



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 26 June 2019
Venue	Wellington House, London

Attendees	
Alison Keen (AK)	Lead Cancer Nurse, Southampton University Hospital
Bonnie Green (BG)	Patient Representative
Georgia Papacleovoulou (GP)	Pancreatic Cancer, Representing Cancer Campaign Group
John Marsh (JM)	Patient representative
Julie Flynn (JF)	Macmillan, Senior Evidence Manager – Data & Influencing
Matt Sample (MS)	CRUK Policy Advisor
Megan Inett (MI)	NCRAS, Engagement and Awareness Manager
Michael Eden (ME)	Consultant Pathologist at Cambridge University Hospitals, UK Clinical Lead and Associate Caldicott Guardian for the National Cancer Registration and Analysis Service, Public Health England
Natalie Doyle (ND)	Nurse Consultant for Living with & Beyond Cancer, Royal Marsden (Chair)
Orfhlaith Kearney (OK)	NCRAS, Engagement and Awareness Admin Assistant
Sophie Morris (SM)	NCRAS, Public Information Manager
Sophie Newbound (SN)	NCRAS, Head of Strategic Engagement and Development
Apologies	
Bhavisha Hirani (BH)	NCRAS, Engagement and Awareness Project Manager
Janette Rawlinson (JR)	Patient Representative
Phillipa Shelton (PS)	Understanding Patient Data, Communications Manager

1 & 2. Welcome, apologies and introductions

SN introduced Natalie Doyle, Nurse Consultant at the Royal Marsden who has been appointed as the independent Chair for the group.

ND welcomed Ali Keen as a new member to the group.

3. Minutes of the last meeting

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.

4. Matters arising

No matters arising were noted.

5. Update on the report to the National Data Guardian

MI informed the group that a progress report was submitted to the National Data Guardian (NDG) at the end of April 2019 and the NDG acknowledged receipt of the report. Further to the last meeting a request was made to the NDG for any feedback in relation to the progress report. NCRAS have not received any feedback to date.

SN informed the group that the NDG office have consulted NCRAS on an update report they are currently planning and so it would be beneficial to publish the latest NCRAS report at the same time. The group agreed and suggested that if NCRAS has not heard back from the NDG office by mid-July then NCRAS should publish the progress report alongside the other reports on gov.uk pages.

The group discussed the accountability for delivering the recommendations within hospital trusts. JM suggested that the Caldicott Guardian within Trusts is critical to ensuring that people diagnosed with cancer are made aware of cancer registration. The group agreed that if possible the accountable role of Caldicott Guardians should be discussed with the NDG.

MI provided an update on the follow-up to the trust guidance documents that were sent out earlier in the year. The team are systematically individually following-up with each Trust and have spoken to 49 so far. 2 completed forms have been returned and a further 12 direct conversations are taking place. This process is also allowing the team to create direct relationships with Trusts and check contact details to ensure the information is reaching the right people.

A multidisciplinary group has been set up to review and make changes to the NDRS website and the first meeting to start the work was held on 25th June 2019. SN is also leading a Digital Discovery programme to better understand the needs of stakeholders and the public when using the range of NCRAS/NDR websites.

Action: SN will share timelines for the Digital Discovery phase when available

Action: SN/MI will contact the NDG to ask if it would be possible to set up a meeting to discuss progress and the accountability at trust level

6. Supporting Healthcare Professionals

MI described the key aspects of the pre-circulated papers which outlined the scoping work that had been undertaken and proposed next steps for improving awareness of cancer registration with healthcare professionals and hospital trusts. Much of the challenge in this area is due to there being no mandate for hospital trusts to ensure information is provided to patients, so all action is reliant on individuals' willingness to engage to take the work on.

The scoping work found that a standard solution will not suit all locations therefore the team will initially work a group of 'pilot trusts' to model practical solutions. The group agreed this would be sensible but highlighted there must be some sites chosen that were outside of London.

JF and MS noted Macmillan's and CRUK's support for disseminating any resources, such as a video resource, through their learning platforms to reach their funded workforce. BG suggested looking at links with GP networks and CCGs. The group raised other possible opportunities including re-developing the current information poster and including an article or interview piece in the Cancer Nursing Practice Journal.

JF mentioned potential opportunities coming up via Health Data Research UK who are accepting bids for digital innovation projects. Macmillan are currently involved in the bid process and could consider including cancer patient data as part of that. JF committed to update PHE with any details that might be relevant.

AK will be attending the National Lead Cancer Nurse Forum on 27th June 2019 and will endeavor to mention this work and the possibility of including it at a later meeting.

MI will start work on the actions outlined in the plan and specifically work with ND and BG to understand initial approaches to modelling best practice at The Royal Marsden and Kingston Hospital.

Action: JF to send MI raw data about healthcare professionals from the original RICCR engagement work

Action: AK to contact MI about possible opportunities for attending the National Lead Cancer Nurse Forum

Action: MI will circulate the young person's information leaflet around once complete

7. Opt-out processes for cancer registration

ME provided the group with an overview of the process if an individual submits a request to opt out of cancer registration.

The process is initiated by the individual submitting an opt out request by filling out form and sending this to NCRAS via post or email.

On receipt of the form NCRAS replies to the individual asking that in order for them to verify their identity they submit two forms of identification, a photo ID and proof of address. As part of this correspondence the individual is also offered a phone call with the NCRAS Caldicott guardian within 24 hours, which is optional.

Once an individual's ID is received, NCRAS can implement the opt-out which means; a. deleting all current information about that individual in cancer registration records b. initiating a 'STOP' which means that any further information that might be sent to NCRAS is deleted before it is collated. This is a one-way encryption of the patient's name and NHS number which stops any records that come into ENCORE – the cancer registration system.

NCRAS keeps the opt-out paperwork for 3 years in case there is any need for follow up.

AK asked if there was anyone else within the team who supports ME with the process. ME stated that there are a number of colleagues who support the process but that as the cancer registration Caldicott Guardian he leads on all the patient contact and conversations with some back up from Jem Rashbass, Director of NDRS when needed. AK suggested that any service with one person accountable sounds like a risk. ME acknowledged the concern but said as the number of opt-out requests is so few that having additional staff would not be good use of public resource. Only half of those offered a conversation will go ahead and ME feels it is better that he can offer consistency in his approach rather than several different people undertaking this role.

ME and SN acknowledged the groups concerns regarding the service and agreed to monitor this in relation to the number of opt-out requests received.

JM queried whether the liaison with people is even needed if the number is so small. ME replied that half of those he speaks to do change their mind when they understand cancer registration better so he feels it is. Also, there is some benefit from opt-out conversations as it provides feedback and allows engagement with patients.

JM asked whether the group could understand the reasons why people opt-out. ME said we can provide a summary of the key reasons ensuring that no patient identifiable data is disclosed.

JF suggested that for the next meeting more definition be given to the topic to focus the conversation on the issues we need to address.

Action: ME to gather information on opt out conversations to give overall themes

Action: SN and ME to define issues to be discussed at the next meeting

8. Case studies

Since the last RICCR meeting the team have re-developed the draft case studies. New versions were shared with members early in the month to gather final feedback. It was agreed the content and format had really improved in the current versions. The group also agreed that 'Case Studies' did not represent the content very well, so this will be changes to 'Cancer Data Stories' going forwards. The first 2 stories will be added to the NDRS website along with a supporting blog. The team also hope to tie this in with Health Information Week (1-5 July). A printed version will also be made available in the coming weeks. GP and MS stated they would happily promote the stories as and when they are released. Further stories will be developed, and the group suggested the team should look at covering more of the patient pathway when scoping the topics.

Action: Any final feedback on Cancer Data Stories to go to SM and OK by COP 28th June

Action: Infographics to be covered at the next meeting

9. Next meeting

The group agreed the next meeting should be before the Christmas period, and ideally in October.

Action: BH to send out doodle poll for meeting dates over next 6-9 months.