey.

Development of a children and young people's congenital heart disease patient experience survey. (aimed at children and young people aged 8-15)

This will include:

- focus groups;
- review of existing questions and literature;
- development of draft questions;
- consultation with stakeholders;
- testing of the draft questionnaire on stakeholders;
- a Report on the process; and
- production of the final survey.

Validation of the existing (Somerville Foundation) adult congenital heart disease patient experience survey. (aimed at adults aged 16+)

This will include:

- review of existing questions and literature;
- testing of the draft questionnaire on stakeholders;
- a Report on the process; and
- production of the final survey.

Implementation of Surveys

This will include:

- programming of online questions;
- testing of online survey;
- hosting of survey;
- building of database for the returns;
- developing the analysis and reporting functionality;
- reporting of results (quarterly basis);
- design and print postcodes with url and QR codes for the survey; and
- courier of 500 postcards to each specialist centre.

All surveys would need to comply with NHS England's Information Governance policies and be reported in such a way as to maintain patient confidentiality. Consideration should also be given to any potential mechanisms which could help

reduce the risk of individuals inappropriately completing multiple surveys. In addition to this it is key that the process is run in such a way to enable learning to be taken from this for other specialties seeking to collect information on patient experience.

Resource Implications

Whilst final costs for this cannot be confirmed until the service has been procured some work has been undertaken to understand the approximate costs of the different elements of this work.

Every attempt has been made to keep the costs as low as possible recognising the resources are already stretched within the NHS. As a result the current proposal involves a survey which can only be completed online in order to ensure there is no need for extra resource to enter paper based surveys into the database. In addition it is proposed that rather than requiring trusts to expend significant energy emailing or mailing patients regarding the survey it is simply publicised using postcards and other materials with further activity to increase participation being at the discretion of the Trust. In addition to this patient and public groups will also be able to promote the survey using their websites and the contacts they have.

Estimated Costs for the online only survey are as follows:

Initial Costs (to be provided by the review)

- Development of a parent congenital heart disease patient experience survey - £15000 + VAT
- Development of a children and young people's congenital heart disease patient experience survey – £15000 + VAT
- Validation of the adult congenital heart disease patient experience survey - £7000 + VAT

Ongoing Costs (to be provided by specialist centres)

- Annual hosting, running and reporting of the surveys - £8000 + VAT

Providers will also be asked to quote for the development and running costs for a paper based survey to supplement the digital survey, reflecting concerns about digital exclusion. This will enable the additional costs to be compared and a decision to be made about the most appropriate approach.

How will the Information be used?

Information provided by PREMS surveys is likely to be most useful for networks seeking to identify areas where they could provide better services for patients. It will both identify areas of good practice and areas of underperformance. This information can also be used to monitor whether or not steps taken to improve services are leading to a more positive experience for patients.

Indicative measures from the surveys will be reported through the Quality Dashboard which will provide easily accessible information on each centres patient experience for both commissioners and the public. This information will be benchmarks across the service which will provide valuable learning for each centre on their patients'

experience of care. However, the relatively low volumes of patients is likely to mean that no concrete conclusions can be made from any differences between centres.

Benefits

The establishment of PREMS will enable information on patient experience to be reported routinely for each centre and network. It will enable Trusts to effectively fulfil their obligations to systematically measure and act upon patient experience and satisfaction and help ensure that patients are at the heart of their services. It will give patients and commissioners sight of the experiences of other patients accessing congenital heart services and as such improve patient choice and enable commissioners to monitor performance and commission more effectively.

Procurement

All services will be procured together from the supplier to ensure best value for money and that the surveys align and are appropriate for the methods of hosting and reporting required. To comply with the NHS England SFI's we will seek a minimum of three quotes (as the spend is between £10K and £50K) and we will work with the Business Services Authority (BSA) to ensure that an appropriate procurement process is followed.

Next Steps

- This proposal to be reviewed and commented on by relevant stakeholders
- Completion of business case and specification to enable formal quotes to be receive
- Receive quotes for the specification
- Distribute to stakeholders for comment
- Distribute to specialist senders for comment and approval
- The services described in this document to be procured.
- Appropriate metrics from these to be added to the Quality Dashboard.