NCIN Scientific Advisory Group
Wednesday, 26 October 2011
1000 - 1300
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
CB	Catherine Boyle	Head of Intelligence and Research, Macmillan Cancer Support
CC	Chris Carrigan	Head of the NCIN Coordinating Team
MCh	Michael Chapman	Research Programme Manager, NCRI & NCIN
MC	Michel Coleman	Professor of Epidemiology & Vital Statistics, CR-UK Cancer Survival Group, LSHTM
JC	Jane Cope	National Cancer Research Institute
AG	Anna Gavin	National Lead for Analysis & Information, 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
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	Service User, NCRI Lymphoma CSG
CT	Catherine Thomson	Head of Statistical Information, CR- UK
AS	Alison Stone (Minutes)	PA to Chris Carrigan, NCIN

Apologies:

David Brewster	Director, Scottish Cancer Registry
Angela Coulter	Director of Global Initiatives, Foundation for Informed Medical Decision Making
David Forman	Head, Cancer Information Section, International Agency for Research on Cancer
John Wilkinson	Director, Northern & Yorkshire Cancer Registry & Information Service

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 21 April meeting were approved.

3. Matters arising from the minutes

Handling of outlier institutions and clinicians

MP gave an update on work with NCAAG, which is to be reviewed to make it more operational. MCh and MP have written a document which is nearly ready for circulation. Bruce Keogh would like the level of confidence at which a provider is considered a potential outlier to be brought in, not out.

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

ACTION: Michael Chapman / Mick Peake

UK Biobank

The proposal for collaborative work has been approved and preparatory work has begun.

Update on review of cancer registration

The independent reviewers are meeting on 14 November 2011 and have asked for a complete summary of the work ahead of that, to enable them to write their outputs. The outputs will be an article in a peer reviewed journal and a longer report that supports their conclusions.

4. NCIN general update

Planning for Public Health England (PHE)

PHE will be an executive agency of the DH. There is still a large amount of uncertainty, but also positivity. PHE will formally come into being in April 2013, but will exist in shadow form from April 2012.

At present, there is no easy answer regarding the implications of cancer registries and the NCIN no longer being independent from each other. The Cancer Intelligence Framework currently under development will help to address this. Devolved cancer registries will not be going into PHE, but the UK focus of NCIN has been flagged up.

It is possible that as part of PHE the NCIN may come under pressure not to publish for political reasons.

The role of the NHS Information Centre in this domain needs to be considered as well. In the research space, Ministers have agreed that the Research Capability Programme (RCP) will join with the General Practice Research Database (GPRD) and will be called Clinical Practice Research Database (CPRD). John Parkinson (currently director of GPRD) will run the CPRD, which will be up and running by the next financial year. The NCRI Informatics Initiative will be included in CPRD, but this will leave some resources.

DECISION: When the construction of CPRD is confirmed circulate notes to the Group.

ACTION: Michael Chapman

Single Cancer Registration System

All cancer registries in England are moving to a single system. Trent Cancer Registry has migrated and the rest will have completed their migration by the end of 2012. This will improve both the timescales and consistency of cancer registration.

With regard to devolved countries AG advised that Northern Ireland may consider migration. Northern Ireland has been ahead of electronic registration and will do an option appraisal to see if it is suitable to move. Given the patterns of cross border flows AG felt that it makes more sense for Wales and Scotland to join.

CC confirmed that historical data will be incorporated. One of the biggest jobs as part of the transition is the removal of duplicates.

NCIN work programme
Included within the programme are:
- Extending the Routes to Diagnosis work
- Emergency presentations
- Routes from diagnosis with Macmillan profiles.

The move towards an integrated work programme across the cancer registries and NCIN is underway.

There is a lot of interest/pressure to develop profiles with regard to commissioning.
Existing profiles have consumed virtually all resources, during a period of budget cuts.

DECISION: Circulate Profiles to Group. Consider adding Profiles to the next meeting agenda.
ACTION: Di Riley

5. <u>Approach to survival and other measures at trust level</u>

SM presented an outline of the project to calculate cancer survival (or similar outcome measures) at trust level. A mock-up of Cancer Service Profiles for Breast Cancer was circulated.

Comments from the Group:
- MC felt that this was a difficult metric to defend. One of the reasons why is the small numbers and the statistical robustness of the indicators produced. MC's second concern is regarding case-mix. How to adjust for variation between hospitals? This could be corrected to a degree if there was solid stage data. Why use treatment as a unit of outcome?
- MP said that variation of treatment rate is largely down to the Trust of diagnosis.
- PA welcomed the approach. The next indicator should be looking at main treatment. PA was not sure that small numbers are a problem, as large outliers can still be looked at. Publishing data will drive up data quality.
- HM shared MC's concerns and also expressed concern regarding incentives: the work could incentivise units to be more selective in choosing patients (i.e. not elderly, co-morbidity.)
- PS asked if a compromise is possible: to use treatment, not outcome, as a guideline.
- MP felt that the data are useful, if presented properly. Small numbers need to be worked out.
- CB asked who will use the data and why; that information should define the proposal.
- MC added that if the aim is only to feedback to a Trust, it doesn't help if information is driven by small numbers.
- MP said that lung cancer audits have driven up standards of care and have changed practice. On the whole there are more benefits than downsides.
- PA added that it cannot just feed information to Trusts. The data needs to be looked at, as part of a package of indications and need to be examined.

SM has tried not to prejudge the best outcome measure. He would like to explore the issues raised by the Group, and have the input of MC and his team over the next few months.

6. Cancer Survival within households

PS presented the proposal, which has arisen from the NAEDI agenda.

- A diagnosis of cancer, for example of a spouse within a household, should raise awareness.
- It could be possible to compare first and subsequent cancers in a household, and adjust for age, sex, year of diagnosis, cancer site.
- The analysis would be to obtain 'expected' survival for cancer type and age group and calculate relative survival of second cancers within a household.
- How to identify related individuals? Possibly use same surname and postcode.
- Exclude any postcode with more than 20 cancer registrations (with different surnames) in a 10 year period.
- Available data: 358,430 potential family members and 195,171 potential family members with cancer within 5 years.

PS feels that the study is crucial to knowing the effects of awareness; if awareness is not raised in a family that has experienced cancer, then it is highly unlikely that early diagnosis can be achieved through increasing awareness.

Comments from the Group:

- MC felt that the idea is ingenious; if there is no impact on survival in the second case within a household, this would suggest that efforts for raising awareness are unlikely to make an impact on early diagnosis.
- HM said that it is a valid question to ask, but was unimpressed by the notion of the study due to the difficulty with the imperfection of classifying the population. In a Nordic country it would be possible to obtain data for an accurate study. People who live alone have a lower life expectancy, so that bias needs to be taken into account.
- AG drew attention to Module 2 of the ICBP: Cancer Awareness Survey: to look at awareness if you or someone in your family have had cancer. For Northern Ireland there is no difference in awareness. It would be interesting to look at whether other countries completed this information.
- SM commented that for a post spousal diagnosis of cancer, other lifestyle factors might have changed too, e.g. reduction of smoking.
- JC said that if you are the carer looking after a family member with cancer, you might pay less attention to your health.
- AG added that there might be the 'worried well' effect, if the spouse attends the GP.

The general view of the Group was that the proposal is worth pursuing, with careful wording. A longitudinal study could be used, to have more clarity, or could go to a cancer registry to find out how poor the numbers are and the information is.

7. Building an e-health research infrastructure for cancer

MCh presented a paper for discussion. The single system will change the speed/way data are collected and it is timely to reconsider the ways in which the cancer registration system can enable research. Changes to the Research Capability Programme mean that there may be NCRI investment available for building infrastructure.

The paper, which deliberately excludes costs for now, sets out four broad themes:

- simple access to information (safe haven)
- linkage
- notification

- trials planning and recruitment.

The Group discussed the proposal, with some specific comments:

- PS asked if reservation or 'patenting' had been considered, in order to avoid duplication. There is a role in managing the applications for data.
- CB was supportive, from a funder's perspective. Procedures are a huge barrier to research and transparency will aid research. JC supported CB's perspective.
- PA felt that the ethics are the difficult part (of the papers) to overcome.
- PS asked if a mock database could be produced before people get to the safe haven facility and MCh advised that this would be investigated.
- HM commented that an extension of this would be a non-disclosive publicly available dataset.

The Group focussed on the issue of duplication. MCh felt that a centralised view across cancer registries is essential. This could be in the public domain. Do overlapping applications lead to more, or less, research? MCh will take this away for further consideration.

Proposal 1

A physical safe haven sounds expensive. A virtual safe haven is more expensive to set up initially but would be better overall. The need for detailed protocol for all users was emphasized.

Proposals 2 & 5

These were discussed in some detail, and with regard to what is permissible for different sets of data/authorities.

Proposals 3, 4, 7

These are not entirely within the core remit but MCh felt that they needed to be tackled. There has been some correspondence with the National Research Ethics Service (NRES). The Group agreed that this could be of benefit. Retrospective consent needs to be considered. Awareness is needed of the incoming change in the guidelines of data transfer, which is likely to become more restrictive.

DECISION: Send examples of consent problems to Michael Chapman.

ACTION: Michel Coleman / Peter Sasieni

Proposal 6

The NCIN does not have these data at present and further clarification is needed.

Proposals 8 & 9

Concern was expressed regarding the timeliness and consent of trials. MC asked why not suggest to the MRC that cost could be included in all trials to flag up long term follow-up, regardless of the trial type. Asking for the consent of every patient for research follow up was suggested.

MCh will revise the paper in light of the Group's comments. The revised paper will be taken to the NCRI Cancer Conference for dissemination and then will be more widely circulated. It is hoped that a concrete proposal can be taken to the March 2012 NCRI Board meeting.

JC requested a more structured consultation with research groups to identify opportunities presented by the research.

DECISION: Revise the 'Building an E-Health Research Infrastructure for Cancer' paper & circulate as agreed with the Group.

ACTION: Michael Chapman

8. RCPath meeting on Cancer diagnostics

HL presented a paper on the meeting at Royal College of Pathologists on 15 July 2011; 'An essential review of current issues from leading practitioners'. Speakers were trying to engage with the laboratory community on the impact of recent guidance on cancer detection, particularly NICE guidelines on ovarian cancer screening. Prostatic and ovarian cancers were under scrutiny.

AG advised caution is necessary on ovarian and prostate cancer testing. The USA is now presenting a balanced view of PSA testing: benefits versus risks/costs.

9. Any other business

Transparency agenda
Publishing data held by commercial bodies – the initial step is a pilot project to publish in December and the Cabinet Office has picked lung cancer audit and is currently deciding the level of data. At present the Cabinet Office is accepting publically available spreadsheets.

DR has been asked to look at the source of data in a particular set of Profiles, as the Cabinet Office would like Profiles to be publically available. DR is to provide information to Mark Davies and Tim Kelsey who are liaising with the Cabinet Office.

The Group discussed this and the risks and merits. There are difficult ethical questions to answer and a major worry concerning incorrect analyses of publically available data.

NCIN Communications bulletin
MCh circulated copies of the most recent bulletin and asked members of the Group to notify him if they wish to receive regular copies.

10. Date of next meeting

The dates for 2012 meetings are:
- Wednesday, 11 April 2012, 1000-1300, NCIN Boardroom
- Tuesday, 02 October 2012, 1000-1300, NCIN Boardroom.