



Terms of Reference: PHE National Cancer Registration and Analysis Service Review of Informed Choice Advisory Group

Summary

The role of the National Cancer Registration and Analysis Service (NCRAS) Review of Informed Choice Advisory Group is to offer advice and to bring challenge to the NCRAS in delivering on the recommendations of the [Review of Informed Choice for Cancer Registration](#).

The Advisory Group will also provide key links to other groups and communities who are implicit to the delivery of the review recommendations. In addition to the primary role, members are asked to act as a conduit for the dissemination of information and influence where relevant and appropriate.

Background

The National Cancer Registration and Analysis Service (NCRAS) is part of Public Health England (PHE). It is responsible for cancer registration in England which supports cancer epidemiology, public health, service monitoring and research. When a person is diagnosed with cancer in the UK, or is suspected of having cancer, information about them is automatically shared with the NCRAS.

The NCRAS has been granted specific legal permission to collect information about cancer patients without the need to seek consent. This permission was granted to PHE through Section 251 of the NHS Act 2006. Every year, this is reviewed by the Confidentiality Advisory Group of the Health Research Authority (HRA).

Further to the National Data Guardian's review of the use and management of health and social care data in July 2016, it was highlighted that the way that people are currently informed about cancer registration needs to be improved. The review recommended that patients should be given enough information to make an informed choice about whether they want their data included in cancer registration and how to opt-out.

The [Review of Informed Choice on Cancer Registration](#) was conducted by Cancer Research UK and Macmillan Cancer Support. It gained the views of 1,400 people affected by cancer, 1,000 members of the public, 340 health professionals and 20 cancer charities and made a number of recommendations to achieve greater awareness of the cancer registry across these groups.

The Review was published in September 2016 and since publishing an initial response in March 2017, PHE has been working to raise the profile of cancer registration with cancer patients, carers, health professionals and the general public. Over the last 18 months PHE has engaged with patients, the public, health professionals, cancer charities and campaign groups to help inform new practices and new resources to address the recommendations set out in the review.

In October 2018 PHE reported to the National Data Guardian on the progress so far alongside our [objectives for the next 12 months](#). One of these objectives was to establish an advisory group of relevant representatives to ensure that our work continues to involve the voice of those with a vested interest in ensuring we raise awareness of our work as well as representatives of our key audience.

Purpose of the Advisory Group

- To provide advice and to bring challenge to the NCRAS in delivering on the recommendations of the [Review of Informed Choice for Cancer Registration](#) (RICCR)
- To provide a method of engaging with the relevant audiences and communities impacted by cancer registration.

Membership

Membership should represent the broad spectrum of those involved with or impacted by cancer registration including;

- People living with cancer
- Carers of those living with cancer
- Cancer charity representatives
- Health professional groups
- Patient and public campaign groups
- The wider healthcare data community

The group may wish to invite subject matter experts or representatives of other groups and professions as required.

Roles and responsibilities of members

- To attend 3 meetings per year either in person or by dial-in
- To offer advice and suggestion to the NCRAS to support them in delivering on the recommendations of the RICCR
- To offer challenge to the NCRAS Engagement and Awareness team to ensure activities remain focused and purposeful
- To support activities to engage the wider healthcare data community and charity organisations to help raise awareness of the use of personal healthcare data (Recommendation 5 of the RICCR)
- Where appropriate advocate on behalf of NCRAS to raise awareness of cancer registration and its role in beating cancer
- Be able to work on small ad hoc projects with NCRAS staff including contributing to the drafting of written materials, reviewing documents and event planning
- To encourage and support the exploration of new activities in response to the Review of Informed Choice for Cancer Registration

Accountability

The Board is accountable to the PHE Cancer Board. Minutes and actions of the Advisory Board meetings will be made available to PHE Cancer Board members and publicly via gov.uk

Remuneration

PHE's Patient and Public Involvement Policy sets out the terms for remuneration for patient and public representatives. If you have any questions in relation to the policy or about how to claim please speak to a member of the team.

Support

The Advisory Group will be supported by members of the Engagement and Awareness team. This will include:

- Arranging travel and accommodation as needed by patient and public members in accordance with the PHE Patient and Public Involvement Policy
- Secretariat support for meeting papers, minutes and actions and for the supply of any additional materials members may request
- Support between meetings if additional activities or information is required

Matters for consideration by members

- Conflict of interest:* As a representative you will be required to disclose any involvement you may have with other organisations, government bodies or corporate/ commercial interests

which could result in a conflict of interest with Public Health England and the National Cancer Registration and Analysis Service

- *Confidentiality:* As a representative of the NCRAS RICCR Advisory Group you are asked not to share confidential information you may have received as a result of your position. If you have any queries in relation to the disclosure of information please speak to a member of the Engagement and Awareness Team.

Review

The terms of reference will be reviewed annually (March 2020).