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### The National Paediatric Toolkit

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**The National Paediatric Toolkit (NPT) is a unique innovation that uses animated methodology to capture the opinions and experiences of children and young people in settings such as healthcare, education and social services – in fact anywhere where the opinions of this traditionally hard-to-engage audience are sought.**

The NPT is a hand-held, computer based survey tool developed at Alder Hey Children's NHS Foundation Trust, one of Europe's biggest specialist children's hospitals, designed by children for children. It features the charming Fabio the Frog and Alder Hey children have been hard at work developing his mannerisms and an army of equally charming friends!

The NPT has been developed at Alder Hey in response to the Trust's own mission for best practice engagement methodology with its young patients. In addition, with the advent of World-Class Commissioning, healthcare providers in both the primary and secondary care sectors are being increasingly evaluated on patient related outcome measures. Indeed, in 2008 health minister Lord Darzi outlined plans for the routine collection of patient recorded outcome measures (PROMs) in his Next Stage Review of the NHS. Collecting patient feedback has become a key requirement for all NHS organisations.

#### Background

Priority Research has been working together with Alder Hey for over seven years developing patient feedback and engagement. Following a traumatic period for the hospital, a group was set up to address the need for children and young people to be able to work in partnership with the Trust in developing services. From this initial work, the group was tasked with developing a Trust wide model for consulting with children and young people about their healthcare in the broadest sense.

Alder Hey had traditionally utilised paper- based questionnaires that were time consuming and generally resulted in poor response rates. In many cases, patients' parents completed the forms on their behalf resulting in survey results that did not reflect patients' views or experiences at all.

Having trialled a number of patient experience survey tools, which the Trust found to have too many shortcomings with their young patients, Alder Hey decided to work with Priority Research in designing their own product – The NPT.

Working with patients, families and staff over a period of three years has resulted in the development of a product which is easy to use, features animations developed with the patients, is totally inclusive and provides staff with "real time" patient experience feedback at the click of a button.

Subsequently surveys carried out across the Trust using the NPT have enabled the hospital to gain an Investing In Children Accreditation in their Oncology Department as well as providing evidence to access charitable funding streams to improve services and facilities for patients, including the employment of a chef in the same unit to provide patients with "food that we want when we want it".

#### The NPT

The system has been designed to be as clinically inclusive as possible. It has been tested with patients with severe head injuries, burns, spasticity, mental health issues, dexterity problems and physical disabilities and special educational needs, ensuring that many patients who would not normally be able to participate in patient experience surveys can now have their opinions taken into account.

Patients are simply handed the touch screen device and then select their answers using a finger, head pointer or the stylus supplied. They can choose the environment they want to complete the survey in (Fabio the Frog® or standard animated), the language they prefer to complete in and then press go and work their way through the questions.

The NPT has been developed to be used by patients in both primary and secondary care environments. Questions are available for three key developmental age groups: children up to nine years, young people up to 17 years and adult patients aged 18 and above. It is a patient experience survey system that has elements specially developed with children and young people for use by children and young people. The NPT also allows patient experience surveys to be run with parents and carers, staff and adult patients using different levels of questions. Each individual question is worded in five different ways – three developmental age levels as detailed above, as well as the parent/carer or staff options. It can be run online or offline in a number of different environments (including Fabio the Frog®) which respondents select from in order to complete the surveys.

There is an extensive list of templates to choose from on numerous topics from general areas such as appointments, transport, waiting and

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reception areas, treatment areas, wards, play and learning and entertainment, visiting, family accommodation, ward food, cafe and restaurants, confidentiality and consent, communication, information, complaints, pain management, overall experience, teenage pregnancy and sexual health. It also has specialised templates for conditions such as Sickle Cell, Renal, Oncology, Cardiology, and CAMHS. Clients can choose their own demographic data fields from GP/ Consultant seen, procedure through to ethnic group and religion etc., and link the information to their own internal reporting systems.

Every question, answer and instruction has 11 language variants to choose from both verbally (to assist with dyslexia, literacy issues and Special Educational Needs) and textually. The NPT also has built in audio and visual impairment facilities to comply with DDA.

It allows patients to communicate their individual priorities for care in a way that they find simple and easy, yet provides much more detail than they could otherwise give. Using the unique Priority Search™ the NPT enables users to define patients' priorities for changes to services, which can define future strategies and spending plans. The Priority Search™ can also be used to define an individual patient's long-term care plan thus feeding into the Individual Patient Plan (IPP).

The survey previewer allows users to set up a survey with just three presses of a button. Select your preferred template and the questions you want to include, decide on the demographic groups you are targeting, and press go. There are currently 2000 questions that are continuously growing in number.

The NPT provides real time bespoke charts and graphs and also has an automated reporting function with pre-defined commentary. A powerful chart wizard gives immediate results, allows the creation of user defined filters and includes a 'snapshot' function that provides survey results between two changeable time frames.

## Conclusion

Dr. Steve Ryan, Alder Hey's Medical Director and Chair of the Children's Pathway Group describes the NPT as "a unique innovation for involving young patients in their care plans and their overall patient journey", which is fun for the children to complete and "effective in getting the essential feedback that we need to continuously improve what we do". Indeed, the NPT is the only application that specifically provides commissioners with the opportunity to respond to and improve the service experience of children, young people, BME communities, looked after children and young people, patients with complex needs, geriatric patients, all ages of SEN and other hard to reach groups both now and in the future.

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