



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 14 th October 2020
Venue	Teams meeting

Attendees	
Alison Keen (AK)	Lead Cancer Nurse, Southampton University Hospital
Bonnie Green (BG)	Patient Representative
John Marsh (JM)	Patient Representative
Laura Schubert (LS)	Engagement and Awareness Project Manager, NCRAS
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 Director – Patient Experience, The Royal Marsden (Chair)
Sarah McCandless (SM)	Senior Manager, Cancer Intelligence Team, CRUK
Sophie Newbound (SN)	Head of Strategic Engagement and Development, NCRAS
Apologies	
Alexandra Callaghan (AC)	Policy Manager for Health, Macmillan Cancer Support
Georgia Papacleovoulou (GP)	Cancer Campaign Group Representative/ Pancreatic Cancer UK
Janette Rawlinson (JR)	Patient Representative

Actions

Action	Lead	Date
Action 4.0: Get in touch with ND and AK to discuss digital options for disseminating information to patients	LS/SN	Winter 2020
Action 4.1: Have a follow up conversation about linking in with the One Cancer Voice forum	SN/SM	Winter 2020

1. Welcome and Introductions

ND welcomed the group to the meeting and thanked everyone for their time in continuing difficult circumstances. Sarah McCandless, Senior Manager in the Cancer Intelligence Team

at CRUK attended as the CRUK representative. Laura Schubert has joined the Engagement and Awareness Team as Project Manager for the next 12 months.

2. Minutes of the last meeting

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

3. An overview of the changes to PHE/NDRS to date

SN provide an update on the transition of PHE and NDRS. Work within NDRS has needed to be reprioritised as a result of COVID-19 but with many of the core activities still continuing and this has been communicated to stakeholders via the NDRS newsletter. Ensuring patients are informed about how NCRAS collects their data is still paramount.

PHE including NDRS are currently going through a transition period following the announcement by the Secretary of State about the creation of the National Institute for Health Protection (NIHP). This work is ongoing and further details will be shared when available.

Due to staff changes and the need to work more formally across both areas of the National Disease Registration Service, which includes cancer as well as congenital anomalies and rare diseases, the Engagement and Awareness Team is also reconfiguring. The team will be applying learnings from the awareness work for cancer and that of the advisory group across the whole of NDRS to include the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

The group agreed that in the current situation a pause to the current meetings and a reflection on the overall purpose of the group is required. Members stated they were happy to be consulted on ongoing work on an ad hoc basis. The work to improve awareness will continue as it remains a significant priority for NCRAS and NDRS. The Engagement and Awareness Team will keep group members informed as the transition work progresses and decisions are made.

4. Sharing ideas and adapting approaches – reaching the public and patients in the current environment

The group recognised ways of working have needed to change because of COVID-19 and its impact on services. The group discussed several ideas and reflections to consider:

- Clinical and hospital teams are focussing on cancer recovery and getting patients back into care, therefore messaging around data is less of a priority for Trusts and frontline staff. Consideration should be given to using other networks and contacts for disseminating our messaging
- Depending on the outcome of the transition period, further clarity may be required around how the national opt out and the individual NDRS opt out is applied
- Digital options to receive information about cancer registration should be considered as fewer patients are coming into hospitals and there is an increase in the use of virtual appointments
- Signposting and linking to online sources of information is becoming increasingly important
- Cancer charities and cancer forums (One Cancer Voice) have a part to play in ensuring the messaging about data is disseminated effectively
- Can examples from the current climate can be used to illustrate the importance of health data

The Engagement and Awareness Team is currently liaising with digital transformation groups within some hospital trusts in the East to look at digital options for our information. A more comprehensive video resource is also in development. The group will be consulted as these projects progress.

Action 4.0: LS/SN to get in touch with ND and AK to discuss digital options for disseminating information to patients

Action 4.1: SN and SM to have a follow up conversation about linking in with the One Cancer Voice forum

5. Digital update

The project to rework the NDRS public facing website is still ongoing using feedback received about the current version of the website. The Engagement and Awareness Team are currently getting the site to a point where user testing can be started. User involvement will include looking at the content as well as the layout of the site and site navigation. The group will be informed and invited to be involved with the user testing when it starts.

6. AOB

ME informed the group that opt out enquiries have increased slightly over the last few months, although overall numbers remain small. He informed the group that most people were happy for their data to remain as part of NCRAS following a conversation with him.

7. Next meeting

The group will be paused until further notice as per agreement earlier in meeting.