NCIN Scientific Advisory Group
Wednesday, 2 October 2012
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
DB	David Brewster	Director, Scottish Cancer Registry
MCh	Michael Chapman	Research Programme Manager, NCRI & NCIN
JC	Jane Cope	National Cancer Research Institute
LEB	Lucy Elliss-Brookes	Analytical Programme Manager, NCIN
CO	Catherine O'Hara	R&I Manager, North West Cancer Intelligence Service
HL	Helen Losty	Service User
SMP	Sean McPhail	Head of Cancer Analysis, Cancer Intelligence Service, South West PHO
MP	Mick Peake	Lead Clinician, NCIN
RS	Richard Stephens	Service User, NCRI Consumer Liaison Group
CT	Catherine Thomson	Head of Statistical Information, CR- UK
JW	John Wilkinson	Director, Northern & Yorkshire Cancer Registry & Information Service
RB	Rachael Brannan (Minutes)	Research Officer, NCIN

Apologies:

Chris Carrigan	Head of the NCIN Coordinating Team
Michel Coleman	Professor of Epidemiology & Vital Statistics, CR-UK Cancer Survival Group, LSHTM
Anna Gavin	National Lead for Analysis & Information, NCIN
Siobhan McClelland	Head of Evidence, Macmillan Cancer Support
Di Riley	Associate Director, Clinical Outcomes Programme, NCIN
Peter Sasieni	Deputy Director, CR-UK Centre for Epidemiology, Barts and the London

1) Welcome & apologies for absence

The Chair welcomed attendees and apologies were noted as above.

Catherine O'Hara was welcomed to her first meeting.

2) Minutes from the last meeting – for approval

The minutes from the 11 April 2012 meeting were approved with one minor change to the attendance list.

3) Matters arising from the minutes

Membership of the Scientific Advisory Group

The Scientific Advisory Group's role and function were discussed at the April 2012 meeting, where it was agreed that a review of the group was necessary after two years of existence. In this discussion, there was consensus among the members that they are happy to contribute to the group, provided NCIN finds their input useful. **MCh** reiterated that the NCIN Co-ordinating Team values the advice received from the SAG and, if possible, as a consequence of the review would like to make more use of members' expertise. Going forward, the NCIN are keen to ensure an appropriate and broad range of independent, impartial and authoritative individuals available to scrutinise NCIN information outputs, and to provide methological and analytical advice.

Members of the Group felt that invitations to join the group should be to those with specific skills and knowledge but a formal appointment process would not be necessary. The group also noted the importance of patient involvement and that the two lay members continue to advise the NCIN on the potential impact of outputs on consumers and the wider health community. PPI was agreed to be a vital part of the advisory process. Moving forward, the group agreed that the number of expert advisors as should be expanded and there should be a reduction in the ratio of NCIN Coordinating Team on the group to better fulfil this advisory role.

DECISION: New members will be invited to the next meeting, once further advice is sought from NCIN's Funders Group.
ACTION: HM/MCh/RB

Terms of Reference

A review of the Terms of Reference was conducted in parallel with the review of membership. Within the group, there was a general consensus that the current Scientific Advisory Group's Terms of Reference (TOR) were fit for purpose but could benefit from some finessing to reflect the partnership with the UKACR, and to align to the vision for the group to be a source of timely, expert advice. The minor changes made to items 4 and 6 reinforce the need for the Group to provide high-quality, independent scientific challenge to NCIN information outputs. Item 4 would be measured against the NCIN vision statement 'using information to improve quality & choice'. Furthermore, the link to UKACR has been more explicitly captured in Item 6 with the introduction of an UKACR representation, Catherine O'Hara (CH) to the group. Concerns were raised by members regarding tone of Item 4 and what exactly 'impact' implied. The group felt that 'who' and 'what' Item 4 impacted upon needed to be defined.

The timeliness of the Group's meetings was also discussed and it was agreed that maintaining the current schedule of meetings was most appropriate. It was agreed that the group receive outputs for

comments outside of SAG biennial meetings where needed, rather than review being a necessary step for every project. The need to review the NCIN's portfolio of work was further considered by the group. 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.

DECISION: To review changes to terms of reference and publish shortly.
ACTION: HM/MCh to discuss and amend.

DECISION: Projects requiring advice outside of the meeting rota to be circulated by email
ACTION: MC/RB

Structure of the NCIN

An overview of the NCIN's committees was circulated by **MCh** with the unconfirmed minutes of the previous meeting. Through the transition into Public Health England, this structure is likely to be subject to change.

Mental Health and Cancer

Following the discussion at last meeting Anna Gavin has continued to investigate what opportunities exist for linking mental health and cancer data. Initial contact has been made with Scotland and Wales, as well as with the Clinical Practice Research Datalink in England. It is likely that funding will be required to take this work further and an application is being considered. **MP** noted that this is an opportunity to take advantage of the variation in the data available in the different UK nations.

4) NCIN update

The group received a written update on NCIN's activities, covering work in support of research and the Co-ordinating Team's analytical work programme, English registry migration to ENCORE and the Transparency Agenda. Members had previously asked that details of the analytical work programme be moved up the agenda for the next meeting to allow more time for discussion. Lucy Elliss-Brookes, the NCIN Analytical Programme Manager was invited to join the group for the meeting and present an overview of on-going worth with the integrated analytical work programme.

NCIN Analytical Programme

LEB presented a brief overview of the NCIN analytical outputs, which are currently in progress or under consideration. Co-ordination of these projects and joint work between cancer registry analysts and the NCIN Co-ordinating Team, is being led by Anna Gavin, who has been asked to act as a Cancer Analysis Champion to facilitate the development of priorities at national level and enhance communication. Anna will be supported by Sally Vernon and Jason Poole as co-chairs of the UKACR Analysis Group and by Lucy Elliss-Brookes as NCIN's Analytical Programme Manager. LEB noted her role is to manage the central analytical programme and work with the UKACR to further coordinate other analytical work. It was further explained that October's analytical work programme will be finalised the week commencing Monday 1st October.

On-going work includes:

Project	**Description**
Assigning patients to MDTs and trust level survival	Agreeing methodologies for assigning patients to trusts of diagnosis and treatment and for estimating survival at a provider level.
Service profiles	Updating and extending NCIN's service profiles for breast and colorectal cancers, scoping service profiles for lung cancers. Publishing radiotherapy profiles.
Emergency presentations	Using rapidly available data sources in order to identify emergency presentations in as near to real time as possible. A proposal has now been accepted by the Department of Health.
Macmillan survivorship work programme	Work to segment and understand the health and experience of cancer survivors. Includes new analyses of the Cancer Patient Experience Survey.
UK Biobank	Undertaking primary analysis to support adjudication of cancer outcomes.

Under consideration

- Comparison of ONS & NCDR (UKACR partnership)
- Cancer of Unknown Primary data briefing (Cancer Research UK partnership)
- Big HES quality/completeness review & comparison with previous linkage methodologies (UKACR partnership)
- Library of code lists to use for national analysis, including life tables (UKACR partnership)
- Pancreatic Cancer UK Study for Survival 2011 update (UKACR partnership)
- Survival Standard Operating Procedures (UKACR partnership)
- Training programme of monthly webinars for UKACR/NCIN analysts

Survival Standard Operating Procedures

Several questions were raised by the group over the Survival Standard Operating Procedures (UKACR partnership). **SMP** explained that the Survival Standard Operating Procedures is a historic document regarding the calculation of survival to facilitate standardisation. The work programme will re-launch an updated version of this guidance as a consequence of requests from PHOs for standardisation. The document will be published through the Public Health England website.

Public Health England Transition

It was explained that planning for the transition of the English cancer registries and NCIN to Public Health England (PHE) is ongoing, including the move to Wellington House near Waterloo. NCIN will form a part of the Chief Knowledge Officer's directorate, with cancer registration staff forming the core of the disease registration function and analytical staff becoming part of distributed knowledge and intelligence teams (with 70% of their work focused on national priorities and therefore, for

cancer, closely linked to the work of NCIN). Some appointments to PHE have now been made. John Newton is the interim Chief Knowledge Officer. Jem Rashbass has been asked to act as shadow Director for Disease Registers. Other senior positions within PHE are currently being recruited.

The group discussed the need to consider the full impact of PHE transition and further thought is required about what the scale of change caused by PHE transition will be. The group asked if NCIN fully understand all the potential risks, the impact should these events occur and the probability of their occurrence. As all PHE staff will be civil servants, questions were raised over what implication there will be for research, information governance and data management. It was agreed that understanding risks is needed now, to avoid research outputs depleting. Questions were raised over the application of the Civil Service Code preventing NCIN from disseminating data. The example of surgeon specific care data being published in Scotland was presented. In the case of this release, t was deemed that public interest outweighs the right of the individual surgeon.

DECISION: Implications of move to PHE for research need to be understood.

ACTION: MC to ensure that this is included in NCIN planning.

5) Proposal for a European platform for cancer outcomes research

JC introduced Paper 4 detailing planned EU activity for cancer outcomes research coordinated by the European Partnership for Action Against Cancer (EPAAC). EPAAC is an EU-funded Joint Action, which aims to 'bring together the efforts of different stakeholders into a joint response to prevent and control cancer'. The EPAAC pilot project for cancer outcomes is tightly linked to the proposal of a European Cancer Information System (ECIS) developed by the EPAAC WP9, under the leadership of Milena Sant (National Cancer Institute, Milan, Italy) and Riccardo Capocaccia (ISS). There has been a preliminary discussion of this paper at a meeting in Brussels in July and there is another meeting in October at which there may be an attempt to start developing some pilot work in this direction. The group were asked to contribute their thoughts as to whether this would be a viable, credible project for NCRI involvement and would it add value to NCRI's portfolio of work. Overall the view of the group was that more information is required to judge the credibility and usefulness of the EPAAC project but that this is worth investigating further.

6) Peri-treatment mortality

MP introduced a paper detailing ongoing activity to examine trends in peri-treatment mortality and develop indicators for benchmarking provider performance. Initial work on 30-day mortality following colorectal surgery was published in 2011. It has been envisaged that this work would be applied to other cancer sites. The advice of the group was sought on whether a bespoke methodology is required for each cancer site/modality or if a standard may be applied. Furthermore, is 30-day peri-treatment mortality an appropriate measure for each cancer type/treatment? Critics of this system point out that perioperative mortality may not reflect poor performance but could be caused by other factors, e.g. a high proportion of acute/unplanned surgery. There is evidence that surgeons with greater case volume or total lifetime experience have better outcomes. It was also noted that there is some evidence of the risk of recording post-operative mortality being a perverse incentive in the USA.

The group recognised that the outcomes of surgery and other treatment, including peri-operative mortality were gaining recognition as important outcomes indicators but were not sure of the value of recording 30 day over 90 day and in hospital peri-treatment mortality. Calls may be made for mandatory reporting of peri-trearment mortality to peer review the clinical management of deaths occurring during treatment episodes. It was felt that the SSCRGs would be appropriate forums to broker discussions about surgical mortality/ other treatment modalities and mortality, and the development of site-specific indicators. Timely engagement from clinicians would be key. The group recognised that it is possible that the NHS Commissioning Board may apply a blanket approach to peri-treatment indicators which may not best serve each site.

SMP noted that 30-day peri-operative mortality had already been discussed at the breast SSCRG and the clinicians showed considerable concern at standardisation of this indicator across all sites. Similar apprehension was raised over the threshold for treatment as a result of the Scottish Audit of Surgical Mortality. The audit aimed to identify all deaths under the care of a surgeon that occur in hospital with each case undergoing a peer review process. This will determine if there are any areas for consideration - where an aspect of care could have been improved - or an area of concern - where the assessor/coordinator felt that the quality of care provided was sub-optimal.

DESCISION: SSCRGs to be approached for guidance on site specific methodology

ACTION: MP to raise this issue at the SSCRG Chairs' Forum

7) <u>Service profiles and provider level survival analysis</u>

SMP presented an overview of the work on agreeing methodologies for assigning patients to trusts of diagnosis and treatment, and for estimating survival at a provider level and also, extending NCIN's service profiles. A copy of the presentation will be circulated with the minutes. He reported that Breast and Colorectal Cancer service profiles will be released by December 2012. It is expected that Lung Cancer Service Profiles will be published towards April 2012.

The question of how can we best use national data to define cohorts to give meaningful knowledge / intelligence at trust level was raised. Suggestions for a defined rule for calculating the population denominator, such as identifying pathology labs as a crude but useful proxy, were discussed. **DB** noted that in the case of lung cancer such a crude measure would be problematic as there would often be no histology data for more advanced cases. **MP** noted that the data are hierarchical and that any analysis needs take this into account. Concerns were also raised by the group about the potential for the creation of league tables by secondary users of the data.

Action – SMP to review provider level analysis at the next meeting

Members discussed the tension between timely reporting of data about a specific provider and the need to ensure that results are robust. **PA** noted that many provider specific outcomes would never reach statistical significance and therefore it is important to publish accurate numbers with rigorous methodology. Furthermore, due to the time-lapse in publication, data are often outdated and irrelevant to current activities.. **MP** highlighted the analysis of the NAEDI campaign using emergency admissions and cancer waits as an example of pragmatic use of timely data, recognising that the use of this data does not replace the ideal randomised control trial. The members discussed the need to balance transparency with the impact of being transparent, suggesting that, despite the dangers of

misinterpretation, publishing emerging data allows patients as well as professionals to recognise the subtle changes in their cancer services but that users must be aware of any limitations.

8) Transparency agenda and publication of data

MCh presented a brief paper on the Cabinet Office's Transparency Agenda, noting that transparency a key part of this Government's efficiency and reform agenda. This is driven by the Public Sector Transparency Board, which was established by the Prime Minister. The Transparency Agenda was explained to be a pledge by the Coalition Government to: make government more open, strengthen public accountability, support public service improvement by generating more comparative data and increasing user choice, and to stimulate economic growth. As part of this pledge, NCIN has worked closely with the Department of Health to release GP and PCT level data into the public domain under an Open Government License (OGL), which the Public Sector Transparency Board have set as the standard for open data.

Through this process, two main concerns were raised 1) the usefulness of data at such a low level of aggregation and 2) the publication of potentially identifiable data. Suppressed versions of the profiles (with suppression of, population denominators less than 1000 and cells with counts of <5) have now been made public through the NCIN website. The unsuppressed versions of profiles are still only available to NHS staff and GPs through either the Cancer Commissioning Toolkit or via PCTs and the Cancer Network GP Leads. It was felt this approach was suitably cautious.

MCh noted the importance of reaffirming how this data should or should not be interpreted. It was explained that the profiles are not for assessing the performance of a practice - there is often no 'right or wrong' answer for an indicator and many are affected by factors beyond a GP's control. But by looking at the indicators together, it is possible to get a 'feel' for those areas (indicators) that can affect or influence others, and to gain an understanding of why one indicator may look high and another low. For example, a practice with an elderly population may be expected to make more referrals with suspected cancer.

An overview of the communication plans and subsequent manageability of stakeholders was presented by MCh. Interest on day one was high with over 3000 unique visitors to the Profiles on the NCIN website. **MCh** reported that the approach to informing GPs about potential press attention was perhaps not as well coordinated as hoped for and required a more thought out, proactive approach that could be applied to all outliers. Notably, one practice had been contacted by the press ahead of NCIN being able to make contact. Working with the RCGP and the trade press as a vehicle to communicate the release was successful. An update of the publically available GP and PCT Profiles will be released in 10 weeks' time ahead of Britain Against Cancer.

In light of the Transparency Agenda, the group deliberated the interest of commercial health organisations in utilising record level data for novel analyses. Those with experience of applications of behalf on industry noted that organisations, such as Dr Foster, have been discouraged from making applications to the ECC for record level data. Members further identified that managing large datasets requires huge logistical resource. It was agreed that in light of the Transparency Agenda, broad consideration regarding the management of data requests and the fitness of data for research

purposes is need to ensure that management of these requests has the necessary degree of independence to prevent data controllers sitting on their data.

9) AOB

None raised.

Date of next meeting

9th April 2013 – location to be determined due to PHE move.