Constitution and Terms of Reference

SCN Partnership Group

The constitution has been agreed by:

Name	Position	Date Agreed
Margaret Ticehurst	Chair, SCN Partnership Group	15/01/2011
SCN Partnership Group		15/01/2011
	Chair, SCN Executive Board	

Membership
Peer Review Measure 10-1A-301u

11-1A-301u There should be a single group for the network having a membership which fulfils the following:

- at least one user representative from each of the localities of the network;
- there should be a named chair drawn from the user representatives above, and agreed by the Network Service User Partnership Group members;
- a health professional member of the Network Board;
- a Network Service User Partnership Group Facilitator;
- at least one nurse member from an NSSG in the network;
- at least one lead clinician member from an NSSG in the network
- an NHS employed member nominated by the Network Board as the network lead for users' issues and information for patients and carers;
- named secretarial / administrative support.

There should be terms of reference agreed for the Network Service User Partnership Group, which include the groups aims and objectives, and that the group is recognised as the primary source of advice to the Network Board on user issues, including:

1) improvements to the patient/carer experience of cancer care;
2) arrangements for sustaining effective user involvement across the network, including;
   i) advice on training, support and mentoring needs of users involved in the service; and
   ii) advice on recruitment of service users to network groups and any working parties including advice on reimbursement of out-of- pocket expenses

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The Sussex Cancer Network has a single user involvement group called the SCN Partnership Group with the following membership which fulfils the following:

- At least one user representative from each of the localities of the network
  Margaret Ticehurst East
  Roger Bacon West
  Carolyn Morris Central
  A full list of current Partnership Group members is available from the Network

- A named chair drawn from the user representatives above, and agreed by the Network Service User Partnership Group member
  Margaret Ticehurst Term March 2010 to March 2012

- A health professional member of the Network Board
  Caroline Huff, Macmillan Nurse Director, SCN

- A Network Service User Partnership Group Facilitator
  Maxine Bullen, Independent Facilitator

- At least one nurse member from an SCN Tumour group
  Caroline Huff, Macmillan Nurse Director, SCN

- At least one lead clinician member from an SCN Tumour group
  Dr Nigel Marchbank, Medical Director, SCN

- An NHS employed member nominated by the Network Board as the network lead for users' issues and information for patients and carers
  Caroline Huff, Macmillan Nurse Director, SCN

- Named secretarial/administrative support
  Amanda Lynch, Sussex Managed Clinical Network Administrator

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Terms of Reference

11-1E-101u The Network Service User Partnership Group should meet at least four times a year and a record of the meeting and attendance should be circulated to the group.

Compliance: A list of meeting dates, records of the meeting and attendance in the last 12 months.

11-1E-102u The Chair of the Network Service User Partnership Group should have an annual review with a member of the Network Board to discuss the work of the Network Service User Partnership Group.

The Network Service User Partnership Group should have produced and agreed a three-year strategy for the Board

The Network Service User Partnership Group should have produced and agreed an annual work programme for the Board.

The Network Service User Partnership Group should have produced and agreed an annual report for the Board.

11-1E-103u The Network Service User Partnership Group should endorse the network guidelines for user involvement. The guidelines should include the following:

- where and how patient feedback is to be obtained by the Partnership Group, MDT's, NSSGs and network cross cutting services and groups, and commissioning groups, and the use to which such feedback will be put;
- the nature and extent of professional support (including service user facilitation) made available to service user involvement across the network;
- where, when, and to what purpose, service user representatives are to be active in the groups and committees of the network and its constituent organisations
- the types and intended impacts of initiatives taken by the Network Service User Partnership Group to improve the patient and carer experience;
- actions taken to enhance the capacity and capability of user involvement across the network.

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Purpose

'My story…. becomes our story….. becomes what are we going to do about it?'

The aim of the SCN Partnership Group is to work, in support of the purpose of the SCN, in partnership with professional colleagues in the planning, development and monitoring of cancer services within the SCN. The SCN Partnership Group is the primary network wide channel for collating patient/carer views. An individual's experience of cancer gives them a unique and important perspective on cancer services.

As a formal part of the SCN structure the Partnership group endeavours to adhere to the principles of good governance

Membership criteria

- To have experience of cancer as a patient, relative or lay carer, **and**
- To live within, or have had treatment in, the **sussex cancer network** area, **or**
- To be an invited professional representative from the **sussex cancer network**.

The membership includes:

- At least one member from each locality in the network
- a health professional member of the network board,
- a nurse member from a tumour group within the network,
- an NHS employed member nominated by the network board as the network lead for users' issues and information for patients and carers. (For the Sussex Cancer Network this will be the Macmillan Nurse Director)
    - a lead clinician member from a Tumour Group within the Network
    - a facilitator
    - a membership Co-ordinator drawn from the lay membership
    - secretarial/administrative support

Aim

To improve cancer services by:

- enabling cancer patients, relatives and their lay carers to participate alongside professionals in the planning, development and monitoring of cancer services within the **sussex cancer network.**
- encouraging and developing links with support and patient groups.
- representing patient and carer views via elected representatives from the Partnership Group.

Objectives

1. Representatives of the Partnership Group, who give of their time freely, will provide the main pool of user representatives on the network groups.
2. Members of the SCN Partnership Group who are members of network groups are expected to endeavour to represent the range of views of the Group and

associated support groups and to disseminate any agreements and recommendations made by the group they attend, and report back.

3. Complaints and issues raised are collated for network review via the SCN Partnership Group.
4. Development of NHS reconfiguration plans will include consultation with the SCN Partnership Group and relevant support groups.
5. Issues raised by the group, will be incorporated into the group's annual work plan prioritisation process.
6. To highlight areas of access, quality, choice and information to the group and then into the SCN Board and Groups.
7. Training will be provided for members by Cancer Voices (Macmillan) or as required.
8. Support the SCN Macmillan Nurse Director with bids to Macmillan Cancer Support.
9. The SCN Partnership Group is a formal part of the network's organisational structure and is recognised by the constituent Trusts and PCTs within the network as:
   - the primary (but not only) source of advice to the network board on user issues including
     a) improvements to the patient/carer experience of cancer care;
     b) arrangements for sustaining effective user involvement across the network, including;
     i) advice on training, support and mentoring needs of users involved in the service; and
     ii) advice on recruitment of service users to network groups and any working parties including advice on reimbursement of out-of-pocket expenses.
   - the source of user representatives on the network board

10. Review progress on the Group's work plan annually and agree initiatives to be carried forward or new initiatives to be implemented
11. Produce an annual report summarising progress on the agreed work plan initiatives
12. The Chair of the SCN Partnership Group will have an annual review meeting with the SCN Macmillan Nurse Director, as a member of the SCN Executive Board, to discuss the work of the Partnership Group.
13. The SCN Partnership Group will produce a 3-year Patient and Public Involvement Strategy which will be presented to the SCN Executive Board by the SCN Partnership Group Executive Board members.

Meeting organisation

1. The SCN Partnership Group is chaired by a patient/carer member of the Group following a nomination and election process. The Chair will be elected bi-annually.

2. The SCN Partnership Group will have at least one Vice Chair drawn from the patient/carer membership following a nomination and election process. The Vice Chair will be elected bi-annually
3. The Chair, Vice Chair(s), Independent Facilitator and SCN Macmillan Nurse Director will organise the agenda, circulation of papers and meeting management.
4. The Membership Co-ordinator will contact, welcome and support new members
5. Administrative support is provided by the **Sussex Cancer Network**
6. The business of the Group may be conducted through subgroups and integration into established clinical groups.
7. The SCN Partnership Group aims to hold 6 meetings a year. The minimum number held will be four.
8. The SCN Macmillan Nurse Director and administration support will try to ensure that the final agenda and attachments are circulated two weeks before the meeting
9. Members have a responsibility to inform any member of the communications sub group of additional agenda items.
10. Minutes: Minutes will be taken at each meeting and circulated to the members A record of attendance will be maintained.
11. Frequency: Meetings will be held every two months
12. Duration: Three hours and thirty minutes
13. Venue: Friars Walk, Lewes
14. The terms of reference will be reviewed annually

Endorsement of Supportive Care, Patient Centred Care, transitional care and self-managed care

11-1E-104u The Network Service User Partnership Group should endorse the network guidelines for the development and delivery of supportive care. The guidelines should include the following:

- patient/carer information: provision of accessible, reliable, timely, high quality and user-friendly information;
- key worker support;
- the opportunity of a permanent record or summary consultation, and care plan at:
  a) diagnosis,
  b) treatment,
  c) follow up care.
- support for carers;
- specialist supportive care, including emotional, psychological, practical, and spiritual care.

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11-1E-105u The Network Service User Partnership Group should endorse the network guidelines for the development and delivery of patient centred care. The guidelines should include the following:

- personalised care ; i.e. care organised around the felt and expressed needs of individual patients and carers, which is delivered (via speech and action) with sensitivity, compassion and respect for the dignity of the patient and carer;
- holistic care; i.e. care which not only meets the health/clinical needs of the patient, but which also addresses wider emotional, practical, psychological and spiritual concerns arising from the cancer patient's diagnosis, treatment and after-care;
- choice in care: i.e. care consistent with the patient's and carers' choices concerning their involvement in decision-making about their treatment and care.

11-1E-106u The Network Service User Partnership Group should endorse the network guidelines for transitional and self-managed care. The guidelines should include the following:

- support for patient's and carer's, as patient moves on from diagnostics and decision making about their treatment towards;
  - primary stage of active treatment
  - living with cancer (including secondary cancer)
  - living beyond cancer
  - palliative care
  - end of life care (including bereavement)
- opportunities for development of capabilities for self-managed care;

The SCN Partnership Group will work with the SCN Tumour Groups and Generic Groups to agree the above guidelines.

11-1E-107u The Network Service User Partnership Group should undertake baseline mapping of:

a) current policies and practices concerned with the patients' experience of care in the network which should cover:

- patient centred care,
- supportive care and
- transitional and self managed care

The baseline mapping should cover whether patients were offered:

- a key worker;
- information (written or otherwise);
- the opportunity of a permanent record or summary consultation, and care plan at:
  a) diagnosis,
  b) treatment,
  c) follow up care.

b) current policies and practices concerned with service user involvement within the network which should cover:

- where and how patient feedback is obtained by the Partnership Group, MDT's,

NSSGs and network cross cutting services and groups, and the use to which such feedback has been put;

- the nature and extent of professional support (including service user facilitation) made available to service user involvement across the network;
- description of recent actions taken to enhance the capacity and capability of user involvement across the network;
- description of initiatives taken by the Network Service User Partnership Group to improve the patient and carer experience;
- where, when, and with what impact, service user representatives are active in the groups and committees of the Network and otherconstituent organisations;
- an audit of local partnership groups in the localities - covering which localities/trusts currently have partnership groups, and which of these groups currently maintain working links with the Network Service User Partnership Group.

This should be completed at least once every three years.

The SCN Partnership Group will work with the SCN Tumour Groups and Generic Groups to complete the baseline assessment as outlined above every three years.

11-1E-108u The Network Service User Partnership Group should produce a service specification for:

a).Standards of patients' experience of care in the network which should cover:

- patient centred care;
- supportive care; and
- transitional and self managed care.

The specifications should cover whether patients are offered:

- a key worker;
- information (written or otherwise);
- the opportunity of a permanent record or summary consultation, and care plan at:
  a) diagnosis,
  b) treatment,
  c) follow up care.

b).Standards of service user involvement within the network which should include:

- the aims and intended outcomes of user involvement within the network;
- where and how patient feedback is to be obtained by the Network Service User Partnership Group, MDT's, NSSGs and network cross cutting services and groups, and the uses to which such feedback should be put;
- professional support (including service user facilitation);
- where, when, and to what purpose service user representatives are to be active in the group and committees of the network and other constituent organisations;
- how the impact and outcomes of service user involvement are to be evaluated;
- how and through what systems the capacity and capability of user involvement should be continually improved across the network.

This should be completed at least once every three years

The SCN Partnership Group will work with the SCN Tumour Groups and Generic Groups to complete the service specification as outlined above every three years.

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11-1E-109u The Network Service User Partnership Group should produce network service needs assessments for:

a) patient and carer experience of services in the network, and

b) service user involvement within the network.

These should be based on the differences between the service specifications (measure 11-1E-108u) and the baseline mapping (measure 11-1E-107u).

These service needs assessments should be completed at least once every three years.

The SCN Partnership Group will work with the SCN Tumour Groups and Generic Groups to produce the SCN service Needs Assessment as outlined above

11-1E-110u The Network Service User Partnership Group should produce a Network Service User Partnership Group strategy which fulfils the following:

a) It should describe the proposed changes necessary to implement the Network Service User Partnership Group service needs assessment (measure 11-1E-109u) over the three complete contracting years subsequent to the assessment. This should be expressed using the same parameters as the Network Service User Partnership Group Service User Specification (measure 11-1E-108u)

b) It should list how the work on Network Service User Partnership Group Baseline Mapping (Measures 11-1E-107u) and partnership Guidelines (Measures 11-1E-106u), are to be schedules over the three complete contracting years subsequent to the assessment.

c) The strategy should include proposals to the Network Board (if needed) for investment in new developments

The strategy should be completed at least once every three years

The SCN Partnership Group will work with the SCN Tumour Groups and Generic Groups to produce the SCN Patient and Public Involved Strategy as outlined above.

11-1E-111U The Network Service User Partnership Group should provide other groups and organisations in the network - which embrace user engagement e.g. NSSGs, NCCGs, Trust patient involvement/partnership groups, the relevant details of the:

a) Baseline Mapping Exercise (11-1E-107u)

b) Service Specification (11-1E-108u)

c) Service Needs Assessment (11-1E-109u)

d) Strategy (11-1E-110u)

The SCN Partnership Group will ensure the baseline mapping, service specification, service needs assessment and Strategy is circulated, as a minimum, to the

- SCN Tumour and Generic Groups
- SCN Lead Managers and Commissioners
- SCN Executive Board
- Circulation of the SCN Partnership Newsletter
- SCN Lead Cancer Nurses

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- Sussex cluster and GP Consortiums

SCN Partnership Group Annual Report 2010 -2011

The SCN Partnership Annual Report has been agreed by:

Name	Position	Date Agreed
Margaret Ticehurst	Chair, SCN Partnership Group	07/05/2011
SCN Partnership Group		07/05/2011
	Chair, SCN Executive Board	

Review Date: 31 March 2012