



RICCR Advisory Group minutes

Title of meeting PHE National Cancer Registration and Analysis Service Review of Informed Choice for Cancer Registration Advisory Group
Date Wednesday 13 November 2019
Venue Skipton House, London

Attendees	
Alison Keen (AK)	Lead Cancer Nurse, Southampton University Hospital
Bhavisha Hirani (BH)	Engagement and Awareness Project Manager, NCRAS
Bonnie Green (BG)	Patient Representative
Janette Rawlinson (JR)	Patient Representative
John Marsh (JM)	Patient Representative
Julie Flynn (JF)	Senior Evidence Manager – Data & Influencing, Macmillan
Matt Sample (MS)	Policy Advisor, CRUK
Megan Inett (MI)	Engagement and Awareness Manager, NCRAS
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
Natalie Doyle (ND)	Nurse Consultant for Living with & Beyond Cancer, Royal Marsden (Chair)
Orfhlaith Kearney (OK)	Engagement and Awareness Administrative Officer, NCRAS
Sophie Morris (SM)	Public Information Manager, NCRAS
Sophie Newbound (SN)	Head of Strategic Engagement and Development, NCRAS
Apologies	
Georgia Papacleovoulou (GP)	Cancer Campaign Group Representative/ Pancreatic Cancer UK

1. Welcome, apologies and introductions

2. Minutes of the last meeting

JR suggested that the pilot trusts in the healthcare professional work should include district general hospital as these are often overlooked.

JR suggested publishing in 'pulse' GP commissioning magazine, to reach the GP and CCG community.

The group agreed the minutes of the last meeting as a true reflection of the meeting. These will be published on the gov.uk pages.

3. Matters arising

3.1 LCN forum

MI spoke to the Lead Cancer Nurse Forum at a recent meeting with AK. AK will send information to the data lead, Caldicott guardian and the lead cancer nurse in each trust. BG mentioned she has been working with MI and Kingston Hospital who are very keen to start the modelling project.

JR suggested looking at Lung Cancer Nursing network and British Thoracic Oncology Group to deliver key messages. SN informed the group that due to resourcing and a plan of events that the team will attend, any additional events will be looked at for next year during the planning stages for 2020/21.

Action: BH to share NDR event calendar with this group.

Action: All to put forward suggestions of events to BH so this can be captured on the NDR event calendar.

3.2 Digital discovery update

The ongoing work has included gathering stakeholder feedback to find out about the needs of cancer registration users and what content is relevant for them. Unboxed won the tender for this work and they are currently undertaking interviews with key groups e.g. commissioners, charities, clinicians, academics, patients etc. Unboxed will feedback on the interviews by mid-December and put forward recommendations.

SM is leading on the update of the NDRS website which is due to be completed in Spring 2020.

Action: SN to provide feedback on digital discovery project at next meeting.

4. Feedback from the National Data Guardian

SN informed the group she met with Ross Thornton (senior project manager with the NDG Office and secretariat for the Caldicott Guardian Council) to discuss general feedback from NDG office and to discuss further the group's suggestion of whether Caldicott accountability at trust level for ensuring that cancer registration information to patients could be mandated. As per previous discussions with the Caldicott Guardian Council, they are supportive of what we are trying to achieve, but do not see their role as the best placed within trusts to oversee this accountability. They are supportive of using their networks to help support the wider

community to ensure patients are adequately informed but mandating their role is not strongly supported.

The NDG office has not provided any specific feedback on the previous progress report. SN said that there was an opportunity to raise issues or further suggestions about how we move forward to the NDG panel if the group felt this was relevant. The group agreed that as some recommendations were proving very hard to implement it would be timely to perhaps rethink how we approach some of these challenges. SN suggested that the group submit suggestions for new pieces of work to address the outstanding review recommendations/wider awareness work still required which could then be considered as part of the Engagement & Awareness team work programme for 2020 – 2021.

AK put forward the idea of asking trusts to include some information and a link about cancer registration on the trust web pages. JR mentioned wording should be standardised for all trust websites.

JR suggested that attending cancer alliances meetings to disseminate the key messages about cancer registration by having a session/slot at these meetings.

The group discussed the National Cancer Patient Experience Survey (CPES) and the inclusion of a question about cancer registration. JF mentioned that the RICCR report did flag the addition of a question as a recommendation but this was not taken on by CPES. The group discussed it was important to ensure any question that was added was done in the right way as to not confuse patients. JR suggested perhaps teaming with UseMyData to work on the questions to stop the confusion as it is very important for patients to hear about cancer registration and that their data is collected.

In the summer the CPES team piloted the inclusion of the cancer registration information leaflet with the survey support materials. The pilot showed that this led to confusion with survey respondents and so it was not considered doable at this time. SM and MS attended the CPES meeting last month and a request to add a link to the website on the covering letter for the next survey was put forward to the forum. This is currently being considered.

Action: All to think about what NCRAS could consider in our planning for next year to help with our cancer registration awareness work

5. Opt-out enquiries

ME confirmed that most of the enquiries received about opting-out are about the timing of when the individual was told and who told them. There is no consensus on when individuals feel they should be informed as it differs from patient to patient and by personal preference.

ME outlined possible confusion when private patients are treated in an NHS trust, as this has an impact on whether NCRAS will receive their data.

This year's opt-out numbers have been similar to last year and there has been a drop in numbers of those who want to speak to ME.

ME highlighted that there was a need to ensure we are clear that any emails being sent from and to a non NHS.net email address are not encrypted. This has caused concerns about the confidentiality of the information being sent over email.

The group discussed the encryption issue and suggested placing clear wording where the contact email is advertised to inform individuals that any emails sent to the phe.gov.uk email address will not be encrypted. JR suggested that the public should also be informed that when emailing the PHE email address a response will come from an NHS account so that people are made aware that it is genuine.

Action: Check the wording on the NDRS website to ensure it is clearly stated that emails to phe.gov.uk will not be encrypted and that responses to these emails will come from an NHS account marked [SECURE].

6. Cancer Data stories

Since the last RICCR meeting six cancer data stories have been released. The stories highlight the importance of data collection and how this is then used to improve awareness, care and treatment. The stories released have received a lot of positive feedback which was summarised in the papers that were circulated before the meeting.

OK ran through the positive feedback from different organisations (NGG, UPD, UMD) and explained that the cancer stories were released with accompanying blogs to add some background and more information as to why the stories are being published. The blogs include researcher or patient quotes to emphasise the importance of the patient data. The cancer data stories are being published on awareness days so that they are more relevant and have more impact.

Organisations are now approaching the team to showcase their work and to ask if it can be included in a cancer data story.

Due to pre-election sensitivity (purdah) no cancer data stories will be released this month.

The next set of cancer data stories and accompanying blog will be released in December.

SM mentioned that there is a NDRS newsletter, which will not be released this month due to purdah. The next newsletter will be released in December. The newsletter has received a lot of positive feedback and OK is looking at creating a survey to try to gather feedback on

content and frequency of the newsletter. JR suggested contacting the cancer alliances and signing them up to the mailing list.

Action: All to send feedback to OK and SM and promote these stories within their networks

Action: All to email OK and SM if they want to be included in the mailing list for the NDRS newsletter and forward to networks that may also want to be included.

7. Data Journey Infographics

OK updated the group on the creation of public facing diagrams that will explain the cancer registration process. The first infographic has been completed and provides an overview of the cancer registration data journey. Further infographics are in development and will provide more in-depth explanations about how NCRAS receives and checks the data, why patient data is used and how it is used.

The purpose of the infographics is to be able to explain to a lay audience the process of cancer registration and the different stages within this.

Action: First infographic to be shared with group with draft minutes.

8. Webinar

In order to reach a wider audience with information about cancer registration the team will be developing a webinar resource. Starting by targeting staff at Macmillan information centres the webinar will help to provide more information to key healthcare staff who will in turn be able to support the dissemination of information to patients. The kick-off meeting to gather content ideas from a number of Macmillan centre managers will take place next week.

JF mentioned that she has located a contact within Macmillan who can help to disseminate the resource once it has been created.

MS mentioned that CRUK has a facilitator programme within primary care and that it could be another opportunity to share the resource when it is finalised.

Action: SM and JF to discuss the process of getting final resource that is developed by NCRAS and contributed to by Macmillan onto Macmillan dissemination channels.

Action: SM to provide update on webinar project progress at next meeting

9. Cancer Data Conference 2020

MI informed the group that the Cancer Data Conference 2020 will be held on 1-2nd July 2020 at Nottingham Trent University. The conference theme this year is "Using data to understand variation and tackle inequalities in cancer". A Conference Programme Advisory Group has been set up to provide stakeholder input into the development of the content and conference programme.

The registration and abstract submission was due to go live on 2nd December 2019, however due to purdah this is no longer possible and therefore the registration and abstract submission will open just before Christmas with a date still to be confirmed.

Action: MI to inform group when the registration and abstract submission goes live.

Action: Group to put forward ideas that should be included in the conference programme to send to MI who can take these to the next conference advisory group.

10. AOB

ME explained that the current process for individuals asking for subject access requests is to supply proof of address and photo ID. However, individuals have criticised the process as being deliberately obstructive in getting access to their data. The group agreed that the process is reasonable and not overly obstructive.