

Under 16 Cancer Patient Experience Survey 2023

Communications and Publicity Webinar

Wednesday 21st March 2024



Say hello and introduce yourselves in the chat



Who are you?

Where are you from?

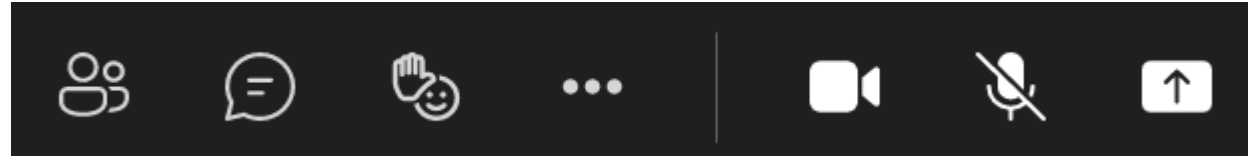
What is your role?

U16 CPES 2023 Communications and Publicity Webinar

- Aims of the webinar
- Background to the survey
- Declining response rates
- U16 CPES 2022 national response rate patterns
- Discussion
- Communications toolkit assets
- Q&A

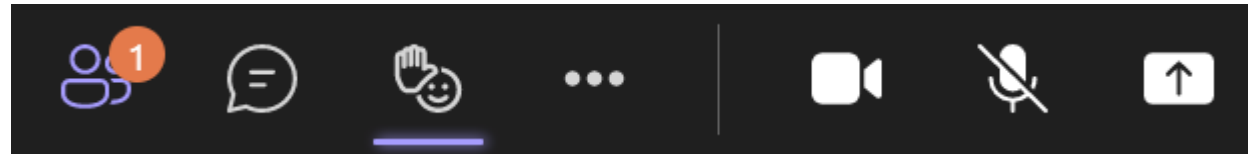


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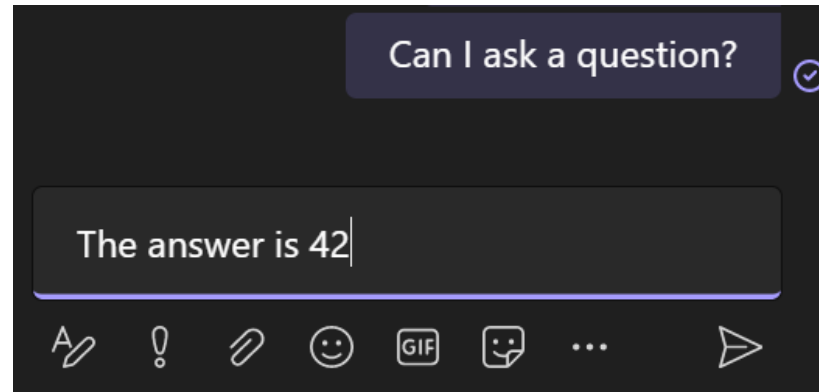
- Keep yourself muted whilst the presentations are ongoing

Please,



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question

Please,



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat

U16 Cancer Patient Experience Survey



- To support survey stakeholders (including Principal Treatment Centres/ NHS Trusts, charities representatives, Operational Delivery Networks and national bodies) to raise awareness of the survey to improve response rates



- To share an updated communications and publicity toolkit including:
 - Guidance
 - Supporting materials such as social media posts, posters, a short promotional video, promotional banners for email signatures and patient letter footers.



Under 16 Cancer Patient Experience Survey



- The Under 16 Cancer Patient Experience Survey (U16 CPES) was developed and is implemented by Picker on behalf of NHS England and is running for the fourth time in Spring 2024.
 - The survey exists to understand the experiences of cancer care among children under the age of 16 and their parents/carers, in England. The survey is designed to help understand and improve cancer care nationally and locally.



- Supported by an Advisory Group of expert stakeholders who meet quarterly to advise on the survey design and methodology.
- Mixed-mode survey (paper and online options).



- Ask about diagnosis, healthcare staff (e.g. communication, respect and dignity), information about care and treatment, care in hospital, care at home.
- Survey website: <https://www.under16cancerexperiencesurvey.co.uk>

U16 Cancer Patient Experience Survey 2023


Three survey versions (0-7 years; 8-11 years; 12-15 years).

CARE IN HOSPITAL

Please answer the following questions about any hospital stays you have had for cancer or tumour care and treatment at the hospital named in the covering letter.

13 Have you stayed in hospital during 2023 (receiving treatment or care in the daytime or for an overnight stay)?

1 Yes **Go to Question 14**
2 No **Go to Question 19**



7 Do staff talk to you, not just to your parent or carer?

1 😊 Yes, always
2 😐 Yes, sometimes
3 ☹️ No

CHILDREN'S SECTION

FINDING OUT ABOUT YOUR CANCER OR TUMOUR

Please think about the time your cancer or tumour was confirmed. If you have had cancer or a tumour more than once, please think about the most recent time you were told in the following questions.

1 Were you told you had cancer or a tumour during 2023?
1 Yes **Go to Question 2**
2 No **Go to Question 5**

2 Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?
1 Yes **Go to Question 3**
2 No **Go to Question 5**

3 When you were told about your cancer or tumour, was information given in a way that you could understand?
1 😊 Yes, definitely
2 😐 Yes, sort of
3 ☹️ No
4 😊 Yes, definitely
5 😐 I did not have any questions
6 ☹️ Don't know / can't remember

HEALTHCARE STAFF

Please answer the following questions about any healthcare staff you saw for your cancer or tumour during 2023 at the hospital named in the covering letter.

5 Do you feel that staff are friendly?
1 😊 Yes, always
2 😐 Yes, sometimes
3 ☹️ No

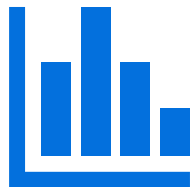
6 When staff speak to you, do you understand what they are saying?
1 😊 Yes, always
2 😐 Yes, sometimes
3 ☹️ No
4 😐 Don't know / can't remember

7 Do staff talk to you, not just to your parent or carer?
1 😊 Yes, always
2 😐 Yes, sometimes
3 ☹️ No

8 Do you see the same members of staff for your treatment and care?
1 😊 Yes, always or mostly
2 😐 Yes, sometimes
3 ☹️ No

9 Are you ever told different things by different members of staff, which leaves you feeling confused?
1 😊 Yes, always
2 😐 Yes, sometimes
3 ☹️ No

U16 Cancer Patient Experience Survey



- We have seen a decrease in survey response rates from 35% in the 2020 survey to 25% in the 2022 survey. Response rates may have fallen due to:
 - Overlap of patients year on year
 - Survey fatigue
 - Declining response rates for surveys in general
- Increasing the response rate will help with the survey's statistical reliability and how accurately the results represent the whole population.

Overlap of patients year on year:



- 53% of those who received a survey in 2022 also received a survey in 2021.
 - The response rate for 2022 patients who also received a survey in 2021 was 19%.
 - The response rate for 2022 patients who did **not** receive a survey in 2021 was 31%.
 - **Therefore – a lower response rate from those who have received two surveys.**



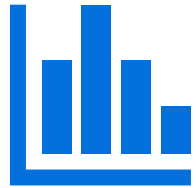
General declines in response rates over time



- Comparing the 2021 response rate for recurring sample members to that for recurring sample members in 2022 is 22% vs 19%, a 3% decline.

- Survey version

0-7 survey	8-11 survey	12-15 survey
25%	22%	28%



- No difference in 2022 response rate by gender.
- Ethnicity response rate: White = 26% versus 21% for all other ethnicities.
- Principal Treatment Centre response rates in 2022 ranged from 21%-32%.
- Deprivation – 2022 response rate increased with IMD quintile.

Response Data 2022

Under 16 Cancer Patient Experience Survey



Introduction

Response rates

How representative of the sample are the respondents?

Under 16 CPES 2022: National response rates and sample demographics

NHS England

Introduction

This document provides data on the response rates of different population groups responding to the 2022 National Under 16 Cancer Patient Experience Survey (U16 CPES), which will help us to understand how well the responses collected reflect the make-up of the eligible population and which groups are less likely to respond.

Response rates are calculated by comparing the total number of patients invited to take part in the survey with the total number of patients who responded. Data from 2021 has been included, where demographics are comparable.

Patients and their parents/carers were eligible for U16 CPES if they:

- were under the age of 16 when they received the care
- have a primary diagnosis of cancer
- have been admitted to a Principal Treatment Centre (PTC) either as an inpatient for cancer related treatment or seen as day case patients for cancer related treatment.

The total number of eligible patients is known as the sample size in this document.

Demographics

The demographics used to split response rates are:

- Age
- Gender
- Deprivation
- Ethnicity
- Diagnostic group

U16 Cancer Patient Experience Survey

Challenges with children's surveys

- Ensuring child participation
 - Appropriate design for a range of ages/cognitive abilities
- Traditionally lower response rates than adult populations
 - Cancer Patient Experience Survey 2022: 53% vs Under 16 Patient Experience Survey 2022: 25%
 - CQC Adult Inpatient Survey 2021: 36% / 2022: 40% vs CQC Children and Young People's Survey 2020: 24%
 - *But* we also see lower response rates for younger adults compared to older adults – e.g. CPES
- Relies on parental consent and passing survey onto child
- Children with cancer receiving treatment at the time of fieldwork (too unwell or never received)



What are we doing nationally?

- Ongoing use of child friendly survey design using colours and images
- Introducing child friendly leaflets into mailing packs for 2023 onwards
- For 2023-2026, Braille and large print survey versions will be available upon request via the survey helpline

Discussion

Under 16 Cancer Patient Experience Survey



U16 Cancer Patient Experience Survey

- What *are you* **currently doing** to publicise the survey locally?

- What **could you do** to publicise the survey locally?



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What can you do to publicise the survey locally?

- Share information about the survey more widely with patients and staff e.g. in hospitals and community spaces, via email and patient letters
- Share information with local charities
- Encourage clinicians to discuss the survey with parents
- Share details of the survey via social media platforms
- Link with children and young people's online forums



Communications Toolkit

Under 16 Cancer Patient Experience Survey



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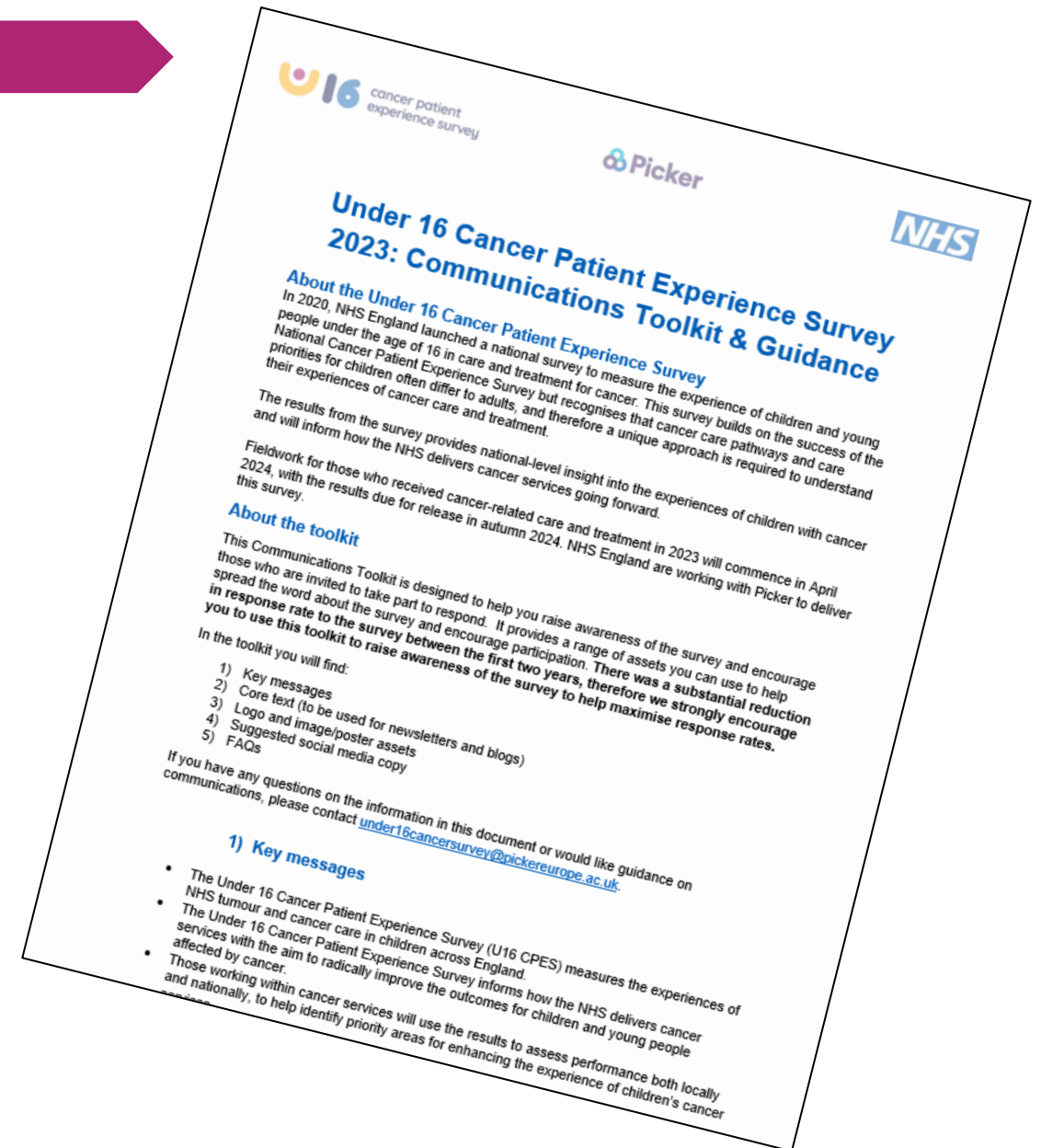
A revised and refreshed toolkit to support Trusts and Principal Treatment Centres to communicate about the survey to patients



Available at: <https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>

U16 Cancer Patient Experience Survey

- Written guidance to support communications about the survey
- Description of toolkit assets
- Pre-written copy to use for different mediums
- Combination of written and visual assets



U16 Cancer Patient Experience Survey



NHS

Under 16 Cancer Patient Experience Survey

If you receive a survey in the post, have your say.

Your feedback will help the NHS to improve cancer services for children and young people.

For more information, scan:



U16 cancer patient experience survey

Or visit:
www.under16cancerexperiencesurvey.co.uk

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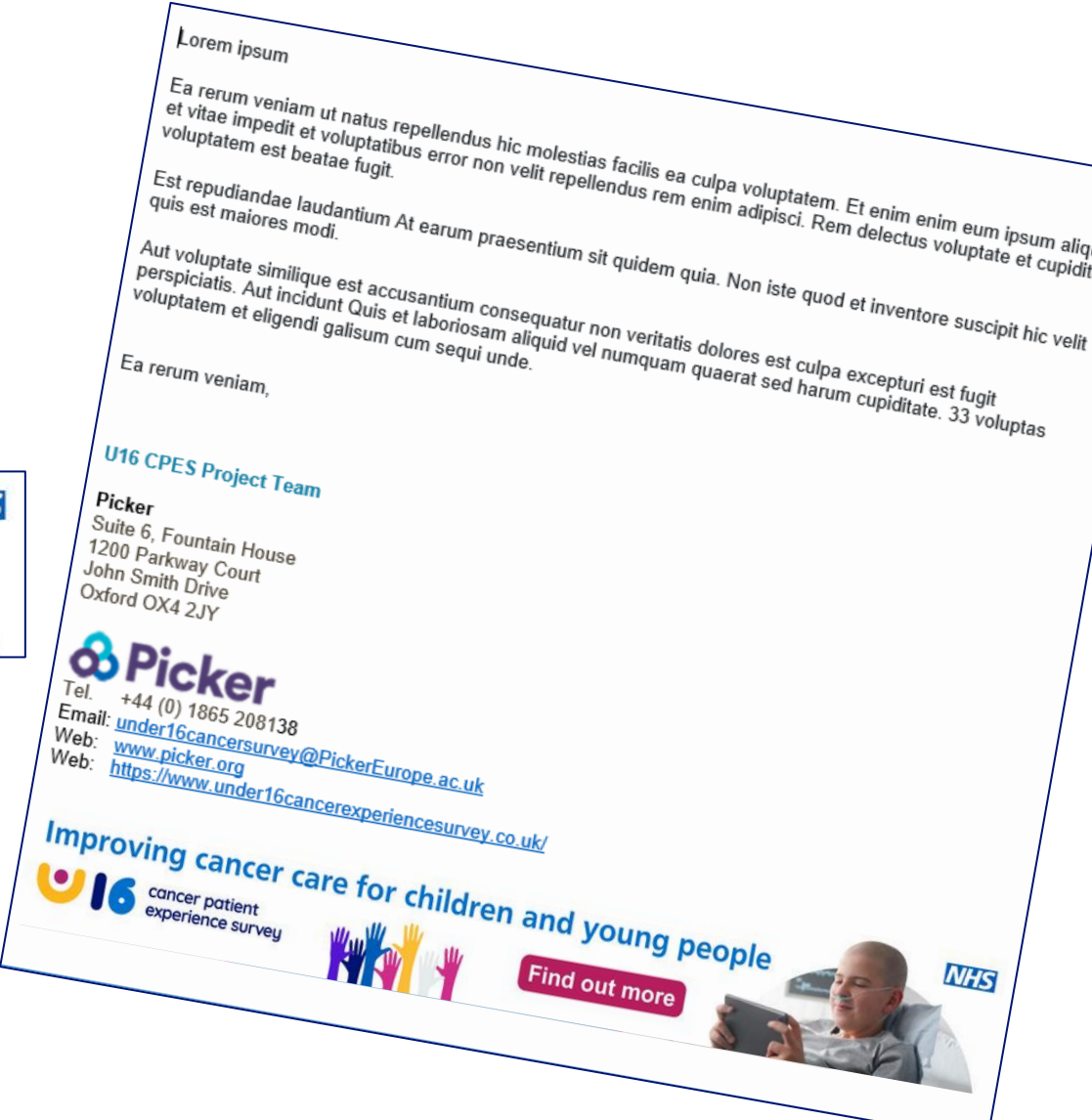
- X (formally Twitter), Facebook, LinkedIn, Instagram
- Multiple images tailored for use on each platform
- Additional text to use with images



U16 Cancer Patient Experience Survey




- Email banner
- Written instructions on how to set it up and remove it
- Effective promotional tool



U16 Cancer Patient Experience Survey




- Footer to add to letters and communication with patients

 cancer patient
experience survey

Improving cancer care for children and young people

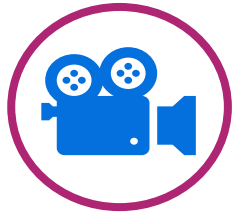
www.under16cancerexperiencesurvey.co.uk



Scan me



U16 Cancer Patient Experience Survey



Q&A

Under 16 Cancer Patient Experience Survey



For more information on the Under 16 Cancer Patient Experience Survey visit:



<https://www.under16cancerexperiencesurvey.co.uk>

If you have any questions about the survey, please do not hesitate to get in touch:



under16cancersurvey@pickereurope.ac.uk

To view the most recent survey results, please see the survey website:



<https://www.under16cancerexperiencesurvey.co.uk/technical-reports>