

Data Gathering Patient Experience and Empathy Map Survey: Paper version

Information sheet

You are being invited to share your experiences as part of a quality improvement initiative within the NHS because you or your child or a person you are the main care-giver for, has a learning disability and / or autism and was diagnosed with cancer or a cancer relapse within the last 3 years, and they were under the age of 25 years at the time.

NHS data shows that some people with a learning disability or autism may have a poorer experience of cancer care than other people. Our group would like to improve that, but we know we can't improve it all at once. We know from our scoping work that the experience of having scans, tests, and investigations can be a particularly challenging experience for these young people. To understand this more deeply and look for areas where improvements could be made, we are focusing on the child or young person's experience of having an X-ray, alongside your experience as a parent or care-giver.

We collected baseline data in December 2023 to February 2024. This has given us an experience score and information about families' experiences 'before' any changes were made. We are now repeating this survey 'after' a change was made at hospitals who care for children and young people with cancer.

Consent and data

By continuing to offer information you are consenting to your information being used to inform the project. Your information will be anonymised before any information is shared or reported beyond the core project team. We may use anonymised quotes from your information when reporting on the project findings to give examples of real experiences. You can request that your information is removed from the project at any time by emailing chief.nurse@cclg.org.uk

Your information is only being used to inform this quality improvement project. We will not tell your hospital team what you personally have told us. That means no-one will directly improve your care for your next X-ray on the basis of the information you are giving now. If you told us something that put another person at risk, we would work with you to take appropriate action around this.

We will tell cancer services and radiology departments about themes that come from our collected findings, alongside asking hospitals to take part in making the improvements that we will suggest for improving care based on the information collected. The themes will aim to identify what services are doing well, as well as where care could be better.

Our core project team (the steering group) includes the following people:

Jeanette Hawkins and Jo Stark	Project Lead. Chief Nurse: CCLG: The Children & Young People's Cancer Association www.cclg.org.uk
Pia Fagelman	Senior Programme Manager, East of England Children, Teenagers and Young Adults with Cancer – Operational Delivery Network.
Davina Hartley	Programme Manager, North West Children's Operational Delivery Network.

Helen Morris	Children's Cancer Network Lead Nurse. Children, Teenage and Young Adult Operational Delivery Network, South West.
Claire Crowley	Lived experience partner and 'cancer mum' to her child with Downs Syndrome.
Neil and Janet Harrower	Lived Experience Partners and 'cancer parents' to young adult with Downs Syndrome.
Dr Kate Oulton	Consultant Nurse for Learning Disabilities & Senior Research Fellow, Great Ormond Street Hospital for Children.
Alastair Lesliedakers	Programme Manager. North West Teenage and Young Adult Operational Delivery Network. For the first year of the project only.
Myriam Jackson	Advanced Practitioner Reporting Radiographer, Society of Radiographers accredited Advanced Practitioner, Trust Lead Paediatric and Forensic Radiographer, Radiology Lung Cancer Lead Radiographer. Representing Society of Radiographers, CYP Imaging Special Interest Group.
Clare Simcock	Lead Radiographer, Great Ormond Street Hospital for Children & Children's Cancer Centre Project. Representing the Society of Radiographers.

We are reporting to a project sponsor: Sue North MBE. CYP Lead, NHS England Learning Disability and Autism Programme of Care. www.england.nhs.uk/learning-disabilities

This project is part of the NHS England Cancer Experience of Care programme: Cancer Experience of Care Improvement Collaboratives. www.england.nhs.uk/cancer/ipe

Who will be collecting your information?

Your information may be collected by completing the survey online using the following link www.surveymonkey.com/r/cclg-this-is-me

If you have questions or would like to know more, please contact chief.nurse@cclg.org.uk

V3.2 LIVE-post change intervention. Cancer Improvement Collaborative: Quality Improvement Project for children, teenagers and young adults with pre-existing learning disabilities and / or autism

Developed by CCLG: The Children & Young People's Cancer Association with the Society & College of Radiographers and Cancer Improvement Collaborative quality improvement group. Intervention test V.1

You are part of the LIVE testing data collection group. We have previously collected data as a 'baseline' from families like you before any change improvements were put in place.

We have now made a recommendation for improvement, and your information is helping to monitor if this is making the changes needed. We will continue recommending changes and monitoring until a satisfactory level of experience is consistently reported.

You can complete this survey each time the child or young person has an X-ray, during the time we are collecting data (until 31st July 2027) for as many X-rays as they need in relation to their cancer care. Please respond based on the most recent experience each time. This will help us to monitor progress over time.

Eligibility:

- Child, teenager or young adult between age of 0 to 25th birthday, who has a learning difficulty and / or autism; (this does not need to be confirmed if you are awaiting the diagnosis) and
- is diagnosed with a cancer (including leukaemia and blood cancers and relapses) or treated for cancer in the last three years.
- Has had an X-ray in any location in order to confirm diagnosis, monitor for signs of cancer or response to treatment, look for side effects of treatment (such as infection) or to assist treatment (such as checking position of an NG Tube or Hickman line).

Exclusion:

- X-ray performed under sedation or anaesthesia.
- X-ray for a different reason than the cancer diagnosis, such as an accident.
- Mobile X-ray performed on the ward.