

## **NCIN Site Specific Reference Groups (SSCRGs) SSCRG Members - Roles and Responsibilities**

### **1. Introduction**

The purpose of this paper is to give a brief summary of the nature of the NCIN's Site Specific Clinical Reference Groups (SSCRGs), and to outline the roles and responsibilities of SSCRG members.

### **2. Background**

The National Cancer Intelligence Network (NCIN) established the SSCRGs in March 2009 to provide clinical and service led specialist advice to support the NCIN's core objectives<sup>1</sup>. In addition to the 12 site specific groups, 2 cross cutting groups have since been established to look at chemotherapy and radiotherapy; and a Primary Care Group is in the process of being set up. From time to time, 'task and finish' groups will be established to look at specific issues such as thyroid cancer and NETS (for example).

In April 2013, the NCIN migrated to Public Health England (PHE) in line with the new organisational structure of the national NHS. The Roles & Responsibilities of SSCRGs members continue as set out below until the next formal review of this document due in April 2015. NHS Organisational membership (eg from the National Policy Team and Cancer Networks) is being passed to appropriate successor bodies.

The SSCRG Terms of Reference (ToR) states that membership of each SSCRG must aim to represent all the key stakeholders relevant to the disease area and should, wherever possible, try to ensure a UK-wide perspective.

All members of an NCIN SSCRG provide specialist expertise in terms of their clinical or service related role, or as consumer and voluntary sector stakeholders. SSCRG membership is of two main types - members from particular organisations where SSCRG membership is part of their role, ('organisational members'), and appointed members. Some SSCRG members also have additional liaison roles to fulfil:

- A liaison role between the SSCRGs and other groups or organisations
- Supporting the integration of the SSCRG work programmes with other national initiatives, such as Improving Outcome Guidance (IOG), the development of NICE Guidelines and Quality Standards, National Clinical Audit and National Cancer Peer Review.

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<sup>1</sup> Promoting efficient and effective data collection throughout the cancer journey  
Providing a common national repository for cancer datasets  
Producing expert analyses, to monitor patterns of cancer care  
Exploiting information to drive improvements in cancer care and clinical outcomes  
Enabling use of cancer information to support audit and research programmes

Organisational membership comprises members of the NCIN co-ordinating team, representatives from the lead PHE Knowledge and Intelligence Team and Regional office of the National Cancer Disease Registry (NCDR) representation from NHS England, and a Peer Review Quality Manager.

The appointed membership includes representation from people or organisations with an interest in furthering the aims and objectives of the NCIN. These include the clinical specialities involved in the multi-disciplinary care of patients along the entire cancer patient pathway (e.g. primary care, screening, diagnostics, nursing, surgery, clinical and medical oncology, end-of-life care, and others relevant to the specific tumour site), NHS managers, members of the voluntary sector, and consumers.

Liaison roles are where members fulfil an additional function over and above their specialist expertise. These include representation from the UK's devolved nations, links with the relevant NCRI Clinical Studies Groups, responsibility for national and other major clinical audits, membership of the Royal Colleges and other professional bodies, and involvement with any other relevant national initiatives including (for example) dataset development, revision of staging systems, measures of co-morbidity and screening.

### **3. Details**

The following section is in two parts. The first sets out the roles and responsibilities of SSCRG members in relation to their specific roles. The second sets out core responsibilities for all members of the SSCRG in relation to a range of cross cutting themes such as attendance and confidentiality.

#### **PART 1 – Members core roles & responsibilities**

##### **3.1 Organisational members**

###### **a. NCIN Co-ordinating team**

Members of the NCIN Core Team will be present at all meetings:

- To provide oversight of all groups activities.
- To assist with the identification of cross-cutting themes and work areas, and to minimise duplication between groups.
- To support the management and administration of the SSCRGs
- To provide links to the NCIN Management Group, SSCRG Chairs Forum, NCIN Scientific Advisory Group and other related organisations.
- To liaise with appropriate national consumer groups.

###### **b. PHE Lead Knowledge & Intelligence Team (KIT)**

The role of representatives from the PHE lead KIT will be to:

- Support the development and definition of any new data sets and the implementation of existing data sets (taking account of the Information Standards Board approval procedures).
- Guide the development of the annual work programme for the tumour site, taking into account the need to develop proposals that support the implementation of national policy initiatives for cancer services.
- Identify the appropriate resources required to undertake the work programme.
- In line with the recommendations of the team, identify the analyses required to undertake the work programme, some of which may be out with the Lead Registry.
- Oversee and ensure the delivery of the work programme (analytical work may be carried out within the lead registry or with approved partner organisations).

**c. PHE regional office of the NCRs (National Cancer Registration Service)**

The role of representatives from the regional office of the NCRS will be to:

- Support the development and definition of any new data sets and the implementation of existing data sets, (taking account of the Information Standards Board approval procedures).
- Advise on the minimum standards of data completeness and quality for key elements of the relevant dataset(s).
- Support the production of regular reports on data quality and completeness for tumours relevant to the SSCRG
- Arrange the linkage of relevant and appropriate sources of data, in particular to bring together information covering the following three main areas:
  - i. Clinical activity, performance and outcomes,
  - ii. Infrastructure and process (e.g. Peer Review),
  - iii. Patient experience and patient-reported outcomes– (aspirational at present).
- Provide expertise on the availability, quality and timeliness of data, for all relevant data sources, for the tumour site.

**d. NHS England representative**

This member will:

- Identify, encourage and support effective links between the NCIN, PHE and NHS England
- Provide feedback from NHS England as to their cancer intelligence needs and how the NCIN should best fulfil them
- Help identify the priorities within the NCIN's work programme that will be of most value to the NHS and most likely to result in optimising service provision
- Help increase awareness within NHS England of what the NCIN has to offer

**e. National Cancer Peer Review (NCPR)**

This member will:

- Assist in the development of Clinical Lines of Enquiry (for inclusion within the NCIN Service Profiles for that cancer area) in collaboration with SSCRG Chair and NCPR Senior Information Manager
- Provide feedback to the relevant SSCRG on analysis of Clinical Lines of Enquiry (CLE)
- Promote discussion on action points from CLE analysis
- Feedback key tumour specific points from the NCPR National Report, and promote discussion on action points accordingly
- Consult the relevant SSCRG on any disease specific national queries arising from measures interpretation
- Feedback to NCPR staff on relevant key tumour information from SSCRGs, eg publication of relevant national reports/guidance/registry briefings

**3.2 Appointed membership**

**f. The Chair**

The Chair of the SSCRG will be responsible for:

- Chairing all meetings of the SSCRG, and agreeing the agenda and minutes in a timely manner.
- Ensuring that SSCRG agendas and supporting papers are circulated according to the Standard Operating guidelines in consultation with the NCIN co-ordinating team.

- Guiding the development of the work programme for the tumour site, taking into account the need to develop proposals that support the implementation of national policy initiatives for cancer services.
- Reporting significant progress and issues to the NCIN Clinical Lead in a timely manner, in consultation with the NCIN co-ordinating team.
- Being a member of, and formally providing feedback to, the NCIN Chairs Forum.
- Ensuring that there is ongoing liaison and reciprocal reporting arrangements with partner organisations, especially the NCRI and professional bodies.
- Being the public spokesperson for the work of the SSCRG and promoting the wider aims of the NCIN.

**g. Clinical members**

Each SSCRG includes clinicians who represent the specialities involved in patient care for that tumour site along the entire clinical pathway. These will vary according to the cancer site in question, and may include (but are not limited to) the following:

- Primary care
- Screening
- Diagnostics (pathology, radiology, endoscopy)
- Medicine
- Surgery
- Clinical oncology
- Medical oncology
- Nursing<sup>2</sup>
- Allied Healthcare Professionals
- Palliative & End of Life care

All clinical members of the SSCRGs will be asked to:

- Contribute their specific knowledge and expertise to identifying and prioritising the most important clinical outcome measures for the relevant SSCRG.
- Advise the SSCRG on details of the specific element of care that contribute to achieving good clinical outcomes for the tumour site.
- Establish what is already known about the disease group within the UK and international variation in clinical outcomes.
- Promote and support the implementation of the core and site specific data items of the Cancer Outcomes & Services Dataset.
- Contribute to the development of the work programme for the tumour site, taking into account the need to develop proposals that support the implementation of national policy initiatives for cancer services across the NHS.
- Ensure that there is on-going liaison and reciprocal reporting arrangements with the relevant professional association(s).

**h. Voluntary Sector Groups/Charities:**

This member will:

- Promote voluntary sector engagement in all elements of the work of the NCIN.
- Keep the SSCRG updated on any relevant work being carried out in the voluntary sector
- Act as a coordinator to ensure interested groups and comparable organisations that are not part of the group are kept informed of all relevant work areas and outcomes.

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<sup>2</sup> It is considered essential to have CNS representation on every SSCRG

- Consult with all relevant voluntary sector organisations as appropriate on topics of particular interest to NCIN.
- Contribute their specific knowledge and expertise to identifying and prioritising the most important patient outcome measures for the relevant SSCRG.
- Advise the SSCRG on details of the specific elements of patient care that contribute to achieving good patient outcomes for the tumour site.
- Establish what is already known about the disease group within the UK and international variation in patient outcomes.
- Promote and support the implementation of the core and site specific data items of the Cancer Outcomes & Services Dataset.
- Contribute to the development of the work programme for the tumour site, taking into account the need to develop proposals that support the implementation of national policy initiatives for cancer services.

**i. Consumers**

These members will:

- Assist the SSCRG in understanding the perspectives of patients, carers and the public relevant to the work of the group and provide a consumer viewpoint in all group activities.
- Identify ways in which the public could and should be better informed about the quality of the services available to enable informed choice.
- Where appropriate, provide a link to other consumer groups, such as cancer network partnership groups, local user groups and the NCRI consumer liaison group, and communicate the work of the SSCRG to these groups in consultation with the NCIN office.
- To regularly attend and participate in SSCRG meetings. To prepare for SSCRG meetings by reading papers, and raising any issues needing clarification with the NCIN co-ordinating team
- To be able to attend occasional training courses and conferences in consultation with the NCIN Co-ordinating team

**3.3 Liaison roles**

**j. Royal Colleges and other Professional Bodies**

Where members have a direct role in a professional body or craft organisation they will be expected to:

- Act as the main channel of communication between the relevant clinical body and the SSCRG especially in relation to projects being undertaken by either party. (*Nb. There may be representatives from a number of Colleges and professional bodies on any one SSCRGs*)
- Ensure reciprocal arrangements are in place for informing the college/professional bodies and the NCIN of relevant projects and developments that have implications for the work of the SSCRG

**k. NCRI CSG**

This member will:

- Be a champion for the cancer information related research within the CSG:
  - Speak up for opportunities for clinical studies using cancer information available in that field.

- Encourage other clinicians to propose research ideas using the information collected by cancer registries.
- Communicate with the relevant NCIN SSCRG about any opportunities identified by the CSG for related studies using cancer information.
- Inform the CSG of potential study ideas identified by the SSCRG
- Encourage the consideration of collaboration with the NCIN in the development and the follow up of clinical trials
- Identify all registry related studies in the CSG portfolio and consider along with other members of the CSG any ways in which they may be improved including:
  - Recruitment: can CSGs facilitate improved recruitment through communication with investigators or support from the NCIN SSCRGs?
  - QA: Is the study supported by the both the CSG and NCIN SSCRG? Could it then be improved?
- Be a communication link between the tumour specific CSG and the SSCRG by identifying any issues from either side and communicating effectively through both and CSG Chair and members and NCIN SSCRG Chair :
  - To identify whether the CSG have any particular issues or initiatives relating to cancer information related research/ the registries the NCIN SSCRGs should be aware of;
  - To identify initiatives led by the NCIN which the tumour specific CSGs should be aware of (e.g. methodological developments, reports due out);
  - To provide a verbal (or, if appropriate, written report) to the CSG on SSCRG activities and vice versa at each meeting.

#### **l. The devolved nations**

These members<sup>3</sup> will:

- Build appropriate links between the SSCRG and the devolved nation, and act as a channel of communication between the two
- Advise the SSCRG on relevant policies and plans in the devolved nations, and ensure that new developments are communicated between the parties

#### **m. National Audits & College Datasets/databases**

Members will:

- Advise on relevant audit activity being undertaken nationally and internationally, and promote the dissemination of examples of good practice in local clinical audit.
- Ensure there are established links with the relevant National Audits and College Datasets/databases, including pathology

#### **3.4 Deputies**

- Chairs, clinical members, voluntary sector and consumer representatives may wish to consider the appointment of a deputy to attend SSCRG meetings in the event they are unable to attend.

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<sup>3</sup> These members are likely to have another role on the SSCRG

## **PART 2: Members General roles & responsibilities**

3.5 All SSCRG members will also be asked to agree to a range of more general, core responsibilities. These are set out below:

**n. Confidentiality**

All members will be asked to respect the principle of confidentiality that underpins participation in the SSCRG, including the overall confidentiality of meetings, the need for patient confidentiality, and the confidentiality of NHS management information.

**o. Communications**

Members will be asked to take every opportunity to promote the aims of the NCIN within their specialist field.

**p. Attendance**

Members are required to regularly attend and participate in the SSCRG meetings, and to give their apologies in advance to the meeting if they are unable to attend. Failure to attend three consecutive meetings may be considered as a reason to seek a replacement member.

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