u16 cancer patient experience survey

Results of a New National Survey to Understand the Experience of Children with Cancer, and their Parents, across England

Tallett, A.[1*]; Liu, Y.[1]; Bilas, M.[1], Abad-Madroñero, J.[1], King, B.[1]; Hayes, C.[2], Williamson, P.[2], Hudson, R.[2], Smith, M.[2]

[1] Picker Institute Europe; [2] NHS England and NHS Improvement

* Presenting author

Background

The Under 16 Cancer Patient Experience Survey measures experience of tumour and cancer care in children across England. Before it was developed, there was no national mechanism to capture experience of care for patients aged under 16.

- The 2020 survey was its first iteration and is expected to run annually. It captures the experience of children aged under 16 who receive care at 13 Principal Treatment Centres (PTCs), and that of their parents or carers.
- The survey enables commissioners, care providers and national bodies to understand and improve care provision nationally and locally.

Methods

- Existing literature informed survey content, along with results of qualitative research with children with cancer and their parents/carers.
- **Three surveys were designed; one for parents/carers of children aged 0-7, and two surveys for children aged 8-11 and 12-15, each with a section for children and a section for their parent/carer.**
- 36 cognitive interviews were conducted to test the survey.
- PTCs (provided by 16 NHS Trusts) supplied a sample of eligible patients aged under 16 who received cancer or tumour care from the NHS in England in 2020. Patient lists were thoroughly checked and duplicates were removed.
- Paper questionnaires with cover letters and up to two reminders to non-responders were posted to parents between April and June 2021. An option to complete the survey online was also available.

0-7 years

8-11 years

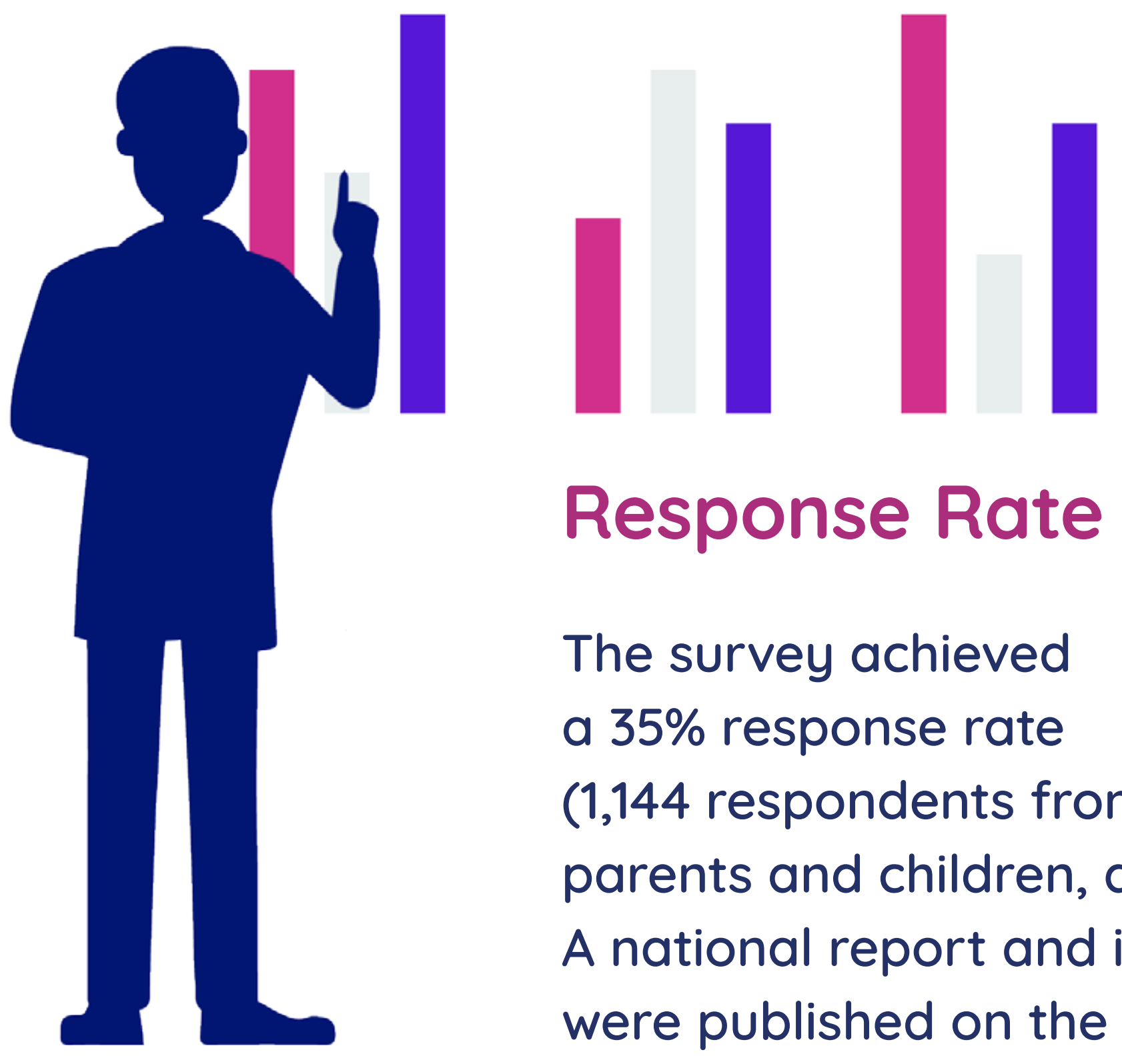
12-15 years

Results

Key national findings included:

- **79%** of parents or carers were definitely told about their child's cancer or tumour in a sensitive way
- **70%** of children said they always understand what staff are saying
- **84%** said that staff always speak to them in a way that is suitable for them
- **76%** of parents or carers felt that staff definitely offered them enough time to make decisions about their child's treatment
- **85%** of parents or carers always have confidence and trust in staff caring for their child
- **45%** of parents or carers felt that their child's care and treatment is definitely offered at a time suitable for their family
- **92%** of parents or carers rated the overall experience of their child's care as 8 or more out of 10

80% of children said they are looked after very well for their cancer or tumour by healthcare staff



Response Rate

35%

The survey achieved a 35% response rate (1,144 respondents from 3,308 eligible parents and children, across 13 PTCs). A national report and individual PTC reports were published on the survey website.

Implications

- **The survey provides the first ever national level insight into the experiences of children with cancer, and their parents/carers, giving actionable feedback on personalised care and patient experience in England.**
- Results were shared with relevant stakeholders including charities and PTCs to drive improvements in care delivery.
- Workshops were held with PTCs to assist understanding and interrogation of their data, and to support action planning and networking.
- The results are also being used to inform work led by the NHS Cancer Programme which aims to support trusts in developing and implementing improvement plans in children's cancer services.
- The survey has recently been cognitively tested again and **fieldwork for the second survey iteration is underway. Results are expected to be available in Autumn 2022.**

For further information, please see the survey website

www.under16cancerexperiencesurvey.co.uk

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