



Understanding children's experiences of cancer care

Developing the National Cancer Patient Experience Survey
for Under 16s

Background

For adults living with cancer in England, patient experience insights are captured through the National Cancer Patient Experience Survey. *However, no formal national mechanism for understanding the experiences of children under the age of 16 with cancer, and their parents, had previously existed.* The cancer care pathways and care priorities for children often differ to adults, and therefore a unique approach was required to understand their experiences of cancer care and treatment. Consequently, NHS England and NHS Improvement commissioned Picker to develop a survey programme appropriate for a younger patient population, to be run in children's cancer treatment centres (known as Principal Treatment Centres) across England.

Our Approach

The survey programme was informed by existing research on children's cancer care experiences, along with learnings from an earlier feasibility study. Further to this, we spoke to 12 parents and nine children in focus group discussions and individual interviews, to understand what aspects of care provision were important to them. This group represented a range of ages, gender, cancer types and stages of treatment (eg recently diagnosed, receiving treatment, relapsed and remission). *The themes identified as important to children and parents regarding cancer care provision included emotional support, clear information and communication, involvement in decisions, and 'being able to continue being me' – minimising the impact on their daily lives.*

Along with examining existing literature, the insight from discussions and interviews informed questionnaire content to ensure the survey asked about aspects of care that mattered most to patients and parents.

Extensive discussions with an expert advisory group, including patients, parents, commissioners, representatives from children's cancer charities, academics, clinicians, and NHS cancer programme representatives, also guided the questionnaire development.

Three paper surveys were designed:

- one for parents/carers of children aged 0-7;
- one for children aged 8-11, with a section for parents/carers; and
- one for children aged 12-15, also with a section for parents/carers.

Colour and images were used in the children's sections to make them more appealing to a younger audience.

Each version was cognitively tested with a total of 24 children and 12 parents across three rounds. The testing involved going through the questionnaires with patients and parents to understand how questions were interpreted and answered, to ensure they measured what was intended. We made amendments to the surveys after each round to improve the wording and format. The covering letters to be sent out with the surveys, inviting children and parents to take part, were also tested. Participants ranged in gender, age and ethnic background, in addition to their cancer type and stage of treatment.

Alongside the surveys, a website was developed in collaboration with our design agency partner Global Initiative. The website supports awareness of the survey and hosts information for patients, healthcare professionals, parents and the public, as well as linking to an online version of the survey and hosting the results (as they become available).



What next?

The survey is being implemented across England in 2021; inviting children aged under 16 who have received NHS cancer care during 2020 to participate. They will be able to complete a paper questionnaire or an online version of the survey on any device. Those who do not speak English will have the opportunity to complete it over the phone using a translation service.

Parents, children, healthcare professionals and other relevant stakeholders are being engaged about the reporting of results, including format and priority question areas.

Impact

Results will be available in summer 2021 and will provide the first national-level insight into the experiences of children with cancer and their parents in England. The feedback will help to create actionable ways to improve aspects of personalised care and patient experience. Commissioners, providers and national policymakers will use the results to assess performance both locally and nationally, to help identify priority areas for enhancing children's cancer services. Workshops will be held once results are available to facilitate understanding of the experience data. These provide an opportunity for peers at different organisations to come together in a protected space, to learn from each other and inspire ideas for improvement.

Testimonial

*"England's under 16s cancer experience survey goes into fieldwork for the first time in the spring of 2021. Getting to this point signifies a big milestone in the history of this project – from a commitment in the NHS' Long Term Plan to a finalised survey tool with which we can reach out to young people and their parents. **Our combined team have worked collaboratively with children, young people and their parents throughout the entire process** – from the design of the website, the questionnaire and the questions through to ensuring the work gains the acceptance of our steering group. With the publication of the survey results, anticipated for the summer of 2021, this long held ambition to gain insight into such a hugely important area will become reality and **will give voice to thousands of children and young people with cancer for whom the NHS cares for every year.** We will be ready to listen and learn."*

Clare Enston, Head of Insight and Feedback for NHS England and NHS Improvement

*"As a Mum of a young cancer patient, **it has been a privilege to be part of this dedicated advisory group** and use our family's experience of cancer care in such a positive way. **It's been rewarding to have contributed along with other stakeholders**, to shaping the development of this important survey which I know will help to improve the experience of children with cancer and their families."*

Laura Troop, Parent Representative member of the Survey's Advisory Group



About Picker

We are a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care.

We work with NHS trusts, government bodies, charities, academic institutions, and commercial organisations, and are an approved contractor for the CQC.

Our eight Principles of Person Centred Care provide an internationally renowned quality improvement framework.

The Picker Principles



Fast access
to reliable
health advice



Effective treatment
delivered by trusted
professionals



Continuity of care
and smooth
transitions



Involvement and
support for family
and carers



Clear information,
communication and
support for self-care



Involvement in
decisions and respect
for preferences



Emotional support,
empathy
and respect



Attention to
physical and
environmental needs

About NHS England and NHS Improvement

NHS England and NHS Improvement leads the National Health Service (NHS) in England. Now working together as a new single organisation to better support the NHS to deliver improved care for patients in line with the NHS Long Term Plan.

For more information about NHS England and Improvement visit www.england.nhs.uk/about.

Picker Institute Europe
Suite 6, Fountain House
1200 Parkway Court
John Smith Drive
Oxford OX4 2JY

+44 (0)1865 208100
picker.org

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