

National Cancer Intelligence Network Site-Specific Clinical Reference Groups (SSCRG) Terms of Reference

1. Purpose

The National Cancer Intelligence Network (NCIN) is a UK wide initiative working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. The NCIN was established in 2008 and became part of Public Health England on 1st April 2013, but maintains strong links within NHS England and provider organisations across the NHS.

The main purpose of the Site Specific Clinical Reference Groups (SSCRGs) is to provide expert clinical and service led advice to support the NCIN's core objectives which can be summarised as follows:

1. Promoting efficient and effective data collection throughout the cancer journey
2. Providing a common national repository for cancer datasets
3. Producing expert analyses to monitor patterns of cancer care
4. Exploiting the use of information to drive improvements in cancer care and clinical outcomes
5. Enabling the use of cancer information to support audit and research programmes.

2. Objectives

For the disease group(s) covered by that SSCRG:

1. To identify and prioritise the most important clinical outcome measures.
2. To identify the key variables which contribute to achieving high standards of care and service provision relating to these outcomes.
3. To support the definition and implementation of data sets that enable the identification of key clinical outcome measures taking account of the Cancer Outcomes & Services dataset, Systemic Anti-Cancer Treatment Dataset and National Radiotherapy Dataset, any other relevant national datasets).
4. To promote the linkage of relevant and appropriate sources of data, in particular to bring together information covering the following three main areas:
 - a. Clinical activity, performance and outcomes
 - c. Infrastructure and process (e.g. Peer Review)
 - d. Patient experience and patient-reported outcomes
5. To advise on the minimum standards of data completeness and quality for key elements of the relevant dataset(s).

6. To support and promote the use of cancer information in the commissioning process and the implementation of best practice as defined by National Guidance such as Improving Outcomes Guidance and NICE Quality Standards as appropriate.
7. To advise the NCIN on priorities for national analyses and publications; and to assist in bidding for additional resources if required.
8. To support efforts to better understand what is already known about variations in clinical outcomes in the UK and internationally.
9. To advise the NCIN on the handling of the publication of reports that name outlying institutions or clinicians and any associated press releases, in collaboration with the NCIN Scientific Advisory Group where appropriate.
10. To advise on relevant audit and research activity, both within the UK and internationally which may have value in promoting the aims of the NCIN. This includes the identification of existing datasets.
11. To build strong links with the relevant NCRI Clinical Study Groups and other appropriate NCRI initiatives.
12. To promote clinical and voluntary sector engagement in all elements of the work of the NCIN.
13. To assist in the writing, editing and interpretation of relevant site-specific NCIN reports.
14. To support the use of data in service improvement initiatives that promote changes in clinical practice and / or service provision which achieve improved patient outcomes.
15. To help identify ways in which data can assist in promoting informed choice for patients and members of the public about the quality of the services available.

3. Membership

The membership of each SSCRG must aim to represent all the key stakeholder communities relevant to the disease area. It should, wherever possible, try to ensure a UK-wide perspective. This will usually include individuals drawn from the following groups:

- The major colleges and professional (craft) groups representing health care professionals involved along the patient pathway in the clinical area covered by the SSCRG. This should explicitly include a senior pathologist.
- The Lead PHE Knowledge and Intelligence Team
- The National Cancer Registration Service
- Any National Cancer Audit group (particularly those funded from the NCAPOP budget) relevant to the tumour site(s)
- The relevant NCRI Clinical Study Group(s)
- Patients (minimum 2 – at least one of whom should ideally be a member of the relevant NCRI CSG)
- The major, relevant voluntary sector groups/charities
- Representation from NHS England, e.g. Strategic Clinical Networks, NHS Improving Quality, Commissioning Support Units, etc.*
- The relevant Quality Manager from the National Cancer Peer Review team.*
- The NCIN SSCRG Co-ordinating team.

*These roles are currently (July 2013) under review as the management structures within the new NHS emerge.

4. Chairs

The Chair was, in the first instance, appointed by the NCIN in consultation with key stakeholders. Since 2011, NCIN has held open recruitment drives for the appointment of new Chairs after a period of 3 years in office.

SSCRG Chairs are expected to be senior practicing clinicians in their field of expertise. They will be someone who:

- Can command the respect of his or her peers
- Is committed to improving the quality of patient care
- Has experience in the collection analysis and interpretation of clinical data.

5. Terms of office

The position of Chair and SSCRG group member will be for a period of 3 years, renewable annually to a maximum of 5 years at the discretion of the NCIN and with the support of the SSCRG membership.

NCIN will run open recruitment for the Chairs positions at appropriate times to be overseen by the SSCRG Co-ordinating Team.

6. NCIN Chairs Forum

The NCIN Chairs' Forum, chaired by the NCIN Clinical Lead, meets twice a year and its membership is as follows:

- Can command the respect of his or her peers
- Is committed to improving the quality of patient care
- Has experience in the collection analysis and interpretation of clinical data.

7. Reporting arrangements

1. The Chair of each SSCRG will be responsible for reporting back significant progress or issues to the Clinical Lead of the NCIN in a timely manner through the SSCRG Co-ordinating Team.
2. The Chair of the SSCRG will be a member of the NCIN Chairs Forum and formally feedback on progress to that group.
3. There will be reciprocal reporting arrangements between the NCIN SSCRGs and all National Cancer Audit groups.
4. A representative of the SSCRG will be a member of the relevant NCRI CSG and there will be reciprocal reporting arrangements between the two groups.

5. The NCIN Clinical Lead will report back to the NCIN Executive, its Management Group, Scientific Advisory Committee. The Chair is also a member of the NCRI Chairs' Forum and reports to them and other relevant national bodies on a regular basis.

8. Frequency of meetings and support

It is envisaged that face to face meetings of the full SSCRGs will take place no more than twice per year. Electronic communication (including use of message boards, the website and email) should be the most frequent form of communication.

The NCIN will provide secretarial support for these meetings.

Travel expenses and policies will be those of the NCIN host organisation.

| Membership of the Chairs Forum | | |
|---------------------------------|---|---------------------|
| Chair | NCIN Clinical Lead | Mick Peake |
| NCIN | Acting Head of NCIN | Di Riley |
| NCIN | SSCRG Administrator | Kris Adewole |
| NCIN | SSCRG Programme Manager | Nicky Coombes |
| Breast | SSCRG Chair | Martin Lee |
| Chemotherapy | Chemotherapy Clinical Information Group | Charles Wilson |
| CNS | SSCRG Chair | Peter Collins |
| Colorectal | SSCRG Chair | Paul Finan |
| Comorbidity | Co-chair working group | Robin Crawford |
| CTYA | SSCRG Chair | Mike Stevens |
| Gynaecology | SSCRG Chair | Andy Nordin |
| Haematology | SSCRG Chair | Robin Ireland |
| Head & Neck | SSCRG Chair | Richard Wight |
| Lung | SSCRG Chair | Michael Lind |
| Pathology | Royal College of Pathologists | Lynn Hirschowitz |
| Radiology | Royal College of Radiologists | Gina Brown |
| Radiotherapy | Chair, Radiotherapy Clinical Information Group | Peter Hoskin |
| Sarcoma | SSCRG Chair | Rob Grimer |
| Skin | SSCRG Chair | Julia Newton-Bishop |
| Upper GI | SSCRG Chair | Bill Allum |
| Urology | SSCRG Chair | Roger Kockelbergh |
| Primary care | Royal College of General Practitioners (and Interim Chair of Primary Care Clinical Reference Group) | Greg Rubin |
| National Cancer Director | NHS England | Sean Duffy |
| NCIN | Research Lead | Ekaterini Blaveri |
| NCIN | Analytical Lead | Anna Gavin |
| NCRI | Medical Director | Matt Seymour |