



PHE National Cancer Registration and Analysis Service response to the Review of Informed Choice for Cancer Registration: October 2018 to October 2019 actions

This document sets out the next set of actions NCRAS will be delivering to increase awareness of cancer registration.

No.	Objective	Key actions and deliverables	Next steps (October 2018-October 2019)	Addresses Review Recommendations	Delivered by	Working with
1	Ensure that information materials on the cancer registry are transparent and where appropriate tailored to relevant audiences. That they are widely	1.1 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	<ul style="list-style-type: none"> <input type="checkbox"/> To further scope the requirement and provision of tailored materials including for teenagers and young people and those with sight impairment <input type="checkbox"/> Biennial review of the leaflet with input from patients, carers, health care professionals, charities and other relevant groups 	2.6	<p>March 2019</p> <p>March 2020</p>	Patients, carers, public, cancer charities, RNIB

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	available and accessible through multiple channels	1.2 Work with providers, charities and other relevant groups such as hospices to ensure inclusion of cancer registry information in their information materials	<input type="checkbox"/> Working with our partners, patient information contacts in Trusts and cancer centres and wider stakeholders, we will identify opportunities to include our information leaflet in new patient information packs and other resources for patients and their families	2.2/2.4	Ongoing	Teenage Cancer Trust, brainstrust, NHSE
		1.3 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.)	<input type="checkbox"/> We will be working with partners to ensure information materials are available in patient information centres and identifying further opportunities to distribute the leaflet, for example, to GP surgeries through the National Cancer Diagnosis Audit (NCDA), hospices working with the Hospices UK and Radiotherapy Centres	2.1/2.2	Ongoing	Macmillan Cancer Support, Cancer Research UK, NHSE, Hospices UK

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		<p>1.4 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</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Working with charity partners and members of APPG for Cancer we will be concentrating on increasing the number of organisations with information about cancer registration on their own websites and linking to our online information <input type="checkbox"/> As per action 3.1 our website content is regularly updated to provide the most relevant information 	2.3	Ongoing	APPG member organisations
		<p>1.5 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</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Action complete subject to an annual review of the opt-out process 	2.6	March 2019	PHE Office for Data Release, patients and the public
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	2.1 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	<ul style="list-style-type: none"> <input type="checkbox"/> Finalise the content and distribution of guidance for Caldicott Guardians. This will include individual and direct contact with Caldicott Guardians within Trusts <input type="checkbox"/> With input from Cancer Nurse Specialist (CNS) we will be exploring the development of tools specifically for the CNS network including newsletters and presentation sessions <input type="checkbox"/> We will scope the potential of a programme of 	3.1	December 2018 TBC	Caldicott Guardian Network, Cancer Nurse Specialists, Cancer Managers, Health Professionals

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		2.2 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	information sessions for health professionals and patients which we will deliver via face to face visits to Trusts and other relevant venues and events		TBC	
		2.3 Initiate discussions on Trust accountability for providing patients with information about the cancer registry with NHSE Quality Surveillance and Caldicott Guardians	<input type="checkbox"/> As an alternative approach, we are including information for Caldicott Guardians about Trust accountability for informing patients about cancer registration. The NCRAS Caldicott Guardian has been consulted as part of the development of this approach and will be supporting the role out to the Caldicott Guardian network	3.2	December 2018	PHE, Caldicott Guardian network
3	Improve our online presence and in particular refresh our website to ensure that it sets out in a clear, concise and accessible	3.1 Improve our web presence to meet stakeholder needs and to provide relevant and up-to-date information	<input type="checkbox"/> New content and updated information is added to the www.ndrs.nhs.uk site as and when required <input type="checkbox"/> As per action 1.4 we will be working with partners to increase the availability of information about cancer registration online and signposting links to our own website	2.3	Ongoing	PHE

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	manner information that patients, clinicians and other users of the service will find useful	3.2 Agree with partners and regular users of cancer registry data a standard acknowledgement in all publications and press releases	<input type="checkbox"/> Action complete. Ongoing monitoring of the use of the acknowledgement	5.1		Office for Data Release, Third Sector, Academia, all other users of registry data
4	Establish a monitoring framework that will allow us to measure progress against the recommendations and our ambitions	4.1 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	<input type="checkbox"/> Working with the existing trust policies, we will develop an exemplar policy on the dissemination of cancer registration information to patients which will be shared with patient information contacts across all Trusts be made available via www.ndrs.nhs.uk <input type="checkbox"/> An annual survey will be undertaken as part of the COSD Roadshow to assess how many Trusts have a policy for cancer registration information	1.1/4.1	December 2018 March 2019	NHSE, Providers
		4.2 Whilst visiting Trusts, data liaison staff will conduct spot checks throughout Trusts to determine if cancer registry information materials are being displayed	<input type="checkbox"/> The NCRAS Data Liaison Team will continue to undertake spot checks of the availability of cancer registration information for patients	4.1	Ongoing	NHSE, Providers
		4.3 Monitor distribution of cancer registration information materials by	<input type="checkbox"/> Record the distribution of patient information leaflets and posters via all avenues (quarterly trust distribution, ad-hoc requests and	4.1	Ongoing	PHE

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		quantity, recipient and follow up requests	<p>distribution via ODR patient contact research studies)</p> <ul style="list-style-type: none"> <input type="checkbox"/> See also action 1.3 which outlines how we will be working to increase the availability of the leaflet by approaching new organisations 			
		4.4 Produce quarterly reports on all measures of success	<ul style="list-style-type: none"> <input type="checkbox"/> We will continue to report to the PHE Cancer Board biannually <input type="checkbox"/> We will continue to embed these changes into normal operating methods <input type="checkbox"/> We will continue to produce progress reports every 6 months (the next one for April 2019) 	4.1	Ongoing	PHE, Patients, carers, public, cancer charities, NHSE

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5	As part of the wider healthcare system, significantly contribute to raising awareness of the use of healthcare data	<p>5.1 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</p> <p>5.2 Actively contribute to opportunities to raise awareness of cancer registry data usage and application in national and local campaigns</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Develop a series of data stories which articulate how NCRAS data is being used and how it is supporting improvements in patient care. The data stories will be presented online in a format that is accessible to the general public <input type="checkbox"/> Continue to work with partners and the public to look and develop opportunities to raise awareness of the use of healthcare data to the general public. See section 6 for information about collaborative working with our stakeholders to advise on these activities 	5.2	March 2018	NHS, Wellcome Trust, Third Sector, Academia, Patient Networks and more

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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	<p>6.1 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</p> <p>6.2 Refresh the role of patient representatives in our work to be relevant and ensure the patient voice is represented</p> <p>6.3 Increase and embed patient and public engagement throughout our work and to inform future planning</p>	<p>□ Work with the advisory group to examine and develop a clear action plan for delivering on the remaining recommendations in particular:</p> <ul style="list-style-type: none"> • the role of ourselves and other organisations in raising awareness of the use of healthcare data • to determine what other actions are required to continue to raise awareness of the cancer registry with patients, public and wider stakeholders to inform our activities beyond October 2019 	All	October 2019	All stakeholders