



Patient and Public Involvement (PPI)

Cambridge Children's Network – Strategy paper

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Date: 03 Sept 2020

Introduction

The NHS has a responsibility to respond to the needs of patients, services users, their families and carers, and the communities it serves. As stated in the Strategic Outline Case (SOC), our ambition for Cambridge Children's is to put children, young people and their families/carers at the heart of our project, demonstrating how it is "a whole new way" by highlighting our unique approach to children and young people's health and wellbeing:

"We have made a commitment to involve children and young people (CYP), not only in the co-design of the services to be provided, but also in the co-production of the development of the hospital building itself. Developing a shared vision for the children's hospital and engaging with patients, their families/carers, voluntary sector, stakeholders and the general public, is pivotal to the success of this project. Listening to views and giving key stakeholders a voice will enable us to develop services that truly meet the requirements of CYP, garner collective ownership and help create a community of interest to provide momentum and support needed to develop fundraising for the hospital."

It is therefore vital that we work in partnership with children, young people and their families (CYPF) to co-develop Cambridge Children's, through a comprehensive and thorough programme of engagement to collect meaningful input, feedback and insight.

The project's communication and engagement plan was approved by the Joint Strategic Board in May 2019 following discussion at the Scrutiny Committee in March 2019, where our proposed approach was supported. Since then there have been a number of engagement activities, primarily utilising existing networks and groups. This paper supplements the existing strategy by refocusing the objectives for the next phase of the development of the Outline Business Case and by bringing forward specific proposals for a Children's Network.

Patient and Public Involvement in Cambridge Children's

Qualitative and quantitative insights gathered through patient and public involvement (PPI) will be used to help us co-create and co-design the project based on the views of CYPF.

There will be different levels of involvement required, depending on the objective and also the CYPF needs and abilities, therefore a varied approach that supports active, accessible and meaningful participation will be needed.

This ranges from information-giving activities and creative ways to stimulate thinking about the new hospital.

We will aim to find a consensus between all key stakeholders and integrate CYPF opinions into the project. We aim to empower patients and families to contribute to decision-making but also work in direct collaboration with key stakeholders.

Particular consideration will need to be put in place to ensure we are able to effectively engage with CYPFs given the restrictions put in place as a result of Covid-19. While virtual platforms provide an obvious solution, this could potentially be a barrier to some members of society. We would like our work to be as safe, flexible and responsive as possible. We will aim to co-produce methods to reach as many CYPF as possible. CYPF of all ages will be encouraged to take part as well as those facing a broad range of physical and mental health conditions; we will take every step we can to create appropriate forums and experiences that accommodate health needs and facilitate participation.

We also need to ensure our PPI is proportionally representative of all future users, for example, we need to consider how we engage with the BAME community, gypsy and travelling community, as well as those living in more rural areas. We also need to ensure our PPI represents our geographical area of coverage, as well as CYPF who use the hospital in different ways, for example because it is their local hospital, or because they have been transferred here for specialist treatment, or because they are simply visiting.

Finally we need to ensure we receive feedback from CYPF of all ages and with a broad range of illnesses (physical and mental).

Our aim is to stimulate an informed conversation, create an atmosphere of mutual trust and confidence between clinicians, project members, patients and families, and contribute ultimately to the development of a whole new way of caring for patients and their families.

Use of existing networks

Patient, family and public involvement already plays a central role in the work of both Cambridge University Hospitals (CUH) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT).

Both CPFT and CUH run existing forums for engaging CYPF, for example ACTIVE at CUH and Patient Participation Forums at CPFT.

There are also a wide range of CYPF forums run by NHS, local authority and third sector partners, with whom we work as part of the STP collaborative forum.

We will attend upcoming engagement events run by CPFT, CUH, the University of Cambridge and our partners both local and outside of the region, utilising identified experts in the field of co-production to support us with engaging with their groups.

These provide us with the opportunity to engage a broader and more diverse group of CYPF through existing participation forums, Citizen's Senates, schools and youth groups.

We will take a collaborative approach with involvement, working with partners across the eastern region to maximise engagement and involvement opportunities, and recruit to our Network and specific workstream roles.

To date, engagement on the project has been largely supported via existing groups and other system-wide networks, including Family Voice in Peterborough and the Young Carers Group run by Cambridgeshire Community Services NHS Trust. There has also been some early engagement with patients on CPFT's Tier 4 wards to seek their views about what is important to them regarding the design of the new children's hospital. The key themes identified from the engagement with these groups will be used as a platform for the network to expand upon and inform the Cambridge Children's hospital.

The engagement approach proposed below goes beyond consultation, ensuring that children and their families are embedded within the project and actively involved in developing plans for the hospital.

Objectives for involvement and engagement

- 1) To ensure CYPF are actively involved in the development of Cambridge Children's hospital.

- 2) To inform, educate and stimulate thinking about the work of Cambridge Children's hospital through a range of creative, engaging, and targeted methods.
- 3) To ensure Cambridge Children's hospital is co-produced with CYPF, through active consultation, listening and involvement.
- 4) To create sustainable and long-term involvement to help continue to shape, develop and evaluate services provided by Cambridge Children's hospital.

Cambridge Children's Network

This Cambridge Children's Network will provide CYPF with a range of different ways they can formally collaborate and engage with the Cambridge Children's hospital project.

We will use the Network to:

- Inform decision making
- Understand the community's experience and aspirations for Cambridge Children's
- Reach out to the unengaged, especially those affected by inequalities
- Work with Healthwatch and the Voluntary, Community and Social Enterprise (VCSE) and local groups
- Focus on patient and community empowerment
- Create clear public information about vision, plans and progress
- Redesign and rethink services and patient pathways
- Promote co production and collaboration in work streams in a range of creative ways

How the Network will run

We will run the Network in two halves, one for children and young people and another for families and carers.

We will provide support to CYPF who get involved with the Network through bespoke training and briefings.

The Network will have a programme of activity aligned to the development stages of the project and linked to workstream priorities, to ensure CYPF views form a regular part of the collaboration process and they are kept-to-date on progress.

Activities may include surveys, focus groups, events, feedback on concepts and communications, and debate at virtual events. As the Cambridge Children's project advances, there will be new requirements for input from CYPF, and we will be able to approach the Network with these requirements as they arise.

Feedback to Network members will also be important so they know they have been listened to, that their opinions have been recorded and something has been done as a result. Not all ideas will be possible, so feedback will help ensure they don't feel ignored.

We have already sought feedback on the development of the Network from patients and carers at CUH and CPFT and will use this intelligence to formally launch Network recruitment from end September/October. We will target existing and past patients from CPFT and CUH, as well as patients and carers from other Trusts across the eastern region.

An involvement form has already been in place on the Cambridge Children's website for nearly a year, asking for people to register their interest. We have also generated interest from family members/carers of children that have accessed our services at the events that have taken place to date. This will allow us to start to develop a database of interested parties, forming the foundations of our Network.

The young people we engaged suggested providing an incentive for their involvement so once they have taken part in a number of engagement activities, we will provide them with a certificate they can include on their CV and something like a gift voucher.

Tiers of involvement

Network members will be offered the chance to state their areas of interest and chose how they wish to be involved.

We will create a matrix of opportunities, including:

- Listening to CYPF about how they want to get involved and what works best for them in their individual circumstances
- Regular involvement with workstreams
- Attending workshops online
- Taking part in surveys
- Reviewing communications about the hospital

Involvement in workstreams

To ensure effective and meaningful involvement, the voices of CYPF need to be embedded within the programme workstreams, as part of the governance process.

When identifying how workstreams involve CYPF in making decisions there eight key considerations that are useful to think through first to ensure engagement is meaningful and productive:

- 1) **Building relationships** - At the core of involvement are the relationships that we build with the people who want to get involved. In the same way we would consider what a new member of staff needs to feel valued and part of the team, it is important to consider this when involving young people and their representatives.
We need to think about:
 - How we build this relationship?
 - Who will be the named person from the workstream that links with them and how will they offer support and supervision?
 - How can we ensure their voices are heard in the workstream?
 - Is involvement a standing agenda item or could the patient/carer co-chair the workstream?
- 2) **Purpose** - We need to identify what the reasons are for involving CYPF in the workstream and what we want to achieve. [The National Standards of Involvement](#) (4Pi) can help us think about this. Involving people who have used services and their families will help us consider what is needed from their perspective as well as the clinical perspective.
- 3) **How to engage** - We will need to consider what involvement activities will best meet the needs of the workstream. For example, are we looking to answer a specific set of questions, which could be done via a survey or would having a patient and/or carer representative

integrated as a member of the workstream provide more in-depth feedback? Do we need a one-off focus group or are there existing events run by other organisations that could provide opportunities to engage?

4) **Reimbursement** - Some activities will require travel expenses, others may require payment for time. We need to be clear at the beginning what reimbursements we are offering people. There is a clear policy around payment for involvement activities, and forms developed to enable people to claim expenses. Please contact the Comms and Engagement workstream for more information.

5) **Expectations** – We need to be clear about what we require from the people we want to involve and consider what experience we are looking for. For example, if we are looking to develop a clinical pathway it is often best to use people who have had specific and relevant experience of that service. We need to consider:

- Are there any specific skills we would like people to have?
- What is the commitment that we require?
- Is one person enough?
- Do they need to have had a DBS and Occupational health screening and what is the length of time we are looking to involved people?

Creating an advert to involve people is a good way to clarify thoughts. Please contact the Comms and Engagement workstream for an advert template.

6) **Contracting** - Creating a contract of involvement clearly stating what is needed for the role can help clarify the role we are looking for and understand what support may be needed. This is especially important if the involvement work is likely to be on going as opposed to a one-off event. There are specific considerations needed when engaging young people such as timing meetings to not clash with school hours and safeguarding measures for online engagement. Within the contract of involvement providing clear information about payment and any other support that will be offered is important. An example of a contract can be accessed from Comms and Engagement workstream.

7) **Advertising involvement opportunities** - Knowing what experience we would like will help identify the best way to advertise involvement opportunities. If we are looking for people who have experience of using our services the best place to advertise may be in the waiting room or by promoting involvement as part of a standard appointment letters. For more general advertising we can use the Children’s Network and there are a number of pre-established groups that we can promote roles through. Please contact Comms and Engagement workstream for advertising support.

8) **Feedback** – It is important we talk to the people who are involved to find out how they would like to be kept updated on progress. This could be in the form of ‘You said - We did’ updates, via the Cambridge Children’s website, or to them directly. If the workstream is meeting regularly this can form part of the agenda.

This engagement ladder can help determine what level of involvement we need:

Involvement	Examples
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Co-production	Consensus building / dialogue / Steering groups / Formalised involvement on strategic groups
Co-design	Task and finish / project groups, appreciative enquiry
Engagement and consultation	Focus groups / road shows / questionnaires / 15 steps
Inform / Educate	Open day / exhibitions / leaflets

Useful links:

The Engage site has many useful resources for people: <http://engage.hscni.net/>

Next steps

- Meet with existing patient engagement leads within children's services in CPFT and CUH to finalise this paper
- Seek formal agreement to begin recruitment to the Network
- Write terms of reference for membership of the Network
- Develop action plan to begin recruitment
- Run a workshop for workstream leads on how to ensure genuine CYPF within workstreams
- Work with D&C workstream to put together a CYPF panel for Stage 3 of design procurement (ideally from Network, but because of time pressures we may need to recruit directly to the panel)
- Work with patient engagement, project and workstream leads to develop plans for engagement opportunities and activities.
- Recruit!