

**NCIN Scientific Advisory Group**

**Wednesday, 11 April, 2012**

**1000 - 1230**

**Boardroom, 18th Floor, Portland House, London**

Attending:

HM	Henrik Møller (Chair)	Professor of Cancer Epidemiology, King's College London.
PA	Paul Aylin	Clinical Reader in Epidemiology and Public Health, Imperial College
MCh	Michael Chapman	Research Programme Manager, NCIN
MC	Michel Coleman	Professor of Epidemiology & Vital Statistics, CR-UK Cancer Survival Group, LSHTM
JC	Jane Cope	Director, National Cancer Research Institute
AG	Anna Gavin	National Lead for Analysis & Information, NCIN
HL	Helen Losty	Service User
SM	Siobhan McClelland	Head of Evidence, Macmillan Cancer Support
SMc	Sean McPhail	Senior Analyst, National Cancer Intelligence Network
MP	Mick Peake	Lead Clinician, NCIN
DR	Di Riley	Associate Director, Clinical Outcomes Programme, NCIN
PS	Peter Sasieni	Deputy Director, CR-UK Centre for Epidemiology, Barts and the London
RS	Richard Stephens	Chair Designate, NCRI Consumer Liaison Group
CT	Catherine Thomson	Head of Statistical Information, Cancer Research UK
JW	John Wilkinson	Director, Northern & Yorkshire Cancer Registry & Information Service

Apologies:

David Brewster	Director, Scottish Cancer Registry
Chris Carrigan	Head of the NCIN Coordinating Team
Catherine Boyle	Head of Intelligence and Research, Macmillan Cancer Support

**1. Welcome & apologies for absence**

The Chair welcomed attendees and apologies were noted as above.

**2. Minutes from the last meeting – for approval**

The minutes from the 26 October 2011 meeting were approved with minor corrections.

### 3. **Matters arising from the minutes**

#### **Responses to consultation on research infrastructure for cancer data**

MCh updated the group on responses to the NCIN's consultation on the services required by research users of data, which had been discussed in draft form at the last meeting. A helpful range of responses were received, including from members of the Scientific Advisory Group, and the summary of responses was circulated to the group.

Of particular interest to the group was the response from the Association of the British Pharmaceutical Industry (ABPI), detailing the difficulties that their members face in accessing information. This led to a discussion of access by commercial organisations around the need to look carefully at the purpose for which requests are made, how results are interpreted, and how to ensure that such use is transparent and open to scrutiny. The group touched on the possibility of charging for access by commercial organisations but focused on how to ensure that uses are for the purposes of medical research and patient benefit. Ensuring that a valid protocol / statistical analysis plan is submitted before data are released was seen as the most effective approach.

#### **Information governance requirements for research groups**

MC described a document received from the Department of Health and Information Commissioners' Office proposing changes to the way in which the information governance standards of research groups that receive patient identifiable data are assessed. Rather than assess this on a project by project basis, the groups will be required to comply with the NHS Information Governance Toolkit. This has the potential to both ease the burden on research groups, who would not need to demonstrate their security measures for every project, while ensuring that the required security standards are met on an ongoing basis.

**DECISION:** Share document outlining this proposal with NCIN Co-ordinating Team.

**ACTION:** Michel Coleman

#### **Cancer survival within households**

PS explained that, following helpful discussions at the last meeting, his group will be pursuing this work. The next step is to make a formal request for the necessary information from NCIN.

#### **Handling of outliers**

MP gave an update on this work which, following some delay, is near completion.

**DECISION:** Circulate document on handling of outliers to the Group when complete.

**ACTION:** Michael Chapman / Mick Peake

### 4. **Role and functioning of the Scientific Advisory Group**

MCh introduced the discussion of the Scientific Advisory Groups' role and functioning, explaining that it seemed sensible to review the group after two years of existence and making clear that NCIN values the advice received and, if possible, would like to make more use of the members'

expertise. The aim of the discussion was therefore to determine whether the group's terms of reference are appropriate and whether the current membership and ways of working effectively achieve this.

There was consensus among the members that they are happy to contribute to the group, provided NCIN finds their input useful (MCh reassured members that their input is valuable). The terms of reference were also agreed to be appropriate, although some minor modifications could be made. More consideration should, however, be given to which of NCIN's projects are reviewed by the group and how this could be achieved, both internally by NCIN, and practically given that some projects may be conceived and completed between meetings of the Scientific Advisory Group. It was agreed that the group should give advice where needed, rather than review being a necessary step for every project. The group might also usefully retrospectively review the work that NCIN has done at infrequent intervals to provide an assessment of the network's impact.

Methodological work was identified as an area where there is scope for the group to be more involved, for example examining the use of funnel plots to show survival by provider, which will become more relevant with the closure of PCTs. The group might also advise where the NCIN is involved with bids for funding or play a role in reviewing applications for data.

In terms of membership, it was suggested that there might be a more formal appointment process to the group and consideration should be given to the balance of *ex officio* vs personal appointments. The relationship of the group to other NCIN bodies was discussed and it was agreed that appointments are ultimately the responsibility of the NCIN's Funders Group. The Chair and NCIN Co-ordinating Team will consider the arrangements for membership and report to the funders. MCh was also asked to provide an organisational chart showing the relationship of the Scientific Advisory Group to the other components of NCIN.

**DECISION:** Consider whether any small adjustments to the terms of reference are required and bring back to the next meeting.

**ACTION:** Michael Chapman / Henrik Møller

**DECISION:** Consider arrangements for membership of the group and report to NCIN's funders.

**ACTION:** Michael Chapman / Henrik Møller

**DECISION:** Circulate NCIN organisational chart.

**ACTION:** Michael Chapman

## 5. **Monitoring emergency presentations**

SMc presented a discussion paper on work, requested by the Department of Health, to track emergency presentations for cancer in as near to real-time as possible and, if possible, to present results for sub-national geographies.

The first issue discussed by the group was the identification of new potential cancer cases and what time period should be searched for an existing diagnosis. One option would be to go back to the start of the data – this would have diminishing returns but, if the length of the comparison became a problem, an appropriate cut-off could be selected on the basis of full information. The

group also asked whether subsequent, as well as initial, emergency admissions might be worth examining.

If there are concerns over the methodology for identifying new diagnoses this could be checked against historic data, where the cancer register would provide an answer. Additionally, it was suggested that identifying the route of admission using inpatient data only may be misleading as some patients, for example with lung cancer, may be seen as outpatients and then present as an emergency at a late stage of disease.

Members wondered whether the indicator needed to be in 'real time' or if it would be stable enough that older data would suffice and the difficulties of identifying tumours from HES could be avoided. The initial results shown did appear stable but some members felt that currency is required to help the service inform and assess actions. It was suggested that the impact of hospital coding should be examined as in many places trusts map closely to PCT and apparent variation between PCTs may be the results of differences in coding at the corresponding trusts. It will also be important to consider how the closure of PCTs would affect the indicator.

#### **6. Mental health influences on cancer**

AG introduced a paper on the interactions between mental health and cancer, the data sources available and on what work might be feasible. JW explained that NEPHO is the lead Public Health Observatory for mental health and that a member of staff there developed the Mental Health Minimum Dataset (MH-MDS). NEPHO also receive data on learning disabilities and are working with NYCRIS to link this to the National Cancer Data Repository as part of work in death certification. NYCRIS / NEPHO would be happy to be involved in work on mental health and cancer.

The group discussed that this will certainly require linkage of very sensitive datasets (the MH-MDS) as well as primary care data as this is where many mental health problems will be diagnosed and treated. Information governance issues will be important and will need to be carefully thought through and strong justification for the work presented. Despite this, it is possible to find ways to link very sensitive datasets, for example working through trusted third parties, and there has been progress towards this in Australia. Regionally, work between Thames Cancer Registry and the South London and Maudsley Trust on the prognosis of cancer patients with mental health problems is underway.

Identifying whether there is a problem (is there general inequality or is there regional variation?) will be an important first step. Older people with dementia were suggested as a highly relevant subgroup (although diagnosis rates are low). The prognosis or number of emergency admissions for residents of nursing homes might also be worth investigating and SWPHO may have done work on this as part of the National End of Life Care Intelligence Network.

The group agreed that this is an area worth investigating. Although resources within the NCIN are limited it may be worth bidding for funds with an academic partner.

#### **7. NCIN general update**

The group received a written update on NCIN's activities, covering work in support of research and the Clinical Practice Research Datalink, the Co-ordinating Team's analytical work programme, the single cancer registration system and health economics. Members asked that details of the analytical work programme be moved up the agenda for the next meeting to allow more time for discussion. In particular, members were interested in hearing more about work on Service Profiles and in discussing the issues raised by the Government's push for transparency and the publication of raw data at the lowest level consistent with protecting confidentiality.

**DECISION:** Ensure service profiles feature on the agenda for a future meeting.

**ACTION:** Michael Chapman / Di Riley

**DECISION:** Give greater priority to the NCIN analytical work programme at the next meeting.

**ACTION:** Michael Chapman

**DECISION:** Ensure that transparency features on the agenda for a future meeting.

**ACTION:** Michael Chapman

## 8. Any other business

### **Information Standard Accreditation**

MC updated the group on an approach by G4S, who are offering accreditation services to the Information Standard (a quality assurance standard for health and social care information). This standard is owned by the Department of Health and managed by Capita. Three organisations, G4S, emqc Ltd and the Royal Society for Public Health, are authorised to certify organisations against the standard. This accreditation is held by some groups within Cancer Research UK and Macmillan. Members did not feel it necessary for NCIN to pursue this accreditation as most information is not aimed at the public.

## 9. Date of next meeting

The date of the next meeting is:

- Tuesday, 02 October 2012, 1000-1300, NCIN Boardroom.