NCIN Scientific Advisory Group

08 February 2010

1400 to 1700

Room 701, Princes House, London

Attending:

DF	David Forman (Chair)	National Lead for Analysis and Information, NCIN
PA	Paul Aylin	Clinical Reader in Epidemiology and Public Health, Imperial College
DB	David Brewster	Director, Scottish Cancer Registry
CC	Chris Carrigan	Head of the NCIN Coordinating Team
MCh	Michael Chapman	Research Programme Manager, NCRI & NCIN
MC	Michel Coleman	CR-UK Cancer Survival Group, London School of Hygiene & Tropical Medicine
JC	Jane Cope	Administrative Director, NCRI Secretariat
AC	Angela Coulter	Director of Global Initiatives, Foundation for Informed Medical Decision Making
JE	Jim Elliott	Research Adviser, Macmillan Cancer Support
SM	Sean McPhail	Head of Cancer Analysis, Cancer Intelligence Service, South West PHO
EM	Eva Morris	Cancer Research UK Bobby Moore Career Development Fellow, University of Leeds
HM	Henrik Møller	Director, Thames Cancer Registry
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
CT	Catherine Thomson	Head of Statistical Information, CR- UK
AS	Alison Stone (Minutes)	PA to Chris Carrigan, NCIN

In attendance for Item 6:

JB	John Butler	Clinical Advisor, Department of Health
MVE	Max Van Eijk	McKinsey & Company, International Benchmarking Study

In attendance for Item 8:

EY	Elaine Young	National Development Lead, Healthcare Quality Improvement Partnership

Apologies:

Robin Burgess	Chief Executive Officer, HQIP
Di Riley	Associate Director, Clinical Outcomes Programme, NCIN
Ruth Yates	Head of Health Intelligence, NHS Stoke on Trent

1. Introductions and apologies for absence

The Chair welcomed attendees and thanked them for supporting the National Cancer Intelligence Network (NCIN). Introductions were made and apologies noted as above.

2. Membership, Terms of Reference and Chair

The Terms of Reference and membership were reviewed. The Terms of Reference have been approved by the NCIN Steering Group. DF asked for any comments on the Terms of Reference and suggestions for additional members to be sent to him.

HM commented that the Terms of Reference are biased towards methodological items rather than substantive. MP felt that future membership should include a health economist.

Other NCIN advisory groups were discussed. The twelve Site Specific Clinical Reference Groups (SSCRGs) steer the work of the NCIN. It may be necessary to set up additional groups (for example a radiological clinical reference group) in future. In response to PS's query on governance of IT/data protection, DF clarified that the NCIN Steering Group provides this function.

MC highlighted that the Terms of Reference implies that the Scientific Advisory Group will oversee all NCIN outputs and this was discussed. It will be important to include members in early releases of NCIN outputs and ensure appropriate circulation of late stage drafts.

DECISION: The Terms of Reference were accepted by the Scientific Advisory Group.

DECISION: Ensure appropriate circulation of late stage drafts of NCIN outputs to the Scientific Advisory Group.
ACTION: DF

DECISION: Include the Scientific Advisory Group in early release of NCIN outputs.
ACTION: NCIN Co-ordinating team

The current Chair will be leaving NCIN on 26 March 2010 and a new Chair will be appointed as soon as possible after this date.

3. Overview of NCIN mission and function

CC gave an overview of the NCIN's mission and function including governance, relationship to the National Cancer Research Institute, the NCIN's key objectives of improved data collection, coordinated national data management and stronger and innovative national analysis.

4. Analysis work with NCIN

- **In-house reports**
- **Site Specific Clinical Reference Groups and lead area reports**
- **Commissioned projects**
- **Research**

DF gave a presentation on the NCIN's Information and Research programme, beginning with Mike Richards's aim to "have the best cancer information service in the world by 2012". To create this the following are needed: quantum improvements in data collection, providers of cancer care to be mandated by contract to provide defined datasets electronically, exploit the potential of NHS and research data linkages, the transformation of cancer information.

DF reviewed and summarised the publication policy, which is to provide analyses of topics not previously available (e.g. ethnicity, prevalence, trial demographics), avoid duplication of existing outputs (e.g. Cancer Research UK Statistics), be user friendly and readily accessible, have professional and public dissemination, be on a collaborative basis, encourage employment of state of art methodologies for analysis. The ambition is to have full UK coverage.

DF gave an overview of in-house reports already produced:

- UK incidence & mortality by network
- One year survival trends
- New UK and regional prevalence estimates
- Incidence in relation to deprivation
- Incidence & survival by ethnicity
- Incidence & mortality by gender.

The second wave of publications will be:

- Disease stage
- Surgery
- Co morbidity
- Hospital in-patient stay
- NHS service use
- Non-cancer outcomes (e.g. heart disease)
- Long term follow-up of clinical trials.

The NCIN is also responsible for electronic products such as the cancer eAtlas and Cancer Commissioning Toolkit.

DF emphasized that the NCIN needs to intervene in the agenda not just report it and needs to step into the world of institutional comparisons e.g. post operative mortality.

On the research agenda, methodological research to compare reliably the performance of hospitals and doctors (league tables) is badly needed. 'Toe in the water' attempts have been made to compare clinical institutions and this has met with a backlash from clinicians. However, datasets are more complete and extensive than have previously been available. The need to deal with concerns and encourage an open culture was emphasized. Professional buy-in and robust methodology needs to be ensured.

DF emphasized that there is no attempt towards exclusivity, in response to PA's concern that the Scientific Advisory Group could be a 'cosy cartel of researchers' that excludes others. Methodology boundaries were discussed and DF stressed that data dissemination has always been a priority for NCIN. MP explained the purpose of the Clinical Outcomes Group, which he co chairs with the National Cancer Director, is to meet with those who use the data and to check that the data are in a useful format. Ways to get this information to the general public are needed. CT commented that different outputs are needed for different audiences. JC stated that research projects need to be captured systematically and DF explained that MCh, in his role as Research Programme Manager for the NCIN and NCRI is doing this.

HM expressed concern at the aim of providing comparisons based on institutions or individual clinicians; he is more comfortable with a level of analysis that compares residential populations. PS queried whether a random part of the country should be picked to test the impact of institution or clinician level comparisons. A lot of planned research is health service rather than epidemiological, although there is a great potential for this. PS would like to see data on screening, health awareness and, if possible, HPV vaccination inked into the national cancer data repository. Good outputs should be made routine and regularly updated rather than conducted as bespoke analyses each time.

5. <u>All Cancer Survival Indices</u>

The report of the APPGC inquiry in December 2009 recommended improved cancer survival indices and MC presented his subsequent work 'A cancer survival index for Primary Care Trusts in England' and circulated the interim results. MC gave an overview of the purpose of the study and requirements, data and methods, and interim results plotted as funnel plots and maps (the maps are experimental at present). Interim conclusions were presented and issues for health policy deployment raised. At the end of his presentation MC asked for feedback and guidance.

- AG asked what MC thinks PCT's will do with the data. Is it too simplistic to assume socio-economic factors are responsible for the differences? MC responded to say that his group have tried to account for socio-economic factors in their analysis.
- HM liked the work but thought it too ambitious in some ways i.e. year-by-year survival estimates may be too rapid for changes to show, smoothing of maps ducks the question of PCT-level survival slightly, the grouping of all cancers except for five might be too much as these are not homogeneous and the level of analysis coincides with the level at which errors in the data occur. MC responded that smoothing is appropriate as there is spatial autocorrelation between areas; the underlying data will be available for PCTs.
- SM thought the study interesting but he challenged the spatial autocorrelation – neighbouring PCTs are not necessarily similar.
- PS asked if the three dimensions; geographic, time and different cancers, can be linked and commented that it would be helpful to see how robust the study is as a measure. He suggested comparing mortality and incidence by PCT and also one year survival for under 75's to over 75's to provide robustness. MC said that there will be a need to look at individual cancers for this; incidence alone won't give information.
- PA was interested by the idea of measuring over-dispersion of survival, which might avoid some of the limitations of funnel plots. DB commented that funnel plots are a sound methodology, although the definition of outliers is very dependent on calculation of control limits.

6. Overview of International Benchmarking Study

MVE gave an overview of the International Cancer Benchmarking Partnership (ICBP) study, the results of which are in the early stages. The study involves twelve partners and will address four cancers (breast, colorectal, lung and ovarian) through five modules, each investigating potential causes of cancer survival differences. MVE views the Scientific Advisory Group as a good complementary group to the academic group recently set up to 'oversee' the ICBP.

PA commented on the use of "lives saved" and queried the identification of institutions. PS commented that it is useful to have palliative care as a broad category.

7. Variation in post-operative mortality

EM gave a presentation on the study '30-day post-operative mortality following colorectal cancer surgery across the NHS in England'. EM gave a brief background on the project and a broad overview of methods and case mix factors. Problems with missing data have been overcome by imputation. EM and Paul Finan have presented the data to the Association of Coloproctology. EM was asked by the Association to check the data but is unsure how to do this.

The Scientific Advisory Group discussed this and provided suggestions. MC commented that checking by clinicians or Trusts would introduce bias and should be avoided. PA was interested in the sensitivity of the funnel plots to the removal of variables such as stage and in which variables are most important. JB suggested that ITU capacity could be useful to include and to contact him via the DH for this information. DB suggested that grade of differentiation and morphology might also be explanatory and could be usefully included.

8. Handling of outlier institutions and clinicians

Elaine Young, National Development Lead for Healthcare Quality Improvement Partnership (HQIP), gave a presentation on the Handling of Outlier Institutions and Clinicians, talking through the methodology, process and specific issues of handling outlier management. A key principle of outlier management is that outliers should be considered "potential" pending further investigation. Factors to be considered are data quality, data completeness, confidentiality/anonymity, indemnity, advice and support, workload and timescales, and providing dedicated time to handle the process. Responsibility for handling outliers can be divided into first level (audit) and second level (local). EY would welcome feedback on the draft; definitive guidance will be issued at the end of Summer/start of Autumn 2010.

DECISION: Circulate copies of Elaine Young's presentation on Handling of Outlier Institutions and Clinicians.
ACTION: MCh

MP would like the Scientific Advisory Group to define the threshold of data quality for identifying outliers. PA said that transparency is more important than data quality and HM suggested that there will never be perfect data. PS suggested that complete data are needed on small particular groups, e.g. those who have died, rather than on all individuals. MC stated that the government statistical service provides guidance on when statistics are fit for purpose and once the threshold is reached they should be released. Guidelines are needed within the

Scientific Advisory Group. AG asked if quality accounts should be considered; when published they would focus attention on data quality. RS commented that as a cancer patient one wants to find a good doctor and outcomes, not look for bad outcomes/have a witch hunt.

9. Discussion of items for future meetings

The aim is to have two or three meetings per year, with the next meeting in October 2010.

Items for future meetings:

- Experience of analysis
- Follow the Terms of Reference points and analyse and scrutinize NCIN's future work
- Use of a second correlated measure to back up outliers.

10. Any Other Business

There was no further business and the Chair closed the meeting, thanking attendees for their participation.