



# RICCR Advisory Group minutes

<b>Title of meeting</b>	PHE National Cancer Registration and Analysis Service Review of Informed Choice for Cancer Registration Advisory Group
<b>Date</b>	Wednesday 27 March 2019
<b>Venue</b>	Wellington House, London

<b>Attendees</b>	
Michael Eden (ME)	Consultant Pathologist at Cambridge University Hospitals, UK Clinical Lead and Associate Caldicott Guardian for the National Cancer Registration and Analysis Service, England
Matt Sample (MS)	CRUK Policy Advisor
Bonnie Green (BG)	Patient Representative
Phillipa Shelton (PS)	Understanding Patient Data, Communications Manager
John Marsh (JM)	Patient representative
Julie Flynn (JF)	Macmillan, Strategic Data and Influencing Lead
Janette Rawlinson (JR)	Patient representative
Bhavisha Hirani (BH)	NCRAS, Engagement and Awareness Project Manager
Sophie Morris (SM)	NCRAS Engagement and awareness Senior Project Manager
Sophie Newbound (SN)	NCRAS, Head of Strategic Engagement and Development
Megan Inett (MI)	NCRAS, Engagement and Awareness Manager
Orfhlaith Kearney (OK)	NCRAS, Engagement and awareness Administration Officer
<b>Apologies</b>	
Natalie Doyle (ND)	Nurse Consultant, Royal Marsden
Georgia Papacleovoulou (GP)	Pancreatic Cancer, Representing Cancer Campaign Groups

## 1. Welcome, apologies and introductions

SN welcomed members and thanked everyone for joining the Advisory Group. SN said that the group does not yet have a Chair. SN would Chair for today but that as part of the later discussion on membership an independent Chair should be considered.

## 2. Purpose of group

SN provided background on the purpose of this group; to be a barometer for NCRAS on its progress to deliver on the recommendations of the Review of Informed Choice for Cancer Registration (RICCR) and to support decision making on its approaches and responses to

challenges. SM summarised the work of the previous advisory group which was project related and that work will now report to this over-arching group.

JM asked about the governance for the group. SN replied that this group will report to the PHE Cancer Board which oversees all PHE's work on cancer and has external stakeholder representation from NHSE, CRUK and Macmillan.

The minutes of these meetings will be made available on the respective gov.uk page once circulated and approved by group members.

### **3. The Review of Informed Choice for Cancer Registration**

JF presented an overview of the Review of Informed Choice for Cancer Registration and the recommendations made as a result of the research and engagement. The group discussed, and the following points were raised by members;

- The need to consider the best time to inform patients about cancer registry
- The need to implement local and national awareness strategies about the cancer registry as well as targeting as many points along the patient pathway to disseminate information
- More widely clarity is still needed to better inform patients on how data is used

### **4. Overview of PHE's response and actions to date**

SN and MI provided an overview of PHE's response to the RICCR recommendations. A [full report](#) can be found on PHE's gov.uk site. The key items discussed were:

- PHE's initial actions were items that could be actioned quickly by changing internal processes and updating information materials. Other highlights include;
- An annual review of the opt-out process and information provided on this. The review involves the PHE Caldicott Guardian, key staff involved in the process and patient and public representatives
- The patient information leaflet will be reviewed annually. This is distributed to over 160 Trusts as well as Radiotherapy Centres, GP surgeries and charities. Trusts have a nominated individual to receive quarterly deliveries and make the leaflet available to patients and families.

- We are working with Teenage Cancer Trust (TCT) to create a cancer registration information leaflet in a format which is friendly to a young audience. MI shared a prototype.
- Distribution of the guidance document to the 177 trusts (information contacts and cancer services manager via PHE data liaison team) – 5 have responded to date. The group discussed how this could be followed up and supported further.
- More work is required to support healthcare professionals to know and share information about cancer registration. MI will share more information with the group later in the agenda.

The group commented on the positive steps that have been made so far to deliver on the recommendations and that the group helped to be able to support further progress from now on.

ME asked the group if everyone was clear on the term opt-out and the difference between the NHS opt-out and the cancer registration opt-out. The group agreed there were different understandings of this. ME explained that if an individual opts out of having their data held and used by NHS Digital for uses outside of their direct patient care through the national data opt-out process, then their data will still automatically be shared with NCRAS. However, NCRAS will honour this opt-out by ensuring none of the individual's *identifiable* data is shared with a third party. In order for a patient's information to be deleted entirely from the cancer registry they need to make a separate opt-out request directly to the cancer registry which may be better termed 'objection' rather than opt-out in order to reflect the legal basis and distinguish it from the NHS opt out. However, if an individual directly opts out of cancer registration this does not mean their data is removed from other healthcare datasets.

There was some discussion about the confusion of having the same term of 'opt-out' for both organisations when it means different things. The group agreed this needs to be tabled as a longer discussion for the next meeting.

**Action:** Agenda item on opt-out processes for cancer registration to be tabled for the next meeting

## 5. Report to National Data Guardian

MI informed the group that PHE reported to the National Data Guardian (NDG) in October 2018 on overall progress so far and the report has been published on gov.uk. The NDG did  
Approved on 26 June 2019

not provide an indicative response to PHE's report and the group recommended that for the next report PHE should ask the NDG office how it views PHE's progress so far. The current report is in draft and the final report will be completed and sent to the NDG by the end of April. MI shared an early draft of the report for comments from the rest of the group.

The following points were suggested by members:

- PHE should consider providing the NDG with details of where there has been challenge to the recommendations.
- To align the progress report to the recommendations to make it easier to understand what has been achieved and where further effort is required
- To ask the NDG office to respond to the report to ascertain how it views PHE's progress against the recommendations

**Action:** If there are any further comments from group members please send to MI by 12<sup>th</sup> April 2019

## **6. NCRAS Case Studies**

SM and OK presented their work to create case studies about the uses and impact of cancer registry data and how it is used to improve treatment, services and outcomes. SM showed the group current prototypes and explained that when complete and approved they would be available on our website and used at events and public engagement activities.

The group felt that the concept was a good one but raised concerns about some of the content and how this may be received by people affected by cancer.

PS suggested that SM and OK could learn from the work undertaken by Understanding Patient Data and the case studies they have produced. The group also agreed that further user testing and more positive messaging was required.

**Action:** All members to look at case studies and provide feedback to OK and SM by the end of April

**Action:** SM and OK to meet with PS to gain further insight to developing case studies.

## **7. Approaches with Health Care Professionals**

MI presented the current plans to approach and involve healthcare professionals to address the RICCR recommendations to support healthcare professionals. MI is meeting with Cancer Nurse Specialist groups over the forthcoming weeks to discuss with them what support

would help them better understand cancer registration and therefore be able to share information with patients as per the RICCR recommendations.

The members discussed the current barriers to the information not reaching patients and suggested a number of routes that MI could explore as part of her initial scoping work. The group agreed that this item needed more time than today's meeting allowed and should be explored further at the next meeting. In the meantime, MI will continue with planned meetings and report back to the group.

**Action:** MI to explore options suggested by group members and compile a report to be circulated prior to the next meeting for further discussion.

**Action:** BG to discuss with her Trust contacts and share feedback with PHE team

**Action:** This item to be tabled for the next meeting

### **8. Terms of Reference, Membership & Chair**

Members discussed whether the group has the appropriate representation from all sectors and audiences. ND had suggested that having a Trust based Lead Cancer Nurse would be a very useful addition to the membership and the group agreed.

JF also suggested that having other clinical input would be beneficial and suggested that we might approach someone from the Royal College of GPs to Chair the meeting. Nigel Mathers was put forward as a possible candidate.

**Action:** SN to approach additional members before the next meeting.

### **9. AOB**

The group agreed that the next meeting should be sooner than 4 months' time as there is a lot they feel can be achieved in this time.

**Action:** BH to send out a doodle poll to find a date for next meeting.