



cancer patient
experience survey



Picker

Developing a National Cancer Patient Experience Survey for Under 16's in England.

Abad-Madroño, J. ¹; Bilas, M. ¹; Boxell, E. ¹; Kalungi, P. ¹; Tallett, A. ¹; Hayes, C. ²; Hudson, R. ²; Smith, M. ²; Williamson, P. ²

(1) Picker Institute Europe (2) NHS England and NHS Improvement

BACKGROUND

The aim of this research was to develop a new national survey for children under the age of 16, along with their parents, to understand experiences of cancer care and treatment. The survey findings will drive improvements in care delivery, allow commissioners to assess performance, and support the work of multiple stakeholders.

METHODS

Survey development was informed by:

Two face-to-face focus groups with six parents/carers of children with cancer

Nine individual video, telephone and face to face interviews with children aged 8-15 with cancer

Existing literature

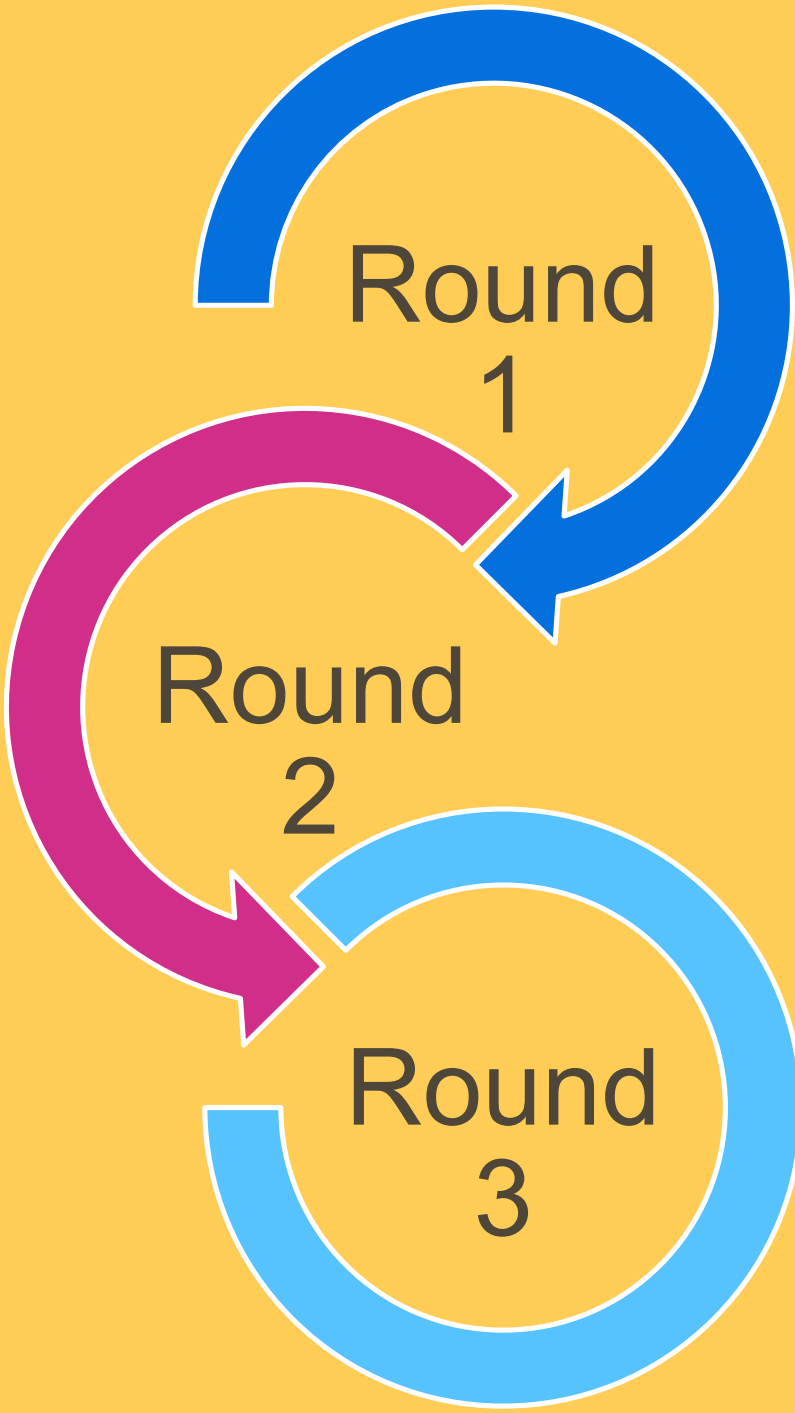
Extensive discussions with an expert Advisory Group

Three paper surveys were designed using Adobe InDesign.

- a survey for parents/carers of children aged 0-7
- a survey for children aged 8-11 to complete, with a section for parents/carers
- a survey for children aged 12-15 to complete, with a section for parents/carers

Child-friendly survey sections were created for children aged 8 to 15. The 8-11 year-old version contained smiley faces alongside scaled response options.

The surveys were cognitively tested with 24 children aged 8-15, and 12 parents of children aged 0-7, across three rounds.



• Discussion & 12 changes to questionnaire & cover letters

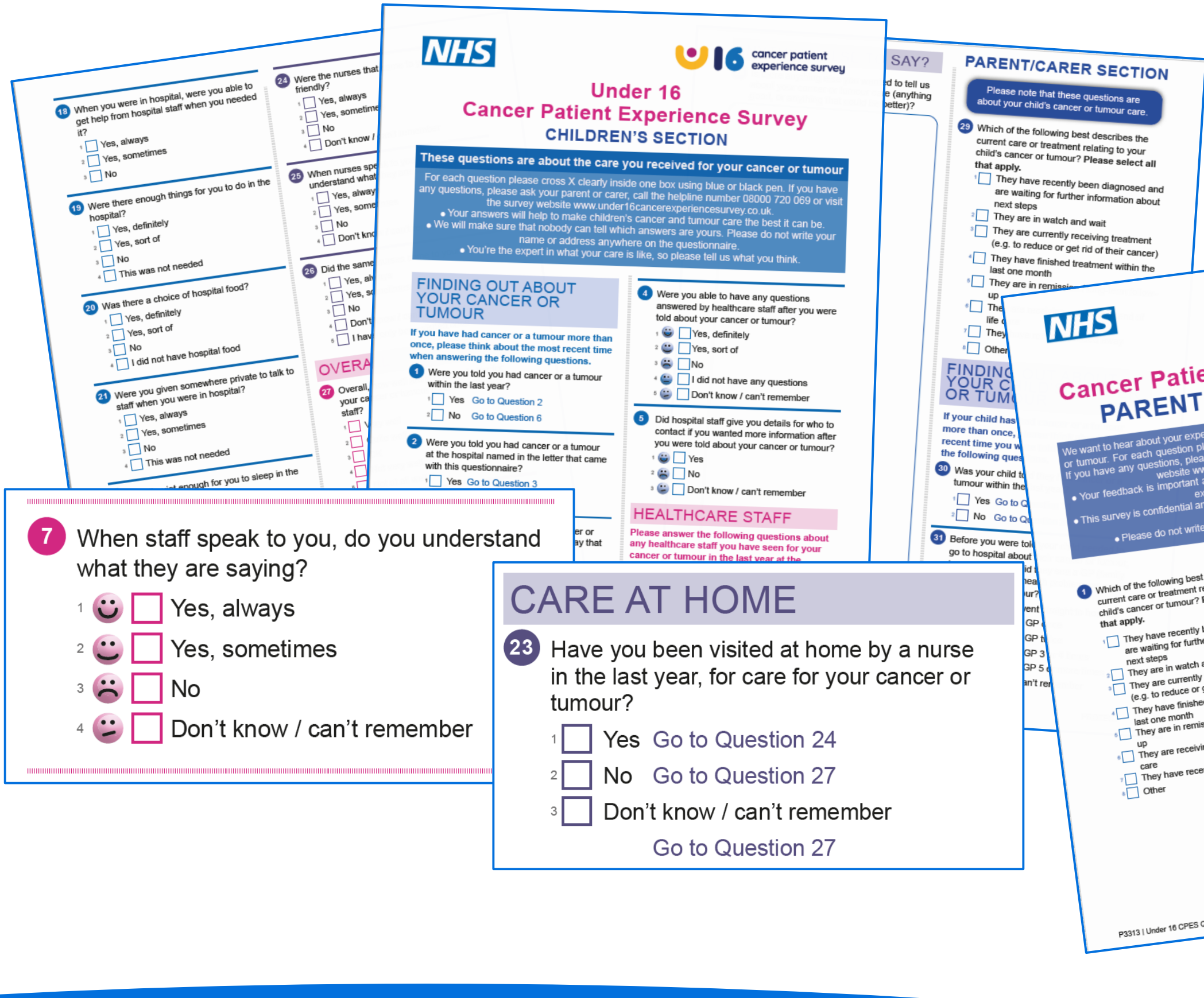
• Discussion & 7 changes to questionnaire

• Discussion & 6 changes to questionnaire

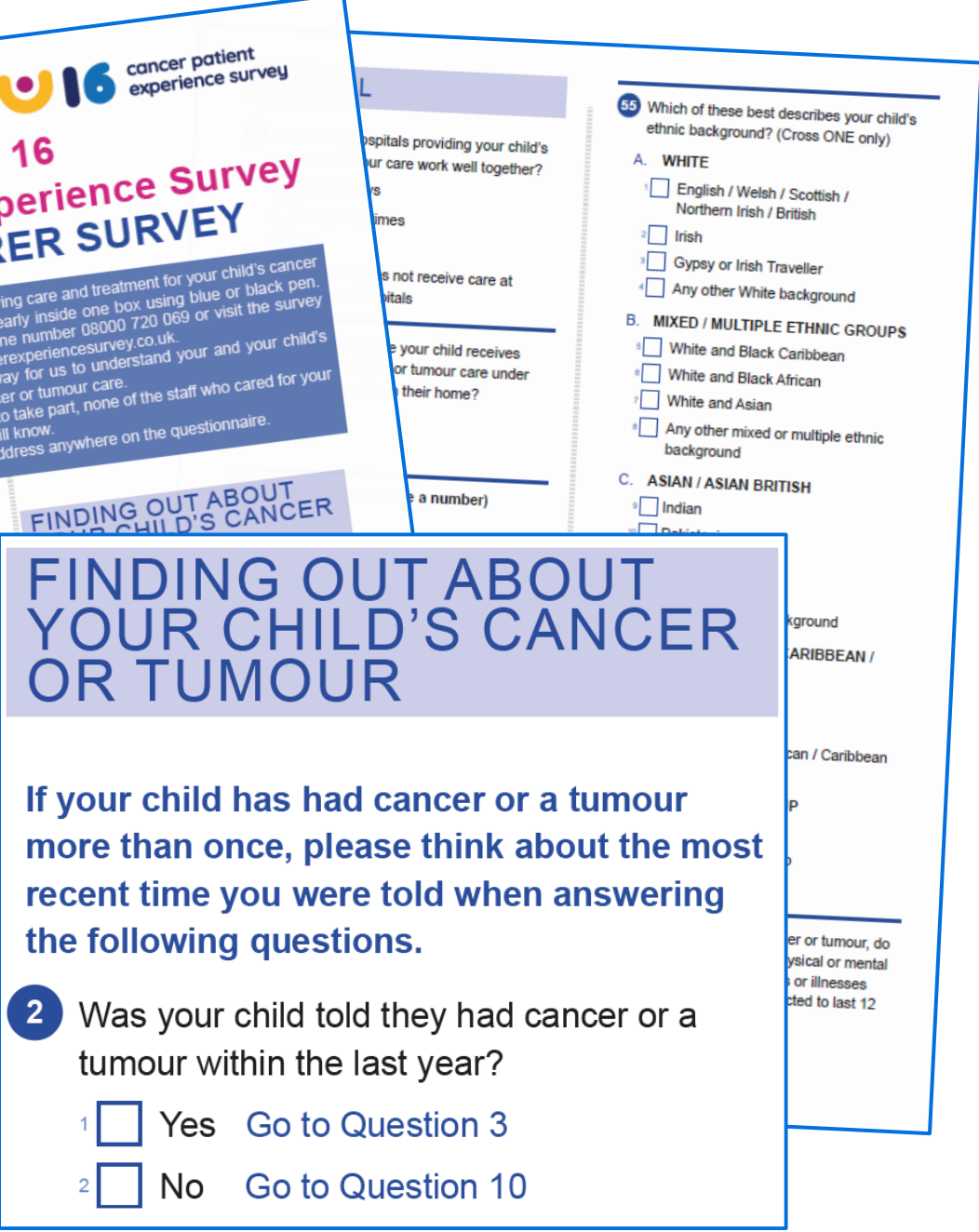
RESULTS

The final questionnaires were composed of 57 questions in the 0-7 year-old version and 71 questions in the 8-11 and 12-15 year-old versions. The survey will now be implemented nationally across England, inviting children aged under 16 who have recently received NHS cancer care to participate.

Children's survey versions



Parent survey version



CONCLUSION

This new survey will provide the first ever national level insight into the experiences of children with cancer and their parents, to provide actionable feedback on aspects of personalised care and patient experience in England. Results will be used nationally and locally to drive improvements in care.