



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 18 th March 2020
Venue	Skype meeting

Attendees	
Alexandra Callaghan (AC)	Policy Manager for Health, Macmillan Cancer Support
Bhavisha Hirani (BH)	Engagement and Awareness Project Manager, NCRAS
Bonnie Green (BG)	Patient Representative
Janette Rawlinson (JR)	Patient Representative
John Marsh (JM)	Patient Representative
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	
Alison Keen (AK)	Lead Cancer Nurse, Southampton University Hospital
Georgia Papacleovoulou (GP)	Cancer Campaign Group Representative/ Pancreatic Cancer UK

Actions

Action	Lead	Date
3.3: SN to provide update on digital discovery project at next meeting.	SN	July 2020
3.4: All to send any events or awareness days missing from the activities calendar to BH	All	April 2020
5.1: SN to share the draft RICCR priorities 2020/2021 with group get comments and thoughts.	SN	April 2020
6.1: SM to develop and share draft design and site map for NDRS	SM	April 2020

website with group for comments.		
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1. Welcome and Introductions

The group welcomed Alexandra Callaghan as the new representative from Macmillan Cancer Support.

2. 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.

3. Matters arising

3.1 Webinar project

SM updated the group on the webinar project which was intended to inform healthcare professionals and those who are in contact with people affected by cancer about cancer registration. After consulting with Macmillan Centre managers, it was found that a webinar is not required as the resources we already have i.e. the cancer registration leaflet, NDRS website and cancer registration video are sufficient to educate people affected by cancer.

Based on the feedback received, we will focus on disseminating the resources we have and to look at new ways of making these available to patients and staff, including providing information to local support centres who host health and wellbeing events for people affected by cancer.

3.2. Royal Marsden project

MI and ND have been working with the audit team at the Royal Marsden to set up an audit to understand baseline activity in relation to the dissemination of cancer registration information at the two main Royal Marsden sites. Following the audit, actions will be taken to improve dissemination, and a follow up will be planned to assess any changes. The audit committee at the Royal Marsden have been positive about the work and happy to support, however following the Covid19 outbreak priorities have changed. MI and ND will continue to liaise with the Royal Marsden to understand what is doable in the coming months.

BG confirmed that Kingston Hospital still has this project on the agenda, but due to work priorities and other pilot projects that are underway there is no capacity at the moment. Once the situation improves within the trust BG will let MI know.

3.3. Digital Discovery

The digital discovery was undertaken by an external supplier to gather stakeholder feedback about the needs of NCRAS users and stakeholders, and to understand their content requirements. Representatives from key groups were consulted during the process including commissioners, charities, clinicians, academics, patients, members of the public etc.

The discovery project concluded in December and the final report included a number of recommendations, central to which was having a single point of access for information related to NCRAS, and to consolidate our online presence by looking at the tools and products we currently have.

SN is currently putting through a business case for the alpha phase of this work which is a 2-3month project to user test alternatives. The aim is to remove all legacy websites and ensure going forward the NDRS online presence is consolidated and consistent.

Action 3.3: SN to provide an update on digital discovery project at next meeting.

3.4. Activities Calendar

The Activities Calendar was shared with the group. This was created to ensure we are aware of the awareness days, cancer events and NCRAS events throughout the year and so that where relevant we can link our public information resources and tools with specific dates across the year, hopefully improving reach and impact.

Action 3.4: All to send any events or awareness days missing from the activities calendar to BH

3.5. Publication Library

The Publication Library allows us to log all publications and other outputs produced by NCRAS or that NCRAS have been involved with since 2018. The Publication Library will include all items from the last 12 months and will be made available on the NDRS website and shared with stakeholder groups. The first version was published in February 2020 and includes publications from Jan 19 - Dec 19. It will be updated on a quarterly basis.

4. Feedback following progress report to the National Data Guardian (NDG)

MI and SN attended the NDG steering group in February to update them on progress and the key challenges that we have encountered. The presentation slides that were sent to the NDG for this presentation were shared with the group.

The key discussion points were:

The challenges around Trust accountability and reporting on how they are sharing information about cancer registration with patients and staff. The steering group expressed a desire to see more Trusts provide information about how they are ensuring patients receive the information about their data being collected

To continue discussions with the CPES (Cancer Patient Experience Survey) to understand how many people are aware of cancer registration

To explore ways of working with the Royal Colleges to provide healthcare professionals with more information about cancer registration

How we work with other organisations to raise awareness of healthcare data use as a whole

The NDG agreed that PHE should report their progress annually to the steering group.

5. RICCR priorities 2020/2021

SN is currently putting together next year's priorities following the conversations with NDG.

Action 5.1: SN to share the draft RICCR priorities 2020/2021 with group get comments and thoughts.

6. NDRS website

SM provided an update on the NDRS website. Following the discovery work the public facing NDRS website will continue to exist, however work is required to make this more user friendly and ensure it meets the main information needs of the public. SM is working to determine where best to host this website and is currently looking into the overall content and design.

Action 6.1 SM to develop and share draft design and site map with group for comments.

7. Next meeting

Wednesday 8th July 2020 from 10.30am to 12.30pm