



National Cancer Registration and Analysis Service Response to the Review of Informed Choice

Background

Population-based cancer registration is an essential public health and healthcare function to improve the care and outcomes of patients who are diagnosed with cancer. When someone is diagnosed with cancer or a condition that might lead to cancer, the doctor or hospital records the relevant details. This applies to people of all ages, including children, and this information is collected by PHE's National Cancer Registration Service. The information or data is then used to understand the types and numbers of cancers, treatment outcomes, and can also support genetic requests from families via their healthcare team to investigate a cancer risk.

The cancer registry has legal permission ([under Section 251 of the NHS Act 2006](#)) to collect and store patient data without the need for direct patient consent.

What the Review of Informed Choice for Cancer Registration found

The review found that awareness of the cancer registry is low across a range of audiences including those living with and beyond cancer, the general public and health professionals.

"6% of people living with cancer and 3% of the public know a great deal or a fair amount about the cancer registry (while) 74% of people living with cancer had never heard of the cancer registry."¹

The following is a summary of the key recommendations from the review:

- awareness of the cancer registry needs to be significantly improved among people affected by cancer. This will make it possible for cancer registration to legitimately function on a separate opt-out system
- information provided about the cancer registry should be accessible and tailored to the relevant audience

¹ Perceptions of the cancer registry: Attitudes towards and awareness of cancer data collection. A report for Macmillan and Cancer Research UK by Ipsos MORI. September 2016

- awareness of the cancer registry needs to be significantly improved among relevant healthcare professionals in order that they can inform patients and guide them to further information
- processes for providing cancer patients with information about the cancer registry should, as far as practicable, be measurable
- Trusts should be accountable for ensuring patients are aware of the registry and their right to opt-out
- there needs to be all round improvement of information that explains how NHS uses healthcare data

Our response

Our immediate aim is to improve awareness of the cancer registry with our stakeholders so that those newly diagnosed with cancer can make an informed choice on whether to opt out of having their data held by the cancer registry.

Our response plan sets out the actions we will take to achieve this.

The plan:

- starts the immediate projects and tasks needed to increase awareness and transparency about our work over the next six months
- sets in motion activities to achieve the organisational change required for PHE to maintain these improvements, and enable PHE to provide a truly transparent and responsive cancer registration service that achieves the full confidence of its stakeholders

No.	Objective	Key actions and deliverables	Addresses Review Recommendations	Measurement of success	Working with	Start date	End date
1	Ensure that information materials on the cancer registry are transparent and where appropriate tailored to relevant audiences. That they are widely available and accessible through multiple channels.	Work with patients, health professionals and the public to revise and refresh the cancer registry information materials. Work with specific groups to develop tailored materials according to need.	2.6	Launch of new cancer registry materials	Patients, carers, public, CRUK, Macmillan, Teenage Cancer Trust, UseMyData, NCRI, BrainsTrust and many other organisations	Dec-16	General information materials launched in May 17/ Development of tailored materials to start June 17
		Work with providers, charities and other relevant groups such as hospices to ensure inclusion of cancer registry information in their information materials	2.2/ 2.4	Increase in the number of organisation's materials that include information about the cancer registry.	NHSE, Trusts, Third Sector and other stakeholders and provider organisations	Apr-17	Sep-17
		Ensure the revised cancer registration materials are easily available to patients and the public in Trusts*, GP surgeries, care homes, hospices and other relevant organisations for people affected by cancer. (* Work with identified patient information contact.)	2.1/2.2	Spot checks by data liaison team (See 4: Monitoring Framework)	NHSE, Trusts, GPs, care homes etc	Jan-17	Ongoing with quarterly reporting
				Number of information materials distributed. Increase in number of requests for cancer registry information. (See 4: Monitoring Framework)	NHSE, Trusts, GPs, care homes etc	Apr-17	Ongoing with quarterly reporting on spot checks and distribution numbers
Improve accessibility to information about the cancer registry through multiple avenues including PHE website, other organisations websites including NHS and charities and other locations as informed by patients and the public	2.3	Number of hits on cancer registry information pages on relevant websites. Increase in places with cancer registry information available to patients and the public.	NHSE, CRUK, Macmillan, Teenage Cancer Trust, Breast Cancer Now, Prostate Cancer, Royal Colleges, local authorities and many more	May-17	Sep-17		

		Review the cancer registry opt-out policy and process in order that it responds to patient and public information needs and it is easily available to support an individual make an informed decision on opting out	2.6	Reviewed by external patient panel on annual basis	PHE Office for Data Release/ Patients and the public	Feb-17	Jun-17
2	Support the improvement of information about cancer registration for health professionals in order that they can provide timely and appropriate information to those affected by cancer	Building on the feedback from people affected by cancer, work with health professional groups to develop the most appropriate approaches to how information about the cancer registry is communicated to those newly diagnosed with cancer	3.1	Agreement on approach(es)	Health Professionals, Third Sector, Royal Colleges	Mar-17	Sep-17
		Working with health professional groups, support the development of tools to support all staff working with cancer patients to have basic knowledge about the cancer registry	3.1	Number of people who access tool(s)	Health Professionals, Third Sector, Royal Colleges	Apr-17	Oct-17
		Initiate discussions on Trust accountability for providing patients with information about the cancer registry with NHSE Quality Surveillance and Caldicott Guardians	3.2	Initial meeting (s)	NHSE Quality Surveillance Team	Mar-17	May-17
3	Improve our online presence and in particular refresh our website to ensure that it sets out in a clear, concise and accessible manner information that patients, clinicians and other users of the service will find useful	Improve our web presence to meet stakeholder needs and to provide relevant and up-to-date information	2.3	Hits to web pages	PHE Digital, all stakeholders	Feb-17	Sep-17
		Agree with partners and regular users of cancer registry data a standard acknowledgement in all publications and press releases	5.1	Rise in number of acknowledgements of use of cancer registry data	Office for Data Release/ Third Sector/ Academia/ all other users of registry data	Apr-17	Ongoing
4	Establish a monitoring framework that will allow us to measure progress against the recommendations and our ambitions	Survey all Trusts to ascertain the patient information contact and to establish whether there is a policy in place regarding making people aware of the cancer registry	1.1/ 4.1	Submit for quarterly reports	NHSE/ Providers	Apr-17	Ongoing
		Whilst visiting trusts, data liaison staff will conduct spot checks throughout Trusts to determine if cancer registry information materials are being displayed	4.1	Submit for quarterly reports	NHSE/ Providers	Apr-17	Ongoing
		Monitor distribution of cancer registration information materials by quantity, recipient and follow up requests	4.1	Submit for quarterly reports	PHE	Apr-17	Ongoing

		Produce quarterly reports on all measures of success	4.1	Quarterly reports	PHE	Apr-17	Ongoing
5	As part of the wider healthcare system, significantly contribute to raising awareness of the use of healthcare data	Strengthen links with the wider community working with healthcare data and public engagement to develop collaborative ways to raise awareness of the use of healthcare data to the general public	5.2	Initiate and host a meeting with partners and stakeholders to discuss possibilities	NHS, Wellcome Trust, Third Sector, Academia, Patient Networks and more	Apr-17	Aug-17
		Actively contribute to opportunities to raise awareness of cancer registry data usage and application in national and local campaigns	5.2	Participation in at least two campaigns or events each year		Apr-17	Mar-18
6	Implement new ways of working to embed the actions from the review to ensure ongoing transparency and that the patient voice is present throughout our work	Develop and implement a workforce development plan that will increase our capability and capacity to respond to stakeholder needs and support improvement to our communications and outputs	All	Outputs that demonstrate the impact of registry related work for patient benefit	All stakeholders	Apr-17	Mar-18
		Refresh the role of patient representatives in our work to be relevant and ensure the patient voice is represented	All	Increase in public engagement in our projects	Patient representatives and networks	Apr-17	Sep-17
		Increase and embed patient and public engagement throughout our work and to inform future planning	All	Produce and implement the NCRAS plan for awareness and public engagement	All stakeholders	Feb-17	Oct-17

Our actions and new ways of working will be focused on the following values and principles:

1. Engagement with people affected by cancer and the wider public will inform the actions that we take, ensuring that the needs of patients and the public are at the heart of what we do;
2. Close working with key partners including health professionals, third sector organisations, academia and other health bodies will enable information about the cancer registry to reach further;
3. Improving our communications and profile to better communicate our work to multiple stakeholders and to see that the work of the cancer registry is acknowledged for its role in healthcare;
4. Developing our capacity and capability to ensure we have the relevant skills and knowledge to deliver on our ambitions.

For further information and to see how you can get involved please contact NCRASenquiries@phe.gov.uk

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