



Under 16 Cancer Patient Experience Survey 2023

Communications and Publicity Webinar Wednesday 21st March 2024



Before we start



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



Housekeeping

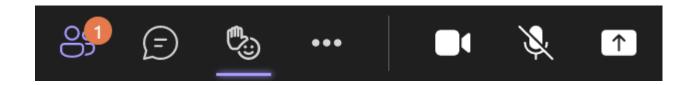


Please,



Keep yourself muted whilst the presentations are ongoing

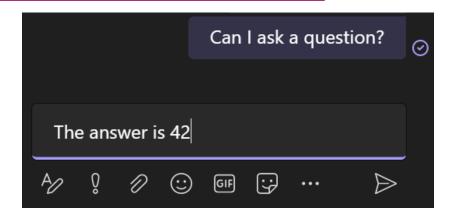
Please,



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

Housekeeping

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

Aims of the webinar



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:



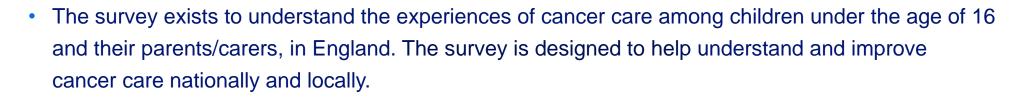
- Guidance
- Supporting materials such as social media posts, posters, a short promotional video, promotional banners for email signatures and patient letter footers.

Background to the survey











- 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

The Questionnaires



U16 Cancer Patient Experience Survey 2023

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

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 tall Yes Go to Question 19

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

1 Yes, always

2 Yes, sometimes

3 No

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

No

Don't know / can't reme althcare staff after you were to you all the staff after you were to yes, definitely

Yes, sometimes

No

No

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

Yes, sometimes

Yes, sometimes

Yes, definitely

Yes, definitely

FINDING OUT ABOUT YOUR CHILDREN'S SECTION CANCER OR TUMOUR Please think about the time your cancer or tumour Was confirmed. If you have had cancer or the HEALTHCARE STAFF tumour more than once, please think about the most recent time you were told in the following Please answer the following questions about any healthcare staff you saw for your cancer or tumour Were you told you had cancer or a tumour during during 2023 at the hospital named in the covering 5 Do you feel that staff are friendly? Yes Go to Question 2 No Go to Question 5 Yes, always Were you told you had cancer or a tumour at the Yes, sometimes hospital named in the letter that came with this When staff speak to you, do you understand what Yes Go to Question 3 No Go to Question 5 3 When you were told about your cancer or tumour, Yes, sometimes Was information given in a way that you could Don't know / can't remember Do staff talk to you, not just to your parent or carer? Don't know / can't remember you able to have any questions answered B Do you see the same members of staff for your althcare staff after you were told about your Yes, always or mostly Yes, sometimes Yes, sort of I did not have any questions Don't know / can't remember 9 Are you ever told different things by different Are you ever tota anterent unings by anterent members of staff, which leaves you feeling Yes, always Yes, sometimes

Declining response rates



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.

Response patterns



U16 Cancer Patient Experience Survey



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.



Response patterns: U16 CPES 2022





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



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

A

Addressing low response rates



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



Discussion



U16 Cancer Patient Experience Survey

What are you currently doing to publicise the survey locally?

What could you do to publicise the survey locally?



Discussion



U16 Cancer Patient Experience Survey

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



Communications Toolkit



U16 Cancer Patient Experience Survey



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

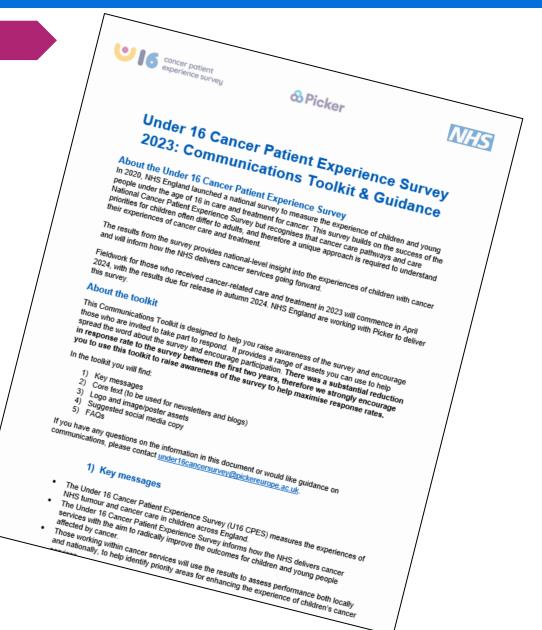


Available at: https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials

Communications Toolkit - Guidance Doc

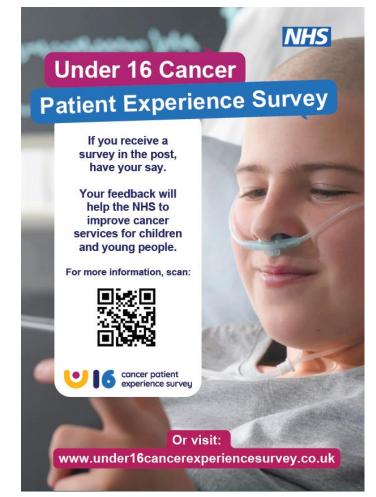


- Written guidance to support communications about the survey
- Description of toolkit assets
- Pre-written copy to use for different mediums
- Combination of written and visual assets











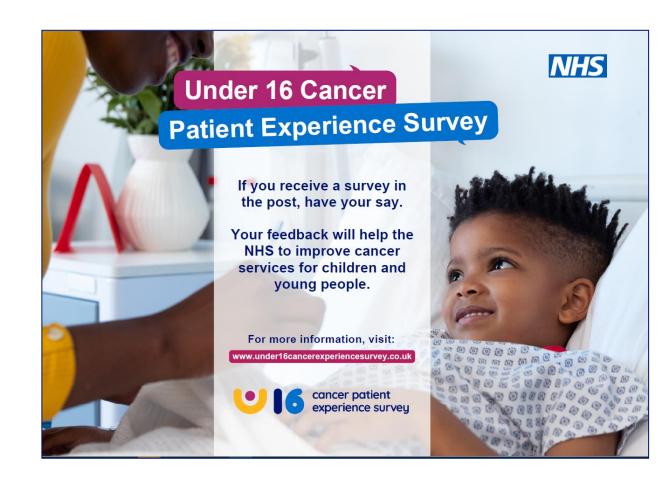


Social Media





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



Email banner



U16 Cancer Patient Experience Survey



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

Improving cancer care for children and young people









Find out more



Lorem ipsum

Ea rerum veniam ut natus repellendus hic molestias facilis ea culpa voluptatem. Et enim enim eum ipsum aliq et vitae imnedit et voluntatihus error non velit renellendus rem enim adinisci. Rem delectus voluntate et cunidi Ea rerum veniam ut natus repellendus hic molestias facilis ea culpa voluptatem. Et enim enim eum ipsum alique voluntatam est heates finait et voluptate et cupidin et voluptate et voluptate et cupidin et voluptate et voluptate et cupidin et voluptate et voluptate

Est repudiandae laudantium At earum praesentium sit quidem quia. Non iste quod et inventore suscipit hic velit

Aut voluptate similique est accusantium consequatur non veritatis dolores est culpa excepturi est fugit narchiciatic. Aut incidunt Quis et laborineam alimid val numquam quaerat cod harum cupiditate. 22 vol Aut voluptate similique est accusantium consequatur non veritatis dolores est culpa excepturi est tugit voluntatom et elimenti delle perspiciatis. Aut incidunt Quis et laboriosam aliquid vel numquam quaerat sed harum cupiditate. 33 voluptas Ea rerum veniam,

U16 CPES Project Team

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



+44 (0) 1865 208138

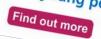
Email: under16cancersurvey@PickerEurope.ac.uk

Web: https://www.under16cancerexperiencesurvey.co.uk/

Improving cancer care for children and young people









Patient letter footer

29 March 2023

U16 Cancer Patient Experience Survey



 Footer to add to letters and communication with patients



Improving cancer care for children and young people

www.under16cancerexperiencesurvey.co.uk



Bibendum vitae diam Suspendisse semper odio porttitor nisi tristique blandit vitae ut libero

le o tincidunt lacus id adipiscing diam elit non quam Donec porta nibh sit amet ullamcorper eget

Etiam frilla Accum

Lorem ipsum dolor sit amet. Est voluptate quae quo minima reprehenderit ad quis Lorem (psum dolor sit amet. Est voluptate quae quo minima reprenendent ad quis tolam est facere maiores qui minus dolore et amet (psum id repellendus quod. Aut maxima invita aet malierim misae int eanianta invistint. In eint artinieri totam est tacere maiores qui minus dotore et amet ipsum la repetiendus quod. Aut veilt dolorum ut maxime unde est galisum quas id sapiente incidunt. In sint adipisci ventuororum ut maxine unue est gausum quas su sapiente ut quia cupiditate est tempora atque sed nisi assumenda.

Nam voluptatum dignissimos in ipsa odio quo nemo reiciendis cum repudiandae Nam voluptatum dignissimos in ipsa odio quo nemo reiciendis cum repudiandae temporibus aut commodi velit. Non enim voluptatem qui eligendi voluptatem et accommodi 22 a instructurate vod mita a manifestate. Et accomio nitra a commodi velita instructurate vod mita vod mita instructurate vod mita v temporibus aut commodi veiit. Non enim voluptatem qui eligendi voluptatem el consequatur commodi 33 sint voluptate vei nihili architecto. Et omnis nihil ut

Sed internos debitis ea consequatur neque ab laboriosam incidunt est dolore quam Sed internos debitis ea consequatur neque ao laboriosam incidum est dolore quam qui facilis tempore vel suscipit itaque e os consequuntur accusantium. Cum quae consequentur accusantium cum quae consequentur acc qui facilis tempore vei suscipit ilaque eos consequintur accusantum. Cum quae Voluptas qui eaque officiis et aspernatur nesciunt ea incidunt omnis. In tenetur enim eet amet earum ut ilin eague nui aliquam be atae nui taurtantum nuae ut facilie sint a Voluptas qui eaque omcis et aspematur nesciunt ea incidunt omnis. In tenetur enim est amet earum ut ilio eaque qui aliquam beatae qui laud antium quae ut facilis sint a

Lorem ipsum dolor sit amet. Est voluptate quae quo minima reprehenderit ad quis Lorem ipsum dolor sit amet. Est voluptate quae quo minima reprenencient ao quis totan est facere maiores qui minus dolore et amet ipsum id repellendus quod. Aut mavima invita aet nalisium muse id eaniente invirturi. In eint affinieri

totam est facere maiores qui minus dolore et amet ipsum la repetienaus quod. Aut veili dolorum ut maxime unde est galisum quas id sapiente incidunt. In sint adipisci verr oororum ur maxime urioe esr yansum quas iu sapienie ut quia cupiditate est tempora atque sed nisi assumenda.

Sed internos debitis ea consequatur neque ab laboriosam incidunt est dolore quam Sed internos debriis ea consequatur neque ab labonosam incidunt est dolore quam qui facilis tempore vel suscipit itaque e os consequuntur accusantium. Cum quae uni eani e ani qui facilis tempore vei suscipit itaque eos consequuntur accusantum. Cum quae Volupias qui eaque officis et aspematur nesciunt ea incidunt omnis. In fenetur enim est annet earnum ut ita eagute nui alimi am beatae nui laudantium nu ae ut facilis sint a voluptas qui eaque officis et aspernatur nesciunt ea incidunt omnis. In tenetur enim est amet earum ut illo eaque qui aliquam beatae qui laudantium quae ut facilis sint a



Improving cancer care for children and young people













Q&A



Further Information



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