NCIN Scientific Advisory Group

04 October 2010

1000 to 1300

Boardroom, Portland House, London

Attending:

HM	Henrik Møller (Chair)	National Lead for Analysis and Information, NCIN
PA	Paul Aylin	Clinical Reader in Epidemiology and Public Health, Imperial College
CB	Catherine Boyle	Head of Intelligence and Research, Macmillan Cancer Support
DB	David Brewster	Director, Scottish Cancer Registry
CC	Chris Carrigan	Head of the NCIN Coordinating Team
MCh	Michael Chapman	Research Programme Manager, NCRI & NCIN
HL	Helen Losty	Service User
SM	Sean McPhail	Head of Cancer Analysis, Cancer Intelligence Service, South West PHO
MP	Mick Peake	Lead Clinician, NCIN
PS	Peter Sasieni	Deputy Director, CR-UK Centre for Epidemiology, Barts and the London
RS	Richard Stephens	Service User, NCRI Lymphoma CSG
RY	Ruth Yates	Head of Health Intelligence, NHS Stoke on Trent
AS	Alison Stone (Minutes)	PA to Chris Carrigan, NCIN

In attendance for Item 7:

KE	Kim Edwards	University of Leeds
JW	James Wells	Monitor Group
AW	Ashley Woolmore	Monitor Group

In attendance for Item 8:

AI	Alex Ives	

Apologies:

Michel Coleman	CR-UK Cancer Survival Group, London School of Hygiene & Tropical Medicine
Jane Cope	Administrative Director, NCRI Secretariat
Angela Coulter	Director of Global Initiatives, Foundation for Informed Medical Decision Making
David Forman	Head, Cancer Information Section, International Agency for Research on Cancer
Di Riley	Associate Director, Clinical Outcomes Programme, NCIN
Catherine Thomson	Head of Statistical Information, CR- UK
John Wilkinson	Director, Northern & Yorkshire Cancer Registry & Information Service

1. Introductions and apologies for absence

The Chair welcomed attendees. Introductions were made and apologies noted as above.

2. Minutes from the 8 February 2010 meeting – for approval

The minutes were approved subject to the following correction, noted by DB.

Item 7, Variation in post-operative mortality: correction of the sentence "DB suggested that grade of differentiation and morphology might also be explanatory and could be usefully included". The unconfirmed minutes had incorrectly recorded "differential" rather than "differentiation".

DECISION: Amend the unconfirmed minutes and circulate the final version.
ACTION: Alison Stone

3. Matters arising from the minutes

- **Chair of the Scientific Advisory Group**

Henrik Møller has been confirmed at the new Chair of the Group, following the departure of David Forman to the International Agency for Research on Cancer. David Forman will remain as a member of the Group.

4. Refresh of the Cancer Reform Strategy

CC updated the Group. The publication date for the Cancer Reform Strategy (CRS) Review has yet to be given, but it is likely to be by Britain Against Cancer, which takes place on 14 December 2010. The deadline for contributions to the (CRS) review was 24 September 2010. The NCIN's contribution is two-fold:

- Innovative & significant work on PCT Profiles & GP profiles
- Traditional work on incidence, mortality and survival.

The next CRS Advisory Board meeting will take place on 8 October 2010 and the NCIN's work will be taken to this meeting.

The PCT Profiles & GP Practice Profiles have used new data, going down to low level numbers. Interpretation of the data is key. In the first instance the data will be held behind the Cancer Commissioning Toolkit (CCT). Other levels of access will be decided by the CRS Advisory Board.

DECISION: Add GP Practice Profiles to the next agenda, for an in-depth discussion, with Sean McPhail and Peter Sasieni to lead this item.
ACTION: Sean McPhail / Peter Sasieni

5. Analysis work within NCIN

- **Update on publications**
- **Future analyses (both central & site specific)**

CC updated the Group on key areas.

Major resection work

This has now been taken to the Site Specific Clinical Reference Groups (SSCRGs) and MP is working with each group. The NCIN is hoping to publish the work to coincide with the NCRI Cancer Conference, which takes place at the start of November 2010. MP gave a brief update on the data and preliminary results. The results show a huge fall in use of major resection with age; large differences by Cancer Network and site; and consistency across Networks in terms of results. The results are not explained by age or by deprivation.

DECISION: Once the Major Resection report is ready, circulate it to the Scientific Advisory Group.
ACTION: Mick Peake / Alison Stone

The difficulties of the Group not receiving early notification of work, in order to be able to input into analyses and methodology was discussed. Using email as a way to review work might be the best way forward.

DECISION: Consider if the Scientific Advisory Group should review work via email.
ACTION: Henrik Møller / Mick Peake

Data briefings

There are a range of data briefings coming out via the Site Specific Clinical Reference Groups. The publications will be highlighted on the NCIN's website.

Peer Review and outcomes data

This is in the early stage of a major piece of work, which requires the involvement of the Scientific Advisory Group, to determine what data can be cut and how they should be interpreted.

Rurality work

National level data has been used for this, with a postcode level index from the Commission for Rural Communities (CRC). The initial work has been published, but now that the CRC has been abolished there is uncertainty over the future direction of the work.

Colorectal cancer report by Eva Morris, NYCRIS

This report on outliers in surgical practice is due for publication.

6. Handling of outlier institutions and clinicians

MP updated the Group. The Department of Health document 'Detection and Management of Outliers' is in near final form, but there is a small window of opportunity for the Scientific Advisory Group to comment. Any comments that the Group wish to make should be sent to MCh within 24 hours. At present the document specifically informs national clinical audits.

DECISION: Circulate Detection and Management of Outliers document to those members of the Scientific Advisory Group not present at 4 October meeting.

ACTION: Alison Stone

DECISION: Send any comments on the Detection and Management of Outliers document to Michael Chapman, by 0900 on 6 October.

ACTION: All Scientific Advisory Group members

7. Macmillan Natural History/Risk Stratification work

Kim Edwards of the University of Leeds and James Wells and Ashley Woolmore of Monitor Group joined the meeting to discuss their work on the natural history of cancer. The work is funded by Macmillan Cancer Support and aims to inform the care offered to cancer survivors by stratifying the risks that they face post treatment. This will be approached using latent variable analysis to identify factors that contribute to the future risk of particular events.

Initially the project will use the national cancer data repository for three sites: colorectal, Hodgkins, multiple myeloma. The investigators hope to extend the datasets used to include primary care data from GPRD and other secondary-care and community-care information.

The Group briefly discussed the project, suggesting in particular that outpatient HES data should be included in the analysis and that an appropriate control group would be required to assess baseline levels of health service use. One possibility is to look at newly diagnosed cancer patients and use information on their levels of service use several years prior to their diagnosis of cancer. Data presentation is also likely to be a challenge given the potentially large number of patient pathways.

8. Routes to diagnosis

Alex Ives, the analytical lead for this project, gave an overview of the work. The remit of the project is to better understand the different routes to diagnosis and to determine whether the routes are associated with survival differences in cancer patients. The patient journey (by patient, not by tumour) was followed backwards from 2007, using inpatient and outpatient HES.

A key finding was that 23% of new diagnosed cancer patients came through the emergency route. This was discussed by the Group, with the following comments:

- DB queried whether it would be possible to target the 23% who come via the emergency route
- PA thought it would be interesting to look at variability across the country, especially by PCT and GP if possible
- RS commented that from the patient perspective it is important to have the Natural History project and the Routes to Diagnosis work running together.

The next stage is to present routes to diagnosis by PCT.

DECISION: Circulate the Routes to Diagnosis technical report to the Scientific Advisory Group.
ACTION: Chris Carrigan / Alison Stone

9. Any Other Business

Clinical Trials

PS flagged up the issue of cost regarding studies where HES data have been applied for. He would like to see people in clinical trials to be flagged in HES, by either:

- Randomisation in a clinical trial recorded in HES, or
- Database of all in cancer clinical trials to allow joint requests for the use of all, rather than on individual requests.

DECISION: Work with partners (CTU, NCRI, NCRN, RCP) to define the linkage process, with regard to access to HES data for clinical trials.
ACTION: Chris Carrigan / Michael Chapman

Nature of future meetings

The Chair suggested that future meetings should be refocused to provide more time for discussion and advice from the group and less time spend in verbal updates of ongoing work.

DECISION: Ensure that the next meeting provides more opportunity for discussion and advice, for example by replacing verbal updates with written papers circulated in advance.
ACTION: Henrik Møller / Michael Chapman

10. Date of next meeting

The next meeting is likely to be in March or April of 2011.

DECISION: Circulate a poll to Scientific Advisory Group Members to obtain meeting dates for 2011.
ACTION: Alison Stone