

Under 16 Cancer Patient Experience Survey Data Sharing Agreement

THIS AGREEMENT is made and will come into force on xx th January 2026	
1	<p>Between:</p> <p>1) Name and address (The Trust); and</p> <p>2) NHS England</p> <p>For the purposes of this agreement, Picker Institute Europe is acting as the data processor under the sole instructions of the data controller, NHS England.</p> <p>Picker Institute Europe a company incorporated and registered in England and Wales under company number 3908160 and a registered charity in England with registered number 1081688 and in Scotland with registered number SC045048 and whose registered office is at Suite 6, Fountain House, 1200 Parkway Court, John Smith Drive, Oxford OX4 2JY ("Picker").</p>
2	Definitions See Annex A
3	<p>BACKGROUND</p> <p>The Trust has agreed to provide the data items (listed in section 6 of this document) with NHS England (for Picker to process) for the purposes of the Under 16 Cancer Patient Experience Survey 2025.</p> <p>The data items provided to NHS England (for Picker to process) shall only be processed in connection with the Under 16 Cancer Patient Experience Survey 2025 and will not be used for any other purposes.</p>
4	<p>Purpose, objectives of the information sharing:</p> <p>The Under 16 Cancer Patient Experience Survey (U16 CPES) is carried out to help the NHS monitor and improve the quality of cancer services so that they better meet patient needs.</p>
5	<p>Legal powers for processing the data/information</p> <p>The Secretary of State for Health and Social Care has given approval for NHS England to receive and process the specified data for the purposes of U16 CPES 2025, under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002</p>

	("section 251 support"), on the advice of the Confidentiality Advisory Group. This approval sets aside the common law duty of confidence and establishes a permissive gateway for Trusts to provide the specified information for the purposes of the survey.	
6	Data items to be processed	
	Data Item	Justification
	NAME AND ADDRESS, INCLUDING POSTCODE	The patient name and address will be needed for sending out postal surveys to patients. The postcode will also be used to determine patients' indices of multiple deprivation. Deprivation may also be used for case-mix adjustment. Case-mix adjustment is a methodology for 'standardising' the data to account for differences and to allow comparisons to be made more fairly. Postcode may also be used to map ICB of residence for analysis purposes.
	PATIENT, PARENT /CARER EMAIL ADDRESS, EMAIL FLAG, PATIENT, PARENT/CARER MOBILE PHONE NUMBER AND MOBILE PHONE NUMBER FLAG	The mobile phone number and email address of parents will be collected to explore the feasibility of using mixed mode methods in future waves. This data will not be used to make contact with patients at this stage but instead to assess completeness and accuracy of the data. A flag will also be included to understand whose mobile number or email address is available (e.g. the child/patient or unknown).
	NHS NUMBER	The NHS number will be included so that checks for duplicates can be made where patients appear more than once within a PTC sample, or if they appear in more than one PTC sample (i.e. if they have been cared for at more than one PTC site over the sampling period). NHS number is also needed to conduct DBS checks so that families of deceased patients do not receive a questionnaire. In addition, the NHS number will be used to link U16 CPES data to the National Cancer Registration and Analysis Service (NCRAS) held by NHS England for further analysis. Confidential patient information is provided to input into NCRAS under NHS England Directions.
	SEX, ETHNIC GROUP, DATE OF BIRTH	These will be used to compare demographic groups' experiences of cancer care. They will also be compared to patients' responses about their age, sex and ethnic group to ensure that the patient sample and response data are accurately matched. Small numbers principles will be applied with analysing, publishing and sharing data. Full date of birth will be required to enable DBS tracing of patients to check for any deceased patients prior to each mailing. Date of birth will be used to identify the age of the patient to ensure they are eligible for the survey, and send the appropriate questionnaire version (there are three versions – one for parents of 0-7 year olds, and two versions for children and their parents, one for those aged 8-11 and another for 12-15 year olds).
	DISCHARGE DATE AND PATIENT CLASSIFICATION	Discharge date will be used to check that the sampling criteria have been followed correctly (all discharge dates should fall within a specified, recent twelve-month period). Discharge date may also be used to de-duplicate the same records within a sample (e.g. by retaining the most recent episode of care).
	ICD-10/11 CODE, SPECIALTY CODE, AND ICD-O-3 CODE	These will be used to check that the patient sample has been correctly drawn, and to divide the patients into cancer groupings for analysis and reporting. However,

		this may depend on numbers of responses and may only be possible by combining data across waves/years.
	NHS HOSPITAL SITE CODE	Site code will be used to determine the treatment site. Treatment site will be used to personalise the covering letters to patients, referring to the hospital where they received treatment.
	NHS TRUST CODE	Trust code will be used for analysis purposes (e.g. benchmarking across trusts).
	PATIENT RECORD NUMBER	This is not the NHS number. This will be a unique number assigned to each record in the data (Note that where there are multiple records for the same patient, each record will be assigned its own unique patient record number). The patient record number will be used in any further communications regarding cases following receipt of the sample. It will also be used in communications with the printing/mailing subcontractor (Greens) to indicate where mailings should be removed (e.g. due to DBS checks for deceased patients or patients opting out).
	Article 6 condition – all Personal Data <u>Trusts and NHS England:</u> Condition 6(1)(e) “...exercise of official authority...”	
	Article 9 condition – special categories of Personal Data <u>Trusts and NHS England:</u> Article 9(2)(h) “...health or social care...” (Racial or ethnic origin, Data concerning health)	
7	How will the data sharing be carried out? Patients’ data will be supplied to Picker only under specific conditions. By signing data security agreements with each PTC, Picker is obliged to keep the information confidential at all times, and to comply with Data Protection Legislation. The Agreement ensures that Picker will abide by the Agreement which describes how patients’ personal data will be sent to Picker, and how the data can be used. NHS trusts may send patient lists to Picker Institute Europe via one of two systems <ul style="list-style-type: none"> • Use of the Picker Institute Europe Online Sample Checking Platform which provides NHS trusts the ability to run an automated check on their samples to identify any errors in compilation. Each NHS trust will have a unique log-in to this secure platform allowing Picker Institute Europe to limit and control a user’s access and what actions they can take. • Over the internet using the encrypted secure upload system based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP). A key size of 256 bits or greater is used. This 	

	<p>is to ensure a high level of security to protect against any accidental or intentional interception during the transfer of patients' details. Once a provider has uploaded their password protected and encrypted sample file to the FTP, Picker removes the patient sample file from the FTP site and it is then saved to a folder accessible only to the named people responsible for checking and processing samples. In addition to being saved within restricted access folders, sample files are also password protected and the password is only known by the named project team. Data will be processed and stored in this location.</p> <p>No data will be transferred outside of the EU.</p>
8	<p>Privacy notices – articles 13 & 14</p> <p>The Trust will publish NHS England produced privacy information (posters, leaflets and website wording) which makes clear that patients can opt out of the survey if they wish to do so ahead of the start of the survey by contacting the trust.</p> <p>NHS England will provide privacy information to patients in the questionnaire front cover, invitation and reminder letters. Survey recipients agree to their personal data being processed for the purposes required for the survey when they complete and return their questionnaire. This information contained sets NHS England's lawful basis for processing as well as the purposes for processing personal data, our retention periods for that personal data, and who it will be shared with.</p>
9	<p>Specify the procedures for dealing with the exercise of subject rights under Chapter III of the UK GDPR, FOIA access requests, or complaints or queries, from Data Subjects and members of the public</p> <p><u>NHS England</u></p> <p>Right to be informed</p> <p>Privacy information contained within the questionnaire, covering letter and reminder letters ensure that the lawful basis for processing as well as the purposes for processing personal data, retention periods for that personal data, and who it will be shared with are clear to the survey recipient.</p> <p>Right of access</p> <p>Survey recipients will have the right to request:</p> <ul style="list-style-type: none"> • confirmation that their data is being processed • access to their personal data

The right to access will be upheld to allow those requesting access to ensure that they are fully aware of the data being used and to allow them to verify the lawfulness of the processing.

Right to access requests will be responded to without delay and at the latest within one month of receipt.

Right to rectification

Survey recipients will have the right to have inaccurate personal data rectified or completed if it is incomplete. Requests for rectifications will be responded to within one calendar month.

Right to erasure and right to object

Survey recipients will have the right to request erasure of personal data or object to processing at any point during the survey fieldwork up to the point at which data are analysed and personal details are removed. Respondents who state as part of their survey return that they would be willing to be contacted again in future to participate in further surveys, will also have the right to erasure or to object should they make a request.

Right to restrict processing

Processing information is made clear to patients in the questionnaire front cover, invitation and reminder letters. Survey recipients agree to their personal data being processed for the purposes required for the survey when they complete and return their questionnaire. Survey recipients will have the right to request the restriction of their data for processing purposes in producing the survey data at any point during the survey fieldwork up to the point at which data are analysed and personal details are removed. Requests will be responded to within one calendar month.

Where the data is semi-identifiable (e.g. a demographic), the eligible population at risk is 1,000 or fewer, and there are 5 or fewer respondents in a particular category, the data has been suppressed to protect the anonymity of respondents. For full details on suppression, please see the Technical Appendix on the survey website.

Right to data portability

Right to data portability will not apply as the data are not collected on the basis of consent, or contract with the subject.

Right to automated decision making including profiling

Automated decision making and profiling does not apply to the survey.

The Trust

	<p>The Trust will respond to subjects' rights requests in respect of the data to be shared in accordance with its own procedures. If the Trust receives a request from a patient that they do not want their information to be shared with NHS England or indicates they do not want to participate in the survey, the Trust will exclude information relating to this subject from the submitted data set.</p> <p>Should the Trust receive a subjects' rights request in relation to the survey after the data has been shared, the Trust will refer the requestor to the survey helpline.</p> <p>How will the organisations keep each other up to date about the amendment, erasure or restriction of use of Personal Data that has been shared under this agreement?</p> <p>NHS England will notify the Trust of any amendment. Erasure or restriction requests will be carried out by NHS England, as they relate to the survey only, the Trust will not be informed.</p>
10	<p>Specify the retention period for the information to be shared</p> <p>All personal information will be held securely and in accordance with the UK General Data Protection Regulation. Patient details will be kept for up to 12 months after the publication of survey results. At the end of fieldwork, name and address information will be deleted for anyone who opts out of participating or who does not return a completed questionnaire. Patients also have the right to remove their personal data at any point during the survey fieldwork.</p>
11	<p>Specify the process for deleting destroying the information when it is no longer required</p> <p>Any data stored on Picker PCs or physical servers will be deleted using certified data destruction software. This writes zeros over the current data, making it impossible to restore. All Picker hard disks are physically destroyed at the end of their lifecycle or due to malfunction. This is carried out prior to disposal or by a certified IT disposal company and a certificate of destruction obtained.</p>
12	<p>Specify any particular obligations on <u>all</u> parties to the agreement:</p> <p>Each organisation signed up to this Agreement will:</p> <p>12.1 comply with its obligations under the Data Protection Legislation, the Freedom of Information Act 2000 and the Environmental Information Regulations 2004 and comply with Data Guidance. The Parties acknowledge that once a Party has received data under this Agreement it will be responsible for ensuring that its own Processing of that data complies with this clause;</p>

	<p>12.2 use the information shared solely for the purposes identified and shall not Process the information for any other purposes;</p> <p>12.3 agree to treat the data received by them under the terms of this Agreement as confidential and shall safeguard it accordingly. Respect for the privacy of individuals will be afforded at all stages of Processing;</p> <p>12.4 notify the other parties to this Agreement of any breach of this Agreement (in particular paragraph 13.1) connected to the sharing of information under this Agreement within 24 hours of first suspecting the breach. This obligation extends to breaches concerning the systems on which the data shared under this Agreement are held, even if the data shared under this Agreement is not directly affected;</p> <p>12.5 notify the other parties to this Agreement of any complaint received from any person about the sharing of data under this agreement or any correspondence from the Information Commissioner or other regulator regarding the sharing of data under this Agreement; and</p> <p>12.6 assist each other, in responding to requests made under the Freedom of Information Act 2000 or Environmental Information Regulations 2004 in relation to the information shared under this Agreement to ensure a co-ordinated and consistent response.</p>
13	<p>Data Protection Officers</p> <p>Each Party shall notify the other Parties of the name, email address, and direct dial telephone number of any Data Protection Officer and promptly notify the other Parties of any changes to those details.</p>
14	<p>Dispute Resolution</p> <p>14.1 In the event of a dispute arising under this Agreement, authorised representatives of the Parties will meet to try to resolve the dispute within five Business Days of being requested in writing by any Party to do so. If the dispute remains unresolved, it will then be referred to a senior manager from each of the Parties who will use all reasonable endeavours to resolve the dispute within a further ten Business Days.</p> <p>14.2 If the Parties are unable to settle the dispute by negotiation, they must, within 5 Business Days after the end of the ten Business Day period referred to above submit the dispute to an independent body or organisation agreed between the Parties. If the Parties are unable to agree on an independent body or organisation within that period, then the dispute shall be submitted to the Centre for Effective Dispute Resolution (CEDR). The mediations will follow the mediation process of the independent body or organisation agreed by the parties or CEDR as appropriate.</p>

<p>15</p>	<p>Variation</p> <p>15.1 Any proposed changes to this Agreement, including the addition or removal of parties, the purposes of the information sharing, the nature or type of information shared or manner in which the information is to be Processed must be notified promptly to the Information Compliance/Governance leads so that the impact of the proposed changes can be assessed.</p> <p>15.2 No variation of this Agreement shall be effective unless it is in writing and signed by all of the Parties to this Agreement.</p>
<p>16</p>	<p>Remedies and no waiver</p> <p>16.1 Without affecting its liability for breach of any of its obligations under this Contract, a Controller will be liable to the other co-signees for and must indemnify and keep the other co-signees indemnified against any fine that results from or arises out of the Controllers, or Processors engaged by the Controller, breach of Data Protection Law.</p> <p>16.2 Each Party (“the Breaching Party”) shall indemnify, defend and hold harmless the other Parties (“the Non-Breaching Parties”) from and against all and any losses, claims, liabilities, costs, charges, expenses, awards and damages of any kind including any fines and legal and other professional fees and expenses (irrespective of whether they were reasonably foreseeable or avoidable) which it/they may suffer or incur as a result of, or arising out of or in connection with, any breach by the Breaching Party of any of its obligations in this Agreement.</p> <p>16.3 The rights and remedies provided under this Agreement are in addition to, and not exclusive of, any rights or remedies provided by law or in equity.</p> <p>16.4 A waiver of any right or remedy under this Agreement or by law or in equity is only effective if given in writing and signed on behalf of the Party giving it and any such waiver so given shall not be deemed a waiver of any similar or subsequent breach or default.</p> <p>16.5 A failure or delay by a Party in exercising any right or remedy provided under this Agreement or by law or in equity shall not constitute a waiver of that or any other right or remedy, nor shall it prevent or restrict any further exercise of that or any other right or remedy. No single or partial exercise of any right or remedy provided under this Agreement or by law or in equity shall prevent or restrict the further exercise of that or any other right or remedy.</p>
<p>17</p>	<p>General</p> <p>17.1 No Party shall assign, transfer, mortgage, charge, subcontract, declare a trust over, or deal in any other manner with any or all of its rights and obligations under this Agreement.</p>

	<p>17.2 This Agreement may be executed in any number of counterparts, each of which when executed and delivered shall constitute a duplicate original, but all the counterparts shall together constitute the one agreement. No counterpart shall be effective until each Party has executed at least one counterpart.</p> <p>17.3 This Agreement and any dispute or claim arising out of or in connection with it or its subject matter or formation (including non-contractual disputes or claims) shall be governed by and construed in accordance with the law of England.</p> <p>17.4 Each Party irrevocably agrees that the courts of England and Wales shall have exclusive jurisdiction to settle any dispute or claim arising out of or in connection with this Agreement or its subject matter or formation (including non-contractual disputes or claims), provided that nothing in this clause shall prevent a Party from enforcing any judgement obtained in the court of England and Wales in any other court with jurisdiction over the other Party.</p>
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