Intelligence

National Cancer Action Team
Part of the National Cancer Programme

NHS

National Cancer Peer Review Programme

Evidence Guide for: Network Service User Partnership Group Measures

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Foreword

This evidence guide has been formulated to assist Networks and their constituent cancer service teams in preparing supporting evidence for peer review. It offers advice and guidance about how a Cancer Network and its Network Service User Partnership Group (NSUPG) can prepare for, and ensure a positive outcome from, a Peer Review assessment of the quality of their approach to user involvement, and the patient experience. The contents of this guide are not exhaustive and organisations should continue to tailor their policies to reflect activity of the respective team, whilst demonstrating compliance with the quality measures. Networks and their constituent teams during the review process will be required to demonstrate ownership of all policies, and assure visiting Review Teams that policy is reflective of practice.

The Guide is written in everyday language in order to help the reader understand the general principles behind the NSUPG standards in relation to service user involvement and the service user experience.

The internal validation proforma for the service covered by the evidence guide is shown in Appendix 1.

Agreement

Where agreement /endorsement to guidelines, policies etc is required this should be stated clearly on the cover sheet of the three key documents including date and version. Similarly, evidence of guidelines, policies etc requires written evidence unless otherwise specified. The agreement by a person representing a group or team (chair or lead, etc) implies that their agreement is not personal, but that they are representing the consensus opinion of that group.

Confirmation of Compliance

Compliance against certain measures will be the subject of spot checks or further enquires by peer reviewers when a peer review visit is undertaken. When self assessing against these measures a statement of confirmation of compliance contained within the relevant key evidence document will be sufficient.

1. Introduction to the Network Service User Partnership Group Measures

The Network Service User Partnership measures are based on national policy and guidelines but unlike many of the measures within the Manual for Cancer Services there is no NICE Improving Outcomes Guidance for User Involvement.

The measures are based on the evidence collated within the document: 'Service User Involvement in Cancer Care: Policy, Principles and Practice'. This was developed by Hugh Butcher. Hugh is a service user member of the National User Steering Group for NCPR; this document brings together previously agreed policy and practice.

1.1 Purpose and functions of the NSUPG

The Network Service User Partnership Group fulfils two interrelated functions within the cancer network:

- Contributing to continuous improvement of the patient and carer experience of cancer services. This function entails service users working in partnership with health professionals to provide advice and guidance to the Network Board on those experiences of cancer care known to be of concern to patients and carers, including:
  - patient-centred care;
  - supportive care;
  - transitional and self-managed care.
- Ensuring that authentic and effective service user involvement underpins work to improve the patient and carer experience of services across the network.

Because these two functions are so interrelated, they are often dealt with in tandem in many of the NSUPG measures, rather than being presented separately. This sometimes may make the measures seem rather 'wordy', but this was felt to be a small price to pay in order to underline their interdependence.

1.2 Using Peer Review Measures to assess how far, and help improve the quality of, how the NSUPG fulfills its functions.

The NSUPG measures have been devised to assure the quality of what the partnership group does to fulfill the functions outlined above, and to stimulate the group to continually improve its performance. The peer review measures for the NSUPG can be usefully grouped under four headings:

a) The first measure spells out the responsibility of the Network Board to establish a Network Service User Partnership Group. It should be noted that the name of the group is not important. If the group wishes to take another name this is acceptable as long as the functions of the group are met.

The remaining measures for the group are organised in three sections;

b) Those concerned with general activities necessarily undertaken by the Network Service User Partnership Group in order to achieve its functions.

c) Those concerned with guidance to the Network Board about implementation of policy and practice designed to optimize both the patient and carer experience, and service user involvement in the network.

d) Those concerned with guidance to the Network Board derived from the Network Service User Partnership Group strategy for achieving continuous improvements to user involvement and patient experience.

1.3 Principles underpinning the Measures

Although the measures may appear complex at first glance the principles are simple.

1) The first measure relates to whether the Network has established a properly constituted **Network Service User Partnership Group. (Measure 11-1A-301u)**

   This first measure can be addressed by answering the following questions:

   - Is there a single Network Service User Partnership Group for the Network?

   - What is the agreed membership of the NSUPG; does this agreed membership fulfill the (minimum) membership requirements set out by NCPR?

   - Does the NSUPG have agreed terms of reference; do these meet the (minimum) requirements for achieving compliance with the NCPR measures?

   - Has the agreed membership, and the Chair of the NSUPG, been agreed by the Chair of the Network Board?

2) The second set of measures relate to whether the Network Service User Partnership Group has **organised itself in such a way that enables it to carry out its business (Measure 11-1E-101 and 11-1E-102)**

This second set of measures can be addressed by answering the following questions:

   - When, and how often, does the group meet?

   - Does it have the members attending?

   - Do the key members regularly attend?

   - Is a record of the meeting made and circulated?

   - Is the activity of the group reviewed each year by the network?

   - Does the group have an annual report, annual work programme and a constitution?

3) The third set of measures is about network service user guidelines. (Measures 11-1E-103u – 11-1E-106u)

   This third set of measures can be addressed by answering the following questions:

   - Has the Network Service user partnership Group considered and endorsed the following four sets of Network guidelines:
     - Guidelines on User Involvement
     - Guidelines on Patient Centred care
     - Guidelines on Supportive care
     - Guidelines on Transitional and Self-managed care

   Also:
     - Have service users been involved in developing these guidelines?
     - Do they reflect the views of Service Users?
     - Has The Network Service User Partnership Group endorsed them?

The names of the above sets of guidelines are intended to describe **four types** of Network guidelines (Hugh Butcher's paper gives his personal view of what you might expect to find in the way of policy and practice under each heading; each Network will, of course, have its own view).

Note that it is not anticipated that Networks will have guidelines that go under these exact titles. Nevertheless networks are required to work to agreed guidelines that can be summarised and grouped under these general headings.

It is expected that as NSUPG's sets out to review, and then engage in further developing, their network's guidelines on supportive care, user involvement and so forth, they will find that in many cases (perhaps most cases) service users have been fully involved in working together with health professionals to formulate such guidelines. Not only that, but those service users may have been happy with them, and are pleased that they have been implemented within their Network. However it is important that the NSUPG, as a whole, has an opportunity to formally endorse such guidelines – it has been formally set up with the remit to do this on behalf of service users.

4) The fourth and final section of the measures is about the NSUPG having an **improvement strategy. (Measures 11-1E-107u – 11-1E-110u)**

   This fourth set of measures can be addressed by answering the following questions:

   - Do you have a strategy for achieving long term improvements to user involvement and the patient experience?

- Have you completed a mapping exercise to find out what currently exists?

- What do you think should exist?
  - have you developed a service specification - that is, written down what you think should be in place?

- What is missing? What are the gaps between what exists and what you think should exist?
  - In other words have you formulated a service needs assessment?

- What is your long term plan for improvements that will close these gaps?

- Write down what and how this will be done. This is the Strategy!

- Have you told other people what you are doing?

So, in brief, the key themes for the Network Service User Partnership Group to be addressed through Peer Review can be summarised as follows:

1.4 A summary of the key themes for the Network Service User Partnership Group

1.4.1. Structure & function of the service

This can be demonstrated through compliance to those measures relating to the establishment of Group – it's agreed membership, agreed terms of reference, secretarial/ administrative support, as well as those measures relating to the general activities of the group – that it meets at least quarterly, that attendance is recorded, that it has an agreed work-programme, that it has produced an annual report.

1.4.2. Co-ordination of care/patient pathways

The primary function of the Network Service User Partnership Group is to ensure consistency of patient-centred care, supportive care, transitional and self managed care and user involvement across the network.

This theme can be demonstrated through compliance to those measures relating to the endorsement of Network wide guidelines.

1.4.3. Patient Experience

The Network Service User Partnership Group, through the base line mapping exercise and service needs assessment, should be able to demonstrate how the network gains feedback from patients, how this is evaluated, and identify what improvements have been put in place for patients' and carers.

In addition, the group may demonstrate within their evidence other initiatives, over and above the existing measures, that give further assurance against this theme.

1.4.4. Clinical Outcomes/Indicators

The Network Service User Partnership Group through the baseline mapping exercise, service needs assessment and the implementation of the NSUPG strategy should demonstrate how the key priorities have been implemented across the Network.

In addition, the group may demonstrate within their evidence other initiatives, over and above the existing measures, that give further assurance against this theme.

2. Preparing for Peer Review

2.1 Introduction to part 2: Presenting the evidence for compliance with the NSUPG measures – via three key documents.

Peer Review requires that Cancer Networks provide evidence for their compliance with NSUPG measures through submission of three documents:

- An NSUPG Constitution. This document sets out the membership, terms of reference, overall strategy, administrative support, and general operating procedures of the NSUPG. While subject to annual review much of the content of this document will normally remain the same over a three to five year period. The NSUPG Strategy is generally drawn up for a similar period, although it should be checked for its continuing fitness for purpose on an annual basis.
- An Annual NSUPG Work Programme. This document sets out what the NSUPG will do over the next twelve months (in the context of the groups aims and objectives, as set out in its Strategy)
- An NSUPG Annual Report. This document records what has been achieved over the previous year, in the context of the goals set out in that year's work programme, plus a reflective commentary on the year's activities.

It is a requirement that each of these documents includes a Cover Sheet confirming that it has been formally agreed by those named as responsible for doing so in the relevant measure.

The next section reviews the three documents in turn: starting with some brief introductory points and the Cover Sheet, the contents of each document are presented in tabular form, with links to the relevant measure, along with some additional guidance for how to demonstrate compliance with the measures.

2.2 The Network Service User Partnership CONSTITUTION

2.2.1. Introduction to the Constitution of the NSUPG

The Constitution for the Partnership Group includes the Group's Membership, Terms of Reference, Strategy, and Service User Specification

2.2.2. Constitution – Agreement Cover Sheet

The Constitution has been agreed by:

Position: Chair of the Network Service User Partnership Group

Name:

Organisation:

Date Agreed:

Position: Chair of the Network Board

Name:

Organisation:

Date Agreed:

Network Partnership Group members agreed the constitution on:

Date Agreed:

Constitution Review Date:

2.2.3. Guidance on Contents, cross-referenced to NCPR Measures

Category	Link to Measures	Guidance for Compliance* (Please refer to full details of the measure)	Additional Guidance
Agreement /Cover Sheet		Include date that the terms of reference were agreed. Confirm agreement by Chair of the Network Board and Network Service User Partnership Group Chair.	Include date for the review of the terms of reference
Membership of the group	11-1A-301u	State names and role of each NSUPG member. There should be named administrative support to the group.	Useful to include details of group's required Quorum. Annual Report should include details of meeting frequency and actual attendance.
Terms of reference	11-1A-301u	Ensure the terms of reference include those points specified at 1and 2 of the Measure	
Service specification	11-1E-108u	Provide a copy of the service specification fully covering points a) and b) of the Measure	
Strategy	11-1E-110U	Details of a network wide NSUPG development plan. The plan should include the following: a list of which aspects of (i) Supportive Care, (ii) Patient Centred Care, (iii) Transitional and Self Managed Care, and (iv) User Involvement, are to be the subject to: • Base-Line Mapping, • Service Specification, and • Guideline Endorsement during each of the years covered by the strategy	

2.3 The Network Service User Partnership Group: WORK PROGRAMME

2.3.1. Introduction to the Work Programme of the NSUPG

The Work Programme for the Partnership Group is produced annually, and provides details of the work to be undertaken over the next twelve months that fulfills selected aspects of the group's three year Strategy i.e. the Work programme spells out which aspects of Baseline Mapping and Measures endorsement are to be the main focus of that particular year's activities.

It may not be possible to undertake the full range of work that will demonstrate compliance with all aspects all the NSUPG Measures in one year, so a selection has to be made; but within three years (the minimum period of time covered by a Group's strategy), all aspects of all measures will have been addressed during the course of completing three annual work programmes.

2.3.2. Constitution – Agreement Cover Sheet

The Work Programme has been agreed by:

Position: Chair of the Network Partnership Group

Name:

Organisation:

Date Agreed:

Position: Chair of the Network Board

Name:

Organisation:

Date Agreed:

Network Partnership Group members agreed the work programme on:

Date Agreed:

Work Programme Review Date:

2.3.3. Guidance on Contents, cross-referenced to NCPR Measures

Category	Link to Measures	Guidance for Compliance* (Please refer to full details of the measure)	Additional Guidance
Introduction			An overview of activity planned over the next 12 months, along with who will be involved/leading particular pieces of work, and where necessary specifying milestones.
Base-line mapping (of all, or selected aspects of the Partnership Group Guidelines)	11-1E-107u	The results of mapping selective aspects of the current Network's policies and practice with respect to a) service user involvement and b) the service users experience of care, agreed by the NSUPG, with results forwarded – with commentary- to Chair of Network Board	Useful to include details of group's required Quorum. Annual Report should include details of meeting frequency and actual attendance.
Service Needs Assessments (of all or selected aspects of the Partnership Group Guidelines)	11-1E-109u	The results of the Service Needs Assessment of a) service user involvement and b) the patient and carer experience of services within the network, agreed by the Chair of the NSUPG, with results forwarded – with commentary - to the Chair of the Network Board	
Endorsement of (selected aspects of) the Partnership Group's Guidelines	11-1E-103 to 11-1E-106	Guidelines endorsed by the NSUPG	

2.4 The Network Service User Partnership Group: ANNUAL REPORT

2.4.1. Introduction to the Annual Report of the NSUPG

The annual report describes, and provides a reflective commentary on, the previous year's activities of the NSUPG including: details on the frequency of its meetings, and who attended them; records that an annual review took place; logs the Baseline Mapping exercises completed, the guidelines reviewed and endorsed, and forth.

2.4.2. Annual Report – Agreement Cover Sheet

The Annual Report has been agreed by:

Position: Chair of the Network Partnership Group

Name:

Organisation:

Date Agreed:

Position: Chair of the Network Board

Name:

Organisation:

Date Agreed:

Network Partnership Group members agreed the Annual Report on:

Date Agreed:

Annual Report Review Date:

2.4.3. Guidance on Contents, cross-referenced to NCPR Measures

Category	Link to Measures	Guidance for Compliance* (Please refer to full details of the measure)	Additional Guidance
Introductions			Define period report relates to (i.e. state year covered). Include short narrative giving summary assessment of the group's achievements and challenges faced over the previous year. The group's annual report should showdetails of which pathways have been developed over the previous year, and which aspects of user involvement have been subject to improvement.
Frequency of meetings and record of attendance	11-1E-101u	Give attendance summaries for the meetings that have taken place over the previous year.	This summary should clearly demonstrate attendance by each named members.
Annual Review	11-1E-102u	Confirm the date that the Chair's annual review took place and who conducted the review.	The NSUPG should note the type and extent of service user engagement in the mapping work.
Baseline assessment	11-1E-107u	The NSUPG should provide a summary and commentary of the Baseline Mapping work completed during the previous year.	The NSUPG should note the type and extent of service user engagement in the mapping work.
Service Needs Assessments (of all or selected aspects of the Partnership Group Guidelines)	11-1E-109u	The NSUPG should provide a summary and commentary of the Service Needs Assessments completed during the previous year.	
Guideline Endorsement	11-1E-103u – 11-1E-106u	The NSUPG should provide a summary and commentary on Guideline Endorsement work that has been completed over the Year	The NSUPG should note the type and extent of service user engagement in the endorsment work

Category	Link to Measures	Guidance for Compliance* (Please refer to full details of the measure)	Additional Guidance
Other activity	The Annual report should record other work completed over the year	Depending on whether the Annual Report is describing activity in the first, second, or third year covered by the agreed NSUPG Strategy, so the content of this aspect of the Annual Report will vary. (e.g. A NSUPG Service User Specification (10-1E-108u) is likely to be drawn up in year one, as this will underpin much other work, in Years 1, 2 and 3; working up a a revised Strategy is likely to take place in Year 3).	
Distribution of information	11-1E-111u	Confirm the date that the information was distributed to other groups in the network.	

3. Glossary

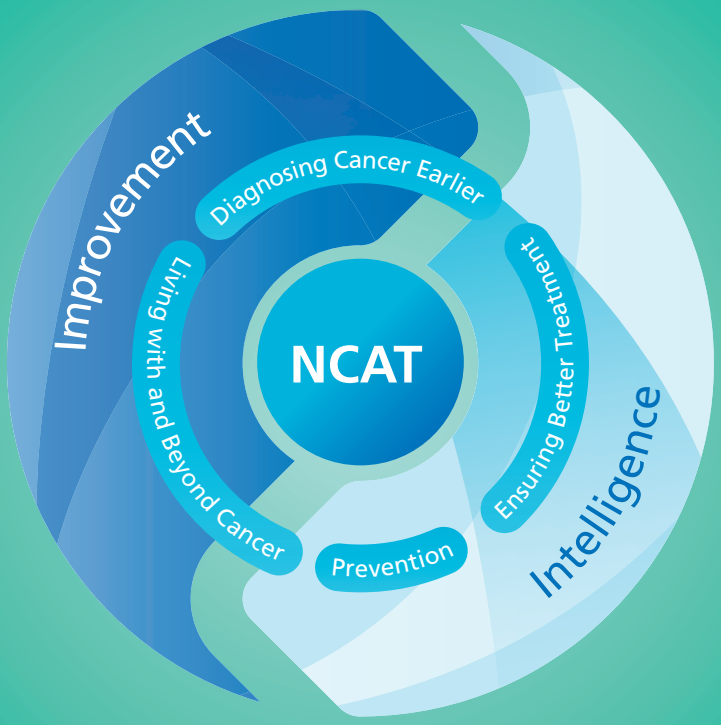
This Glossary defines terms and acronyms used in this document and in the 'Manual for Cancer Services: Network Service User Partnership Group Measures' (National Cancer Peer Review-National Cancer Action Team, 2011)

(Terms in *italics* are explained in another entry in the Glossary)

Term	Definition
Baseline mapping	A baseline map is an assessment of what is currently provided (i.e. a description of the 'current situation') e.g. a map of the type, availability and quality of local cancer information services.
Cancer Networks	Cancer Networks are organisations established to bring together health authorities, hospital trusts, primary care groups, and voluntary sector health providers to support heath service *commissioners* in delivering high quality, integrated, and equitable cancer care in a sub-regional population of two to three million people. There are about twenty eight Cancer Networks across England.
CQC	Care Quality Commission. The Care Quality Commission is the independent regulator of health and social care in England – whether provided by the NHS, local authorities, private companies, or voluntary organisations. It aims to make sure better care is provided for everyone - in hospitals, care homes and people's own homes.
Carer	Someone who provides support to a person with cancer – family, partner, friends – often (but not always) in an unpaid capacity.
Commissioner	A person, group, or organization that buys healthcare services for the local population.
Guidelines	Written recommendations on how things should be done (see also I.O.Gs)
Holistic Care	A comprehensive system of care that considers the physical, emotional, social, economic, and spiritual needs of the patient 'in the round'.
I.O.G.	Improving Outcome Guidance. A *NICE* approved IOG is produced nationally for each cancer type and includes guidance on, amongst other things: • How patients should be referred (referral pathways), • Protocols for treatment and standards of care • Network wide mapping of services and finding out where barriers exist (gap analysis) • Service configuration i.e. how services should be provided in line with national policy and guidelines • Network wide audit of services
Key Worker	A cancer patient's Key Worker is someone who takes on the function of coordinating the patient's care, ensuring the patient knows who to access for information, advice, and specialist support. The Key Worker can be any healthcare professional who plays a significant role with the patient but often is the Clinical Nurse Specialist in the hospital.

Term	Definition
Network Board	The Management Board of a *Cancer Network*
NICE	The National Institute for Health and Clinical Excellence is a *QUANGO* responsible for providing national guidance on promoting good health and treating ill health.
NSSG	Network Site Specific Group. ***Cancer Networks*** set up multi-disciplinary sub groups (which include service users) to address cancer services for specific cancer types (e.g. Breast, Urology). Their roles include monitoring service quality, aspects of service improvement and redesign, research, and so forth.
NSUPG	Network Service User Partnership Group. *Cancer Networks* have established User Partnership Groups made up of patients and carers and local health and social care professionals to enable *service users* to influence the development, delivery and evaluation of cancer services.
Patient-Centred Care	Care that is respectful of and responsive to individual patient preferences, needs, and values, thus ensuring that patient values guide all clinical and care decisions.
Pathway	The path that a patient follows from first contact with a health professional to talk about symptoms, through to tests, diagnosis, treatment and supportive care, aftercare/follow-up, survivorship. Reference will be found to sub-pathways e.g. Clinical Pathway, Care Pathway, and Information Pathway and so on.
Peer Review	A process used for checking the work performed by one's equals (peers) to ensure it meets specific criteria.
QUANGO	Quasi Non-Governmental Organization. An agency that is financed by government but acts independently of it.
Self-managed care	Entails patients (with their carers) becoming active and effective partners in their own health care. It generally requires adequate support and facilitation from health and social service providers, health educators and health policy planners.
Service User Involvement	The process of active engagement of patients and carers in determining how cancer services are planned, commissioned, delivered and evaluated.
Service Specification	A service specification sets out what should be provided by a particular service (parameters and detailed requirements).
Service Needs Assessment	An assessment of what needs to change/improve if the delivery of a service is to fully conform to the *Service Specification*. (In service improvement exercises it is based on the difference (the gap) that is seen to exist between the *service specification* and the *baseline map*).

Term	Definition
Service Users	General: Cancer patients and their carers ('carers' includes family members and friends). More specifically: cancer patients and their carers ('carers' include family and friends) who are involved in working with health service professionals to improve the patients experience of cancer care services'.
Strategy	A plan of action to reach your goal.
Supportive Care	Supportive care is care that helps the patient and their family to cope with cancer and its treatment. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It emphasises: • Provision of accessible, reliable, reader-friendly information • The support of a Key worker • Support for family and carers • Access to other specialist support: emotional and psycho-social support, rehabilitation opportunities, financial and employment advice, community self-help, and so forth
Transitional Care	Coordination and continuity of health care as patients transfer between different locations (e.g. hospital care to community care) or different levels of care (A&E to Urology Unit) within the same, or other geographical locations.
UPG	User Partnership Group. A group made up of patients and carers, and local health and social care professionals, to enable *service users* to influence the development, delivery and evaluation of cancer services. UPGs have been established in many healthcare organizations e.g. Hospital Trusts, Hospices and *Cancer Networks*. See also *NSUPG.*



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