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England

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## **PHE National Cancer Registration and Analysis Service response to the Review of Informed Choice for Cancer Registration – progress update October 2018**

### Background

In March 2017 we published our response plan to the Review of Informed Choice for Cancer Registration (RICCR) ([www.gov.uk/government/publications/review-of-informed-choice-for-cancer-registration-ncras-response](http://www.gov.uk/government/publications/review-of-informed-choice-for-cancer-registration-ncras-response)). This document provides an update on our progress to date to deliver on the RICCR recommendations. Highlighting the changes we have made to core business as a result, and outlines the next set of actions we will be delivering in the forthcoming months.

In implementing the recommendations, we have worked closely with a wide range of stakeholders including NHS England, cancer charities such as Cancer Research UK, Macmillan Cancer Support and Teenage Cancer Trust as well as many patients, their families and the wider public. It has been our aim to try and ensure that as many patients as possible are made aware of cancer registration, and how they can opt out if they choose. We acknowledge there is still more to do.

For further information please contact us on: [NCRASfeedback@phe.gov.uk](mailto:NCRASfeedback@phe.gov.uk)

**Objective 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**

1.1 Work with patients, health professionals and the public to revise and refresh the cancer registry information materials. Work with specific groups to tailor materials according to need

Actions completed:

- In early 2017 we undertook a project to review the existing cancer registration information materials. We established an advisory board with membership including people with experience of cancer as a patient or carer, staff from Macmillan and CRUK with expertise in developing information materials and members of NCRAS. We delivered 4 workshops inviting people with experience of cancer to review the current cancer registration information materials and to help shape the content for new materials. We also involved members of the public from the PHE Peoples' Panel, who have no personal experience of cancer, to review the first draft of the new materials in order to understand how someone seeing the information for the first time might receive it. A new cancer registration leaflet and poster were approved by the advisory board and received the crystal mark from the Plain English Campaign. Distribution began in October 2017 (see action 1.3 and 4.3 for further information on leaflet distribution).
- In May 2018 we received feedback from the Confidentiality Advisory Group (CAG) that amends were required to ensure the leaflet provided sufficient information about the details of cancer registration. In September 2018 we produced version 2 of the new leaflet which encompassed these recommendations as well as patient and public feedback on the updated version.
- We have undertaken an online survey and a workshop with Teenage Cancer Trust to ascertain young people's views and suggestions regarding information materials for the younger age group. We are currently discussing the next phase for this work.

Changes to practice and next steps:

- We will conduct a biennial review of the leaflet with input from patients, carers, health care professionals, charities and other relevant groups. The next review will be undertaken in March 2020.
- We will also continue to encourage feedback and reflect minor changes as required on an ongoing basis. Included in the new leaflet is an email address for people to send their comments ([NCRASfeedback@phe.gov.uk](mailto:NCRASfeedback@phe.gov.uk)).
- We will scope further the requirement for tailored materials including for teenagers and young people and those with sight impairment and develop these as required.

## 1.2 Work with providers, charities and other relevant groups such as hospices to ensure inclusion of cancer registry information in their information materials

### Actions completed:

- During our workshops to review the patient information materials with patients and members of the public it was suggested that the information materials should be included in charity information packs. We have had preliminary discussions with some charities about the inclusion of cancer registry information in their own materials. We will be prioritising this in our next round of actions.

### Next steps:

- 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.

## 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)

### Actions completed:

- The leaflet and poster are distributed to 160 acute hospital Trusts. We have identified the patient information contact at each Trust to whom the leaflets are sent every 3 months. The number of leaflets disseminated is based on the number of cancer diagnoses in the previous year. The NCRAS Data Liaison Manager allocated to each Trust is available to support in the supply and distribution of the information leaflet and poster.
- The identified patient information contact decides on the most appropriate place to host or distribute the leaflets within their Trust. For example, new patient packs, at Macmillan Information Support Centres, located in specific clinics within Trusts and directly given to patients by supporting health care professionals.
- The information leaflet is also being provided to private care providers and disease specific clinics within Trusts where requested.
- Trusts and organisations are encouraged to contact NCRAS via a dedicated email address when they require more materials. There is no limit to the number of leaflets they can request.

### Changes to practice and next steps:

- We monitor the quarterly distribution of leaflets and poster (see action 4.3 for further information on leaflet distribution).
- 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 UK and Radiotherapy Centres.

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

Actions completed:

- We have supported the development of a new patient and NHS facing website ([www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)) that provides information about cancer registration and patient choices. See action 3.1 for further information about the website.
- We have worked with colleagues at Macmillan Cancer Support and Cancer Research UK to ensure their online information about cancer registration is up-to-date and provides clear links to further information.
- We have worked in consultation with NHS England and NHS Digital to ensure that where possible information provided online about the rollout of the National Opt-Out was clear and accurately represented individual's choices in relation to cancer registration data.
- Patients who receive the patient information leaflet or who see the information poster are signposted to the newly developed public facing website ([www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)) where they can find out more and get additional information about how to opt out.
- There is a contact email address provided on the website that allows individuals to contact NCRAS directly with their individual queries.

Changes to practice and next steps:

- It is now a requirement that all Office for Data Release (ODR) approved research studies that will be contacting cancer patients directly, must include a copy of the PHE cancer registration leaflet or a direct web link to the PHE cancer registration leaflet as part of the participant information pack or invitation letter.
- As per action 3.1 our website content is regularly updated to provide the most relevant and up-to-date information available.
- Working with charity partners and members of the All Parliamentary Party Group 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 existing online information.

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

Actions completed:

- We reviewed the cancer registration opt-out process in consultation with patient representatives, Cancer Research UK and Macmillan Cancer Support, the NCRAS Caldicott Guardian and PHE Information Governance representatives. The outcome was to update information available to

patients and their families. This is available on the NDRS website including a FAQ section and will be regularly reviewed and updated to ensure it remains fit for purpose.

- Every individual who wants to opt out is guided and individually supported by the NCRAS Caldicott Guardian.

Changes to practice and next steps:

- An annual review of the opt-out process and information will be conducted in consultation with cancer patients, charities, the NCRAS Caldicott Guardian and PHE IG representatives. The next update will be in March 2019.
- We welcome feedback from all users of our information and can be contacted via [NCRASfeedback@phe.gov.uk](mailto:NCRASfeedback@phe.gov.uk)

**Objective 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

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

Actions completed:

- In June 2018 Dr Jem Rashbass, Director of the National Disease Registration Service, wrote to 1700 MDT leads to remind them of their teams' role in the distribution of cancer registration information and to ensure Trusts are aware of the support that NCRAS can give to help improve that process.
- We have consulted with cancer clinicians, clinical nurse specialist, charities, cancer information support manager, the NCRAS Caldicott Guardian and NCRAS colleagues to review our approaches, to better understand the processes for disseminating information through Trusts and to discuss further ideas for engagement with health professional groups. Through this engagement process we have identified that Caldicott Guardians and Cancer Nurse Specialists are 2 key audiences that are engaged with receiving additional information about cancer registration and supporting improvements in practice at Trust level. For that reason we are concentrating our efforts in developing new materials for these groups.
- As a result of consultation we are developing a guidance document for Caldicott Guardian's to support them to implement a policy to ensure all patients receive information about cancer registration. The guidance document highlights some specific actions they can take and how they can advise healthcare staff on ways to inform patients. It is currently in the final stage of development.

Changes to practice and next steps:

- We will now be focusing our efforts on finalising the guidance document for Caldicott Guardian's and the process by which it will be disseminated. We will be taking steps to engage directly with the Caldicott Guardian of each hospital Trust to advise them about the guidance and how it can be put into practice. The NCRAS Caldicott Guardian will support as key contact with the network.
- 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.
- We will scope the potential of a programme of information sessions for health professionals and patients which we will deliver via face to face visits to Trusts and other relevant venues and events.

### 2.3 Initiate discussions on Trust accountability for providing patients with information about the cancer registry with NHSE Quality Surveillance and Caldicott Guardians

#### Actions completed:

- We held an exploratory meeting with the NHSE Quality Surveillance Team (QST). QST advised that they are unable to assess Trust accountability for providing information about cancer registration as part of their current programme of activity.

#### Next steps:

- 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.

**Objective 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**

3.1 Improve our web presence to meet stakeholder needs and to provide relevant and up-to-date information

Actions completed:

- In consultation with patients, cancer charities, and patient information and health data experts a dedicated public facing website has been developed. Aimed at both patients and clinicians, the website focuses primarily on the utility of the data as well as giving extensive information about how the data is stored securely and used for public good in the most controlled manner possible. The site contains video resources as well as interactive graphics of some of the NCRAS datasets [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)
- Information about how to opt-out and the necessary links and forms are provided on the website.
- The website is signposted from the information leaflet and poster and through links from some partner websites.

Changes to practice and next steps:

- New content and updated information is added to the [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk) site as and when required.
- As per action 1.4 we will be working with others to increase the number of partners with information about cancer registration available on their own sites and with signposting links to our own website.

3.2 Agree with partners and regular users of cancer registry data a standard acknowledgement in all publications and press releases

Actions completed:

- A standard acknowledgement of cancer registry data has been developed and disseminated to regular and new users of cancer registry data ensuring that all outputs using cancer registration data (including journals, academic papers and online publications) include a clear acknowledgement.

Changes to practice:

- It is now part of all data release agreements that the standard acknowledgement be added to any publication based on the data we have provided.



#### **Objective 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**

###### **Actions completed:**

- We have identified a patient information contact for each Trust who is the recipient of the patient information materials. We maintain this database on an ongoing basis and new contacts are added as they are identified.
- In early 2017 the NCRAS Data Liaison team investigated the existence of Trust policies for distributing information about cancer registration. This information was recorded as a baseline. In January and February 2018, as part of the NCRAS Cancer Outcomes and Services Dataset (COSD) Roadshows, 35 Trusts completed a follow-up survey about their policies and practices for distributing cancer registration information materials. 9 Trusts said they had internal guidance available for the distribution of cancer registration information. These results indicated Trusts needed to be encouraged to develop and implement policies.
- Follow up consultation with Trusts who said they had existing policies in place was undertaken and used to help shape the document that will be distributed to Caldicott Guardians.

###### **Changes to practice and next steps:**

- 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](http://www.ndrs.nhs.uk)
- An annual survey will be undertaken as part of the COSD Roadshow to assess how many Trusts have a policy for cancer registration information.

##### **4.2 Whilst visiting Trusts, data liaison staff will conduct spot checks throughout Trusts to determine if cancer registry information materials are being displayed**

###### **Actions completed:**

- When undertaking data engagement activities in Trusts, Data Liaison Managers look for the availability of patient information materials in the areas they visit.
- 71 Trusts currently have the leaflets displayed in information centres and/or patient clinics.

#### Changes to practice and next steps:

- The NCRAS Data Liaison Team will continue to undertake spot checks of the availability of cancer registration information for patients.

#### 4.3 Monitor distribution of cancer registration information materials by quantity, recipient and follow up requests

##### Actions completed:

- A distribution reporting schedule has been developed to capture the distribution of all cancer registration information materials.
- Including January 2017 to August 2018, 387,894 information leaflets and 164 posters have been distributed to 160 acute Trusts and a further 12 care providers. A further 8250 leaflets will be distributed directly to 160 Trusts in October 2018.
- In June 2018 a further 7,500 leaflets were distributed directly to patients by the University of Sheffield's third-party processor, Quality Health alongside their patient contact materials for a recruitment exercise for a cross-sectional Patient Reported Outcome Measures (PROMs) survey of patients diagnosed with bladder cancer since 2008.

##### We will continue to:

- Record the distribution of patient information leaflets and posters via all avenues (quarterly Trust distribution, ad-hoc requests and distribution via ODR patient contact research studies).

#### Changes to practice and next steps:

- 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

##### Actions completed:

- Monthly reports on the distribution of information materials on an ongoing basis.
- Provided a biannual update on progress and projects to the PHE Cancer Board.

##### Changes to practice and next steps:

- We will continue to report to the PHE Cancer Board biannually.
- We will continue to embed these changes into normal operating methods.

- We will continue to produce progress reports every 6 months (the next one for April 2019).

**Objective 5: As part of the wider healthcare system, significantly contribute to raising awareness of the use of healthcare data**

**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**

**5.2 Actively contribute to opportunities to raise awareness of cancer registry data usage and application in national and local campaigns**

**Actions completed:**

- We are a member of the Wellcome Trust Understanding Patient Data steering committee which helps provide strategic direction and oversight of the overall work of the Understanding Patient Data initiative. We worked alongside them in the development of a series of health data animations, including a cancer specific animation which launched 12 March 2018. These animations are providing an alternative medium for patients and the public to see and hear about cancer registration. According to Understanding Patient Data's own campaign metrics, the cancer animation was viewed 244,525 times from 12 March to 12 April 2018.
- We have developed an enhanced version of the film which provides further details and information about cancer registration and is available via [www.ndrs.nhs.uk](http://www.ndrs.nhs.uk). We are working to encourage others to signpost to the animation for further information on cancer registration.
- We have been working with charities representing the rare and less common cancers including brainstrust, Cancer52 and Pancreatic Cancer UK on the 'Get Data Out' (GDO) programme. This programme is supporting the release of routine cancer data into the public domain with a focus on rare and less common cancers. For each cancer type, the programme releases information about incidence, routes to diagnosis, treatments and survival. Data about brain tumours has been released so far and programme is now moving onto pancreatic, testicular and ovarian cancer with data releases planned for the end of 2018.
- We will continue to deliver the annual Cancer Services, Data and Outcomes Conference with the involvement of patients, carers, the public, charities, clinicians and researchers to develop and deliver the programme.
- PHE worked with NHS England and NHS Digital throughout the development and rollout of the National Opt-Out programme. PHE provided information to support the development of the campaign messaging and information materials ensuring the difference in the opt-out process for cancer registration was highlighted.
- We shared a paper on how the national opt-out will be applied to cancer registration data with stakeholders at the PHE Cancer Stakeholder Coordination Group and the PHE Cancer Board.

- The NCRAS Caldicott Guardian spoke at the National Caldicott Guardian Conference in May 2018. At the event, the accessibility of high quality data for direct and indirect patient care, molecular/genetic data and the IG challenges and successes were covered and discussed.

Changes to practice and next steps:

- We will be developing 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 public.
- We will continue to work with partners and the public to look and develop opportunities to raise awareness of the use of healthcare data to the public. See section 6 for information about collaborative working with our stakeholders to advise on these activities.

**Objective 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**

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

6.2 Refresh the role of patient representatives in our work to be relevant and ensure the patient voice is represented

6.3 Increase and embed patient and public engagement throughout our work and to inform future planning

Actions completed:

We have made some headway in increasing patient and public involvement in our activities which include:

- In January 2018 the PHE Cancer Stakeholder Coordination Group was established. This group provides an opportunity to bring together key stakeholders to discuss priorities and planning in relation to the development and use of cancer data. 2 patient representatives sit on the board.
- In July 2017 we appointed a Patient Engagement Manager who has led on establishing a multidisciplinary advisory board to support the scoping of specific patient and public engagement activities. This board is helping to shape a number of activities that are aimed at raising awareness of the use of healthcare data.
- There will be a patient experience focus to the plenary session of the National Disease Register annual training event in partnership with UseMyData which will highlight a patient's journey from diagnosis to present day and their understanding and opinion on cancer registry and data use.
- We are continuing to provide patient and carer bursaries for the NCRAS annual conference. In 2018 over 50 cancer patients and carers attended the conference. The individuals who attend are all part of wider advisory groups, patient groups and research networks and therefore provide a significant opportunity to spread the message about cancer registration to a wider audience.
- In consultation with patient representatives, the PHE Office for Data Release have developed lay summaries for research projects using cancer registration data. An ongoing project is underway to ensure all historic projects from 2017/2018 will include a lay summary. These lay summaries are linked to the Data Release Register and available through the ODR website. Going forward it will be a stipulation of the ODR data release process that a lay summary be included as part of all applications for cancer registration data use.
- A chair has now been recruited for the independent board which will advise the PHE Data Release Advisory Board (DRAB) in matters related to access to and secondary use of data that PHE holds. Terms of reference will be developed and members including lay representatives and other stakeholders are being sought.

### Changes to practice and next steps:

Since the publication of the Review of Informed Choice we are significantly more aware of the need for us as an organisation to consider how we improve our communication and dissemination of information with patients, the public and our many other stakeholders. We acknowledge that there is more to do to address the outstanding actions; to examine and determine the role of patients and the public in our work, and how we can continue to maintain and build on the work we have begun as a result of the RICCR, to instill a culture of transparency and engagement throughout our activities. Our next steps will include:

- Continue to work with the patient, public and stakeholder advisory group to ensure the patient voice is explicit in our work moving forward.
- Examine and develop a clear action plan for delivering on the remaining recommendations in particular:
  - 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