



Protecting and improving the nation's health

PHE National Cancer Registration and Analysis Service response to the Review of Informed Choice for Cancer Registration – progress update April 2019

Recommendation 1: Hospital trusts should be accountable for ensuring that patients are made aware of the cancer registry and their ability to opt-out during a face-to-face interaction with a member of staff at the earliest appropriate time after diagnosis.

- 1.1 Each hospital trust should have a policy in place outlining how people with cancer will be made aware of the cancer registry and their ability to opt-out at the earliest appropriate time after diagnosis. This should include clear lines of accountability and responsibility within the trust, as well as how trust staff should be trained and supported to inform patients.
- 1.2 The Caldicott Guardian in each trust is ultimately accountable for ensuring this policy exists and is implemented across the trust. The Lead Cancer Clinician, or equivalent, should then work with the Caldicott Guardian and MDT Leads to ensure implementation. NHS England's Quality Surveillance Team should ensure that the policy is being implemented as part of their peer review of cancer services.
- 1.3 The trust policy should state which member(s) of trust staff is responsible for deciding, on a case-by case basis, who is best placed to make the patient aware of the cancer registry and at what stage in their journey after diagnosis. This decision-making process should be flexible enough to account for variation in patients' routes to and from diagnosis, including whether they will undergo active treatment or enter palliative care.

Progress update:

- Further to the scoping work with Trusts and health professionals in the last period, we met with the National Caldicott Guardian Council to discuss the role of the Trust Caldicott Guardian in supporting this work. The Council advised that any guidance on disseminating information to patients and their families should be specifically targeted at healthcare staff delivering cancer services in trusts. They advised that while Caldicott Guardians can provide support, a member of the cancer services team would be better placed to take the recommendation forward.
- As an alternative approach we developed a set of guidance documents aimed at colleagues working in cancer services in acute trusts. Three documents were developed in consultation with healthcare and cancer charity colleagues; the NCRAS Caldicott Guardian and the NCRAS Data Liaison team. The first provides [guidance on actions trusts should be taking](#) to ensure as many patients as possible are told about cancer registration. The second is an [FAQ document](#) aimed at healthcare professionals to help improve their awareness of cancer registration and therefore their ability to support patients and families. The third is a [form](#) that trusts have been asked to complete

detailing their local practices for disseminating information to patients about cancer registration, the lead person for ensuring it happens and how other staff are made aware of the need for this to take place.

- The documents are available on the [NDRS website](#) as well as downloadable from the CancerStats2 platform which all organisations with an N3 connection can access.
- In January 2019 the guidance documents were sent to at least one cancer information contact in 177 acute hospital trusts. The individuals included the nominated cancer registration patient information contact in each trust, as well as Cancer Managers where appropriate.

Recommendation 2: There should be multiple channels through which people affected by cancer can find out about the registry and all communication materials need to be tailored to the relevant audiences.

Local actions:

2.1 Local care providers should make information about the cancer registry available in places where people affected by cancer will see it. This should include displaying leaflets and posters in hospital information centres, waiting rooms, GP practices and hospices, for example.

Progress update:

- The 2019 National Cancer Diagnosis Audit commenced in April, and at the time of this report over 630 participating GP practices in England have received copies of the patient information leaflet and a cancer registration FAQs document. Hard copies of the information materials have been provided to CRUK Facilitators who will be using them in their engagement activities with participating practices throughout the audit period.
- As key points of contact in some cancer patient's care pathway we contacted 41 radiotherapy centres in England to request they make the information leaflet available to patients. 16 additional centres are now displaying the poster and making the leaflet available to patients. Some centres will now provide a copy of the leaflet directly to patients during their first appointment and others will include a copy in patient appointment letters. We are following up with those who have not yet responded to the request.
- We are in the process of contacting 155 Macmillan Information Centres in England to provide them with our information leaflets.
- We contacted Hospices UK to determine whether it was possible to make the cancer registration leaflet available to hospice staff and patients in hospice care. This proposal was taken to a meeting of Hospice UK National Clinical Leads who concluded that "the decision was unanimous that by the time hospices become engaged in care this would not be a priority or of sufficient interest to have it in the public areas." We are grateful to Hospices UK for their consideration of this proposal.
- We are working with *brainstrust* to include our information materials in their patient information packs 'Brainboxes'. *brainstrust* distribute an average of 100 boxes to patients per month. *brainstrust* have also committed to have the information leaflet available at any events they attend.
- We have approached several other organisations to enquire whether they can also include our information in their patient packs. Many now only have online information or in having to prioritise what is included in their information packs, have determined that the cancer registration leaflet is not a high enough priority.

2.2 Local care providers should include a short statement about the cancer registry and where to go for more information when they refresh relevant patient information leaflets and web pages, or in appointment letters, if appropriate. This should include integrating information into leaflets developed locally.

- As part of the guidance documentation we sent to trusts (see recommendation 1) we included a suggested statement about cancer registration that could be included in local relevant information materials.

National actions:

2.3 Information about cancer registration should be included in websites used by people affected by cancer, including those of the NHS, PHE and cancer charities.

Progress update:

- We have taken several steps to increase the number of organisations that have cancer registration information available on their websites. We have been in direct contact with over 50 organisations including members of the Cancer Campaigning Group, who endorsed the Review of Informed Choice for Cancer Registration when it was published in 2016. Two organisations from the Cancer Campaigning Group updated their online information. The feedback we have received from organisations who have not updated their websites is generally that cancer registration information is not a priority for their website users.
- To date we are aware of 9 organisations that have specific information about cancer registration on their websites.
- We will continue to work with organisations to encourage the provision of online information via their own websites where possible.

2.4 NHS England, PHE and cancer charities should integrate information about cancer registration into existing leaflets, for example about urgent GP referrals for suspected cancer, along with where to go for more information.

- This will be a focus of our work over the next 12 months. We will be discussing and seeking input on ways to approach this action at the next RICCR Advisory Group meeting.

2.5 PHE should also consider establishing an information line, staffed by experts, for patients and healthcare staff wishing to find out more about the cancer registry.

- We have explored the possibility of providing a helpline but have concluded that this is not a viable for a number of reasons:
 - The number of enquiries we receive about cancer registration including enquiries about opt-out and subject access requests remains very low.
 - All enquirers are offered a one to one telephone call with the cancer registration Caldicott Guardian to discuss their query and if wishing to opt-out, to explain the implications and process.
 - A staffed helpline service would need to be available Monday to Friday during working hours and based on the current level of enquiries this would not be an appropriate use of public resource.

2.6 PHE, working with people affected by cancer and cancer charities, should refresh its existing materials on the cancer registry. This could include ensuring that:

Progress update:

- As per recommendation 2.2 we have included a suggested statement about cancer registration that could be included in local relevant information materials in the guidance documentation sent out to acute trusts.
- Since the previous update we have revised the cancer registration information materials following feedback from the Confidentiality Advice Group (CAG) who requested more information and clarity be provided on the data that is collected, the different uses of patient data and more explicit information on an individual's right to opt out should they wish. This version was approved in December 2019 and went into circulation in January 2019.
- Following on from the scoping work we undertook in 2018, we are continuing to work with the Teenage Cancer Trust (TCT) to develop a cancer registration information leaflet specifically for teenagers and young adults. TCT are supporting the involvement of young people affected by cancer to help develop the leaflet. When ready, the leaflets will be made available at TCT units in principal treatment centres in England. An electronic version will also be made available on the TCT and [National Disease Registration Service \(NDRS\)](#) website. This work is due for completion in May 2019.
- Working with the RNIB a Braille, large print and audio version of the patient information leaflet is now available. The large print and audio version are available on the NDRS [website](#) and all file formats can be requested. The ability to request alternative formats of the information leaflet is indicated on the general leaflet.
- We have committed that if the leaflet is requested in an alternative language we will take steps to make this available without unreasonable delay.
- We have embedded an annual review of the opt-out policy and procedures. In March 2019 we examined the feedback we have received from people choosing to opt-out and as a result we will be implementing a number of amends to the process:
 - A review of the Office for Data Release (ODR) aspects of the process, which will include checking if data on individuals choosing to opt-out has been shared with other organisations
 - Re-drafting the opt-out form to make it clearer and easier to understand especially in relation to the requirement for identification verification as part of the data protection process
 - Including additional information in the internal SOP about record retention periods
 - Amending the templates for opt-out correspondence to ensure we are being clear about all aspects of the process when communicating with individuals asking to opt-out
 - Reviewing the information provided on the NDRS website to include a clearer explanation of the steps involved to opt-out of cancer registration and a more thorough explanation of why individuals are asked to provide identification documents as part of the process.

Recommendation 3: All healthcare staff that directly interact with people affected by cancer (including support staff and health professionals in primary care and palliative care) should be able to answer basic questions about the cancer registry and signpost to further sources of information.

3.1 PHE should make basic information and training on the cancer registry available to all support staff and health professionals that work with people affected by cancer. This

should reinforce the importance of informing patients about the cancer registry and should be co-developed with people affected by cancer and cancer charities.

Progress update:

- We are working with a number of Cancer Nurse Specialist (CNS) groups to discuss the role of the CNS in providing information to patients about cancer registration and to gather initial ideas for tools or resource development that could support them in this task.
- Working with Macmillan's Workforce Specialist Advisor and members of our RICCR Advisory Group including a Nurse Consultant, we have gathered ideas that could help to disseminate information and resources to healthcare professionals once available. These include making an online learning resource available via the Macmillan online learning platform.
- As a result of our discussion with the National Council of Caldicott Guardians we are discussing ways to link with the Royal Colleges including the Royal Colleges of GPs.
- We will be exploring ways to engage with Cancer Alliances to understand the role they might be able to play in ensuring patients are informed of cancer registration.
- We are also liaising with colleagues from NHS England who were involved in developing communications for Healthcare Professionals in relation to the national opt-out programme.

3.2 Named individual(s) within each trust should become designated 'local champions' of the cancer registry. PHE should help identify and support these local champions so that they can oversee and support the provision of information to health professionals and patients in each trust. These individuals should receive additional training so that people affected by cancer and interested staff can be directed to them.

Progress update:

- The role of 'local champions' was discussed with the National Caldicott Guardian Council and we will explore this as part of our discussions with other healthcare professional groups.

Recommendation 4: The implementation of local and national awareness-raising strategies should be measurable.

4.1 PHE's Data Liaison Team should work with local care providers to monitor their progress in informing patients about cancer registration. This could include:

- Keeping a record of which hospital trusts have a policy in place for ensuring that people affected by cancer are made aware of the registry, and which of those are being satisfactorily implemented.
- Conducting walk-throughs and spot-checks to determine whether patient information materials are being displayed.
- Monitoring the number of leaflets it is providing and to which local care providers.

Progress update:

- As a part of the guidance documentation developed for trusts (see recommendation 1) a form was produced and shared with patient information contacts within the acute trusts. The form supports trusts to record their local practices for informing patients about cancer registration. Trusts were asked to complete and return the form. Since dissemination of the documentation in January 2019, we have received 8 completed

forms. We will be working with the Advisory Group and Data Liaison Team to follow up on this action. The resource is also available on the [NDRS website](#) and via CancerStats2.

- Spot checks for patient information materials is now an embedded function of the Data Liaison Team. When the Data Liaison Team are unable to locate the information materials they will endeavour to follow up with the information contact within the particular trust to ensure they are making the leaflet available to patients.
- Since the previous report in October 2018, a further 22 spots checks have been undertaken. 21 of the trusts checked had the patient information clearly displayed, were providing copies of the leaflet in patient information packs or had staff members distributing the leaflets directly to patients. A new supply of leaflets was organised for the single trust that did not have the leaflets available at the time of the check.
- An ongoing record of the number of leaflets that are distributed is kept. This includes exactly how many leaflets are sent out and to where.
- 204,785 leaflets have been distributed in the period October 2018 - April 2019.
- Since October 2018 leaflets have been distributed to regular recipients in 164 acute NHS trusts, 16 radiotherapy centres, 2 private care providers, 2 charities, 3 support centres and 7 disease specific clinics.
- 30 of the above are new distributors since the October 2018 progress report.

4.2 NHS England should consider including a question asking patients whether they remember being told about the cancer registry in the Cancer Patient Experience Survey when it is next reviewed.

Progress update:

- We have investigated whether a question on cancer registration awareness can be included in the Cancer Patient Experience Survey (CPES) but at the current time we have been advised this is not possible. We will continue to investigate ways to implement this action.

Recommendation 5: General awareness of how the NHS uses healthcare data, including cancer data, should be improved.

5.1 All organisations using cancer registry data should credit the registry in public communications and sign-post to further information. This should include occasions when:

- NHS England and others deliver products that are underpinned by cancer registry data e.g. the cancer dashboard and national cancer statistics.
- Cancer charities use cancer registry statistics or analysis in published research, media stories or cancer intelligence tools.

Progress update:

- All PHE outputs using cancer registry data now include the data use acknowledgement statement and all work produced in partnership with other organisations must also include the data acknowledgement. Moreover, where data is released publicly such as our Get Data Out programme with charities these releases will also include the acknowledgement.

- The acknowledgement is included in the PHE Office for Data Release data sharing contract. This stipulates that any data recipient must acknowledge the cancer registry as the source of the data.
- In November 2018 NCRAS was contacted by the Patient Participation Group for Bowel Cancer Intelligence UK based at Leeds University asking for a revision of the citation to reflect the patient's role in providing data. NCRAS discussed options with the group and agreed to update the citation in line with the UseMyData citation to reflect the patient at the heart of the data along with the role of the system:

"This work uses patient data collected by the NHS that has *either been provided by, or derived from, patients as part of their care and support*. The data are collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE)."

5.2 Every organisation using healthcare data (including PHE, NHS England, NHS Digital and cancer charities) should take responsibility for highlighting the ways in which healthcare data, including cancer data, are used for direct care, planning services and research and the benefits that brings to patients and the wider public.

Progress update:

- We are developing a series of case studies to explain how data is being used in research and to plan NHS services. We have collected several examples and are in the process of producing these for a public audience. These case studies are being developed with the involvement of patients and public members and our Advisory Group. These first phase of case studies will be published on the NDRS website in June 2019.
- In addition, we are creating a series of infographics to demonstrate what cancer registration data is used for. These infographics will focus on eight key areas and be displayed on the NDRS website alongside the case studies. The areas include: 1) understanding cancer, 2) improving diagnosis, 3) improving treatment, 4) improving survival, 5) genetic matching, 6) quality of life, 7) evaluating policy, 8) helping the NHS to plan services. We will also include a summary infographic on the website that broadly explains why patient data is collected.
- As a member of the Understanding Patient Data steering committee we are continuing to work with the wider data community to shape how we communicate about the use and benefits of healthcare data. We have adopted the data terminology set out by UPD and are working to ensure this is applied consistently in all our communications.
- We are hosting two cancer data events in 2019 which will focus on specific areas of cancer data; data for rare and less common cancers and the developments in genomic and molecular data. The event programmes are being developed in conjunction with our partners and will support awareness of how these data sets are being collected, used for analysis and research and to support improvements in outcomes and patient care. Patients, carers, members of the public, healthcare professionals and cancer charity representatives will be invited to attend.
- In March 2019 we held the first meeting of the NCRAS Advisory Group for the Review of Informed Choice for Cancer Registration. The purpose of the group is to offer advice and to offer constructive challenge on our work to deliver on the recommendations. The Advisory Group will also provide key links to other groups and communities who are implicit to the delivery of the review recommendations. In addition to the primary role, members are asked to act as a conduit for the dissemination of information and influence

where relevant and appropriate. The group includes patients, charity, healthcare and research representatives and will meet four times per year.

Final version – 30 April 2019