Specialist Palliative Care
Findings from 2012/2013 Self-Assessment
April 2013
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Introduction

The introduction of the SPC Peer Review Measures for 2012/13 generated a considerable level of concern and comment. In particular the definition of a SPC MDT and the apparent misunderstanding of typical SPC practice were especially contentious. The response of National Cancer Peer Review (NCPR) to this feedback included a revised approach to the Self-Assessment process, advice not to change current practice just to fit with the current measures and the provision of further support to Cancer Networks and individual providers. This support was provided by an independent, experienced SPC professional and broadly consisted of an allocated day per network, where required, as well as additional consultations with individual providers.

The purpose of the visits was to:

- Bring together the relevant constituents to clarify the peer review requirements and establish a shared understanding.
- Identify an agreed way forward for progressing the 2012/13 peer review schedule.
- Support the specialist palliative care providers, particularly those within the voluntary hospice sector, to agree an acceptable definition of the role and function of the MDT.
- Highlight the benefits and advantages of participation in the National Peer Review process.

Voluntary hospice providers were included in the measures for the first time and the allocated support provided the opportunity for further exploration of the implications for their engagement in the Peer Review process. A total of 29 visits were made across 22 Networks in England with a further five meetings with key individuals.

The Network visits included attendance at Network SPCG meetings, facilitated workshops and discussion groups, presentations and one to one discussions. While attendance was variable in terms of numbers and representation there were many occasions of insightful and considered discussion and debate, resulting in a wide exchange of views, commentary and ideas.

The following report is intended to provide feedback on the above and make recommendations on the way forward with SPC Peer Review. Its main focus is on the Service Provider Organisation and SPCMDT measures. Evaluation of the Network Board and Network SPCG Measures are not included here given the current situation of significant change and role of the Networks within the new NHS reforms. It is already envisaged that a new national service specification will be developed by the National Commissioning Board which will inform any further changes in Peer Review Measures therefore it is intended that the recommendations of this report will provide an appropriate holding position for 2013/14.
As previously agreed there is no quality judgement applied to the findings and all respondents are anonymous with no identification of individual Networks or providers. The report and recommendations take account of:

- Emerging themes from Self-Assessment narrative, workshops and discussions
- Identification of the core aims of SPC services
- Characteristics of SPC practice
- The impact of new NHS commissioning arrangements and requirements
- The shift of SPC from cancer to a more generic framework
- The position and significance of SPC in the End of Life Care Pathway
- The appointment of the National Director for End of Life Care as a point of reference for any future development of national service specifications, operational frameworks, standards or guidelines.

It is important to acknowledge that there was little or no resistance expressed towards the principle of Peer Review for SPC. The majority of clinicians supported the concept of service review and welcomed the opportunity to demonstrate excellence in practice. The Peer Review process was also generally regarded as a constructive mechanism for service development and an important lever in prioritising resource allocation.

There emerged many examples of creative and inspiring practice, demonstrating a commitment and enthusiasm for the specialty which frequently overcame the potential obstacles of cross sector, cross boundary working.
Key Findings

The source of the findings detailed below is taken from the self-assessment reports, the accompanying narrative and the content of discussion and feedback from the 29 site visits.

This data presents a national overview of the findings from the Specialist Palliative Care Review Programme in 12/13.

- A total of 282 teams were included in the assessment for this period, comprising of 171 Trust MDTs and 111 hospice MDTs.
- 208 trusts chose just to complete a Self-assessment (SA), whilst 34 teams chose to complete both a self-assessment and an internal validation (IV).
- 40 (14%) teams did not complete an assessment (37 hospices and 3 Trusts).

<table>
<thead>
<tr>
<th>Number of teams</th>
<th>Number Reviewed</th>
<th>SA</th>
<th>IV</th>
<th>% compliance (Median)</th>
<th>% compliance (Mean)</th>
<th>IR</th>
<th>SC</th>
</tr>
</thead>
<tbody>
<tr>
<td>282</td>
<td>242</td>
<td>208</td>
<td>34</td>
<td>77%</td>
<td>75%</td>
<td>5 (2%)</td>
<td>15 (5%)</td>
</tr>
</tbody>
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There were a number of high performing teams in 2012/2013:
- 11 teams (4%) achieved 100% compliance
- 126 teams (45%) achieved ≥ 80% compliance

However, there were also a small number of low performing teams:
- 11 teams (4%) had compliance of 50% or under
Configuration of services
Analysis of the Self-Assessment returns provided overwhelming evidence of a multi-professional team approach to patient management across all SPC services in England. All the responses received pointed to the presence of a SPC MDT in all patient settings. Descriptions of the teams illuminated some differences in team personnel and operational arrangements across the different clinical settings.

Hospital settings are typically made up of a core membership of Palliative Care CNS’s and Consultants in Palliative Medicine. The availability of other professionals is variable and often dependent on the willing engagement of interested individuals rather than contracted, employed staff. There are a significant number of services claiming a lack of resources and understaffing as potentially compromising service delivery and successful Peer Review compliance. These staff issues were related in the main to Consultants and CNS’s.

Community services also appeared to have a limited core membership representation, being in the majority of cases CNS led services. The regular, consistent involvement of Palliative Care Consultants in the community appears to be more variable and generally more limited. The accompanying narrative indicates this to be a matter of essential clinical prioritising due to limited medical time and availability and not a reflection on need or importance. Where there is AHP and/or social worker involved this appears, in most cases, to be provided and funded by a local voluntary hospice.

Inpatient units were consistently reported as having a broad and inclusive membership of the SPC MDT. In the majority of units there is usually AHP and social work representation on a regular basis, with many reporting chaplaincy and psychology as being regularly represented. A recurring theme for inpatient units was the requirement for a CNS to be members of the MDT. Most units appear not to attach the title CNS to senior nurses on the inpatient wards. In reality the inclusion of senior ward nurses is considered the most relevant and appropriate nurse representation.

Day Care and Outpatient Clinics also appeared to have less multi professional representation but the level of clinicians/practitioners involved appears to reflect the primary purpose of the activity rather than a limit of resources. Outpatient clinics usually have consultant and CNS present, while Day Care often sees AHP’s included as part of the core team membership.
The Peer Review Measures require there to be a “formal SPC MDT specified and constrained according to the measures” The following “ground rules” were specified to enable a rational network to exist and to function without destructive or uncontrolled practice:

- All SPC in-patient services in the network should be covered by one SPC MDT or other and any one SPC MDT should be the only one for a given geographic area.
- All out-patient/community care services should be associated with one or other SPC MDT and any one SPC MDT should be the only one for a given geographic area.
- All consultants in palliative medicine in the network should be core members of a SPC MDT.

The discussion and feedback at the on-site visits together with the self-assessment returns indicate this requirement of a formal SPC MDT, to have created the most controversy and unrest. The description of the SPC MDT as given in the self-assessment reports shows there is a clear difference of interpretation attached to this measure. Descriptions demonstrate the MDT is either considered to be a local (i.e. individual service or ward) MDT or locality (also referred to as Co-ordinated or super) MDT. This is where a multi-professional team has been configured from across a discreet geographical area to consider the most complex patients who meet previously agreed referral criteria. Establishing a locality SPC MDT, into which other teams refer, appears not to be the usual nor, in many cases, the preferred, way of working.

Having carefully scrutinised the Self-assessments the following picture has emerged of current practice and typical service configuration.

**Specialist Palliative Care Multi-Disciplinary Team**

In twelve of the Networks there was no evidence of Locality SPC MDTs. The descriptions given in the self-assessment reports of the SPC MDT indicated that all organisations in these 12 Networks had self-assessed against a local (individual) service or ward SPC MDT. Only one Network appeared to have achieved a locality wide approach across all organisations.

All remaining networks demonstrated a mix of service configuration, with some geographical sections of the Network adopting a locality model and others retaining a local (individual) service approach. Of the existing locality teams the majority had been established in response to the Peer Review requirements. Most had been in existence for only a few months being, in most cases formed in the latter part of 2012.

Two networks had chosen to adopt this model prior to the publication of the Peer Review Measures. In one case this was a response to the presence of 3 small hospices, geographically close together, where it was considered an expedient method of sharing resources more effectively.
There was some difference of opinion as to the usefulness of the locality SPC MDT model. While formal evaluation hadn’t been undertaken in the majority of cases, mainly due to the short duration they had been in existence, anecdotal evidence indicated that the locality SPC MDT was useful in:

- Promoting increased integration of services
- Improved understanding of the function of the various provider within a given area
- Providing an educational opportunity
- Sharing of expertise and knowledge
- Review of complex patients
- Wider MDT opinion/clinical challenge
- Improved team working
- Support for difficult decisions
- Enabled regular AHP involvement

Feedback was also received on the challenges of adopting this model of SPC MDT which included:

- Inconsistent interpretation of the referral criteria resulting in inappropriate patient referral
- Reluctance to refer – benefits not readily understood resulting in low referral numbers
- Unconvinced of need and usefulness
- Process of updating colleagues on the outcomes of the meeting – inadequate IT and administration systems
- Practical organisational details – who makes decision to cancel etc.
- Staff time and the additional workload considered burdensome
- Effort outweighed the benefit

Summary

- All services exhibit a strong commitment to a multi-professional approach to care.
- There is the existence of a SPC MDT in all units and across all services.
- The self-assessment reports demonstrate that there are two distinct interpretations of the SPC MDT.
- The majority of submitted returns are from organisations who have measured themselves against a definition of a SPC MDT which relates to a local, single service.
- The majority of Locality SPC MDTs have been established in response to the Peer review Requirements
- Most Locality SPC MDTs have been in existence for a short period of time only and have yet to be evaluated
Additional Significant Commentary and Feedback

Detailed below are the most common recurring themes on service configuration.

- There was frequent reference to the relationship between the SPC Measures and the Cancer Site Specific Measures and what was considered to be an unhelpful association.
- It was widely felt that insufficient recognition had been given to the unique differences pertaining to SPC practice and that SPC requirements were being driven by the cancer agenda.
- Observation was made on the fundamental difference between the primary purpose of the Cancer MDT and the SPC MDT. The former is considered to be the mechanism for patient treatment/management decision making. For SPC the management decision making process is delivered, in all cases, by the SPC MDT in the place where the patient is residing i.e. a local MDT.
- The primary benefit of the Locality SPC MDT emerged as enhancing coordination, communication and integration and providing opportunities for education and development.
- In all services the local, individual SPC MDT remained the primary focus of clinical decision making.
- The Locality SPC MDT’s have no direct influence on patient management.
- The Locality SPC MDT is seen as an additional meeting for which there is little time to attend.
- Concern was expressed that only a minority of patients would be referred for discussion at the Locality SPC MDT. If this remained the Peer Review criteria for the SPC MDT then there would be no measure of the majority of SPC’s area of practice and patient care.

Contentious Measures

Some individual requirements frequently gave rise to frustration, particularly where the requirement was felt to be unrealistic or unnecessary. The issue of contentious measures has been recognised and acknowledged by the National Peer Review Team with an agreement for amendment or removal. The following Measures were the ones most often mentioned in this category.

- 12-3R-113 Attendance at Advanced Communications National Training Programme

There is wide agreement among SPC providers as to the importance of communication skills training for all members of the core multi professional team. There were significant numbers who expressed the view that insistence on the completion of the Advanced Communication Skills training as the only valid evidence of compliance was impractical and unnecessary. The local availability and waiting times to access the course proved problematic in many instances. In addition it was acknowledged that the starting point of different staff varied considerably and it was felt by many that staff should be able to participate in the training most relevant to their needs.
**12-3R-125 The SPCMDT should produce a report at least annually on clinical trials, for discussion with the NSPCG.**

It is implied in this measure that patient participation in clinical trials is a regular and necessary activity within SPC. Feedback indicated that this is at odds with the majority of current local practice. In the cases where non-compliance was evident the most common reasons given were lack of funding and the viability or practicality of conducting clinical trials in a local/district setting. In the instances where the measure was met the accompanying narrative and reports usually identified the lead clinician but often indicated the absence of any current or recent trials.

**12-3R-101 The core team specific to specialist palliative care should include:- two consultants in palliative medicine**

This requirement generated a considerable amount of discussion. The issues raised varied depending on which definition of a SPC MDT was being used. For the *Locality* SPC MDT there was concern regarding availability of consultant resource. The view was expressed that the current number of consultants available severely compromised the ability to comply with this measure. For the *individual service* SPC MDT the view was expressed that the presence of two consultants was unnecessary at each MDT. However it must be stressed that the value of peer support, the avoidance of isolation and the prevention of potential maverick practitioners were all seen as important factors by an overwhelming majority. Several examples were given, both during site visit discussion and documented in the Self-assessment narrative, of the means by which units and Networks have addressed these potential risks.

These three measures constitute those most frequently referred to by the majority as causing difficulty and frustration. Predictably opinion was given on several other measures but there was an insufficient consensus to justify inclusion here.

Additional measures which raised concerns were **12-3R-121 SPC MDT Agreement to Network 24hr Telephone Advice Service specification** and **12-3R-122 SPC MDT Agreement to 7 Day Visiting Service Specification.** Both of these appear to be fully endorsed in their aspiration but create an anxiety over compliance in the absence of the funding required for their delivery.
Emerging Themes

Several themes of a more general nature frequently recurred which are worthy of documenting as a means of informing any future development of the SPC Peer Review process. These include:

- **I.T. Requirements.**
  This issue is raised frequently in the self-assessment reports. The lack of IT capacity and resource is reported as a considerable hindrance to effective practice and communication. The extent to which there are shared electronic systems and recognised patient data bases in place is variable. An added dimension is the level of inclusion of voluntary sector providers in NHS systems. This issue appears particularly pertinent to those organisations engaged in *Locality* MDT’s. Concern was expressed that the governance issues pertaining to shared systems, shared patient records and permission for sharing clinical/patient information remained unresolved in many cases. Where organisations had adopted video conferencing or similar techniques for holding multi-organisation/cross sector MDT’s the funding of the equipment and identifying a responsible lead officer proved problematic. It was strongly expressed, especially by the voluntary hospices’ that it is unreasonable to create regulatory requirements where the means of compliance is outside the control of the service provider.

- **Lack of Focus on Outcomes.**
  It was generally reported in the site-visit discussions and workshops that the approach to Peer Review was very *process* orientated and would benefit from a more outcome based focus. While there was a high level of consensus on the aims of the measures there was frequent disagreement about the methodology applied to the evidence. A frequent example was the requirement for two consultants in every SPC MDT. There was widespread agreement that safe, supported consultant practice was essential but there were a variety of legitimate ways of achieving this and that reliance on the presence of two consultants was unrealistic. Giving greater precedence to the required outcome and placing less emphasis on the process generally was a frequent request.

- **Cancer MDT Association and References**
  It is a widely (and strongly) held view that the Peer Review understanding of the SPC MDT is defined by the structures within Cancer and the important differences between the two specialities is not sufficiently recognised. It is understood that the decision making process for cancer management requires the input of a variety of medical/clinical disciplines in order to follow the relevant diagnostic and treatment pathway. People requiring specialist palliative care are usually supported by a multi-professional team of the same speciality rather than a multi-disciplinary team. Their role is to manage a more rapidly changing patient scenario requiring frequent, regular review.
• **Workforce Issues**
There was some reference to the lack of senior clinical resources which was compromising the ability to comply with some of the measures. It appears that the configuration of services in some areas is determined by the resources available. Where long term vacancies existed alternative service management arrangements were described.

• **Core Principles for Specialist Palliative Care Services**
Included in the feedback from site visits and individual discussions was the view that the SPC Peer Review Measures would benefit from a clearer statement of the core principles of specialist palliative care services. It has been suggested that these may be defined as:

- Patient care to be agreed through a multi-professional approach, including team discussion prior to decision making.
- An integrated approach to care and a robust system of communication between care settings.
- Provision of an equitable out of hours service.

An important function of specialist palliative care which is distinct from the generalist practitioner is the management of complexity. This provides SPC with an essential leadership role across all primary and secondary care settings.

• **Changes to Role of the Network**
The new NHS reforms figured largely in the feedback. There were many expressions of concern over the ability of the network specialist palliative care groups to continue their acquired level locality wide engagement without the support currently provided by the network staff. For many respondents the ability to continue with locality SPC MDT’s and other joint activities was a serious concern.
Recommendations

1. Contentious Measures
It has been agreed that the measures causing most contention will be removed for the next round of assessment. Feedback identified the following in the category of most contentious:

- **12-3R-113 Attendance at Advanced Communications Training Programme**
  There is wide agreement among SPC providers as to the importance of communication skills training for all members of the core multi professional team. There were significant numbers who expressed the view that insistence on the completion of the Advanced Communication Skills training as the only valid evidence of compliance was impractical and unnecessary. The local availability and waiting times to access the course proved problematic in many instances. In addition it was acknowledged that the starting point of different staff varied considerably and it was felt by many that staff should be able to participate in the training most relevant to their needs. It is understood that evidence of compliance needs to be objective and unambiguous and a single “one size fits all” approach can create a more reliable measure of evidence. However it is also important that the measures and the evidence are realistic, relevant and achievable.
  Removal or increased flexibility regarding this measure is recommended to include other validated communication skills courses or the production of evidence of the skill level of the practitioner members of the SPCMDT.

- **12-3R-125 The SPCMDT should produce a report at least annually on clinical trials, for discussion with the NSPCG.**
  It is implied in this measure that patient participation in clinical trials is a regular and necessary activity within SPC. Feedback indicated that this is at odds with the majority of current local practice. In the cases where non-compliance was evident the most common reasons given were lack of funding and querying of viability in a local/district setting. In the instances where the measure was met the accompanying narrative and reports identified the lead clinician but often indicated the absence of any current or recent trials. **It is recommended that this measure be removed and further consideration given to a more appropriate means of ensuring ongoing developments and research in SPC.**

- **12-3R-101 The core team specific to specialist palliative care should include:- two consultants in palliative medicine.**
  This measure has proved unnecessary in the local SPC MDT’s and impractical in some locality SPC MDT’s. The feedback indicated a clear understanding and acceptance of the need to minimise the potential for unsafe, unsupported or maverick consultant practice. A genuine concern was expressed of failing to meet the measure while not believing there to be any real risk to patient care.
There were many examples given of how the integrity of consultant practice was maintained in circumstances where the consistent presence of two consultants was not achievable.  

*It is recommended that the submission of evidence of safe practice be permissible in the event of the availability of only one consultant in the SPC MDT*

- **12-3R-121 SPC MDT Agreement to Network 24hr Telephone Advice Service Specification and 12-3R-122 SPC MDT Agreement to 7 Day Visiting Service Specification**

While there was no criticism of the aspiration of these measures in reality there were many instances of lack of delivery. Invariably resources were the limiting factor. Failure to comply was again a real concern.  

*It is strongly recommended that these measures be retained but are reviewed following the Palliative Care Funding Review and the introduction of any new CCG requirements.*

### 2. Specialist Palliative Care Multi-disciplinary Team

The definition and function of the SPC MDT is the most critical issue in the SPC Peer Review Measures and undoubtedly at the heart of the expressions of concern and frustration received. SPC MDT’s are a fixture of all SPC services. Historically shared characteristics of SPC are the emphasis on holistic care and the importance of multi-professional decision making. The usual SPC MDT has a local or single service focus. In response to the SPC Peer Review Measures some palliative care services developed a new, additional locality SPC MDT which focused on the co-ordination and integration of care across an agreed geographical area. The self-assessment reports indicate that organisations have measured themselves against one or other of these models of a SPC MDT. All SPC services have a well-established local SPC MDT while a significant minority have also adopted the additional locality SPC MDT into which their local SPC MDT’s refer.  

*It is recommended that for 2013/14 teams continue to measure against the same teams as 2012/13. In the event of changes to locality SPC MDT’s as a consequence of reduced Network support, teams may apply the local team definition.*

### 3. Specialist Palliative Care Core Aims

The feedback indicated that the SPC Peer Review Measures would benefit from a clearer statement of the core aims of specialist palliative care services. These may be defined as:

- The management of patient care to be agreed through a multi-professional approach, including team discussion prior to decision making.
- An integrated approach to care and a robust system of communication between care settings
- Provision of an equitable out of hours service
It has been noted that an important function of specialist palliative care, distinct from that of the generalist practitioner is the management of complexity. This complexity has been described as being defined not just by the patient’s level of need but on the skills and confidence of the non-specialist palliative care practitioner. This provides SPC with an essential leadership role across all primary and secondary care settings. It would be beneficial to explicitly acknowledge these aims within the background information included in the Peer Review Manual. This would generate greater confidence in the SPC measures as being informed by the commonly shared principles and practice within the speciality rather than being driven by the structures within cancer.

*It is recommended that these aims (or as agreed by the Advisory Committee) provide the context for the SPC Peer Review and are included in the Introduction to the specialist palliative care measures.*

4. **NHS Reforms**

The current programme for SPC Peer Review is heavily associated with the structure of Cancer Networks. The role, function and organisation of the Networks are radically altered in the latest NHS reforms. The NHS Commissioning Board and the newly constituted Clinical Commissioning Groups will have considerable influence on the design and delivery of services. It will be essential that all Service Specifications and Quality Measures meet the requirements of any new funding or commissioning bodies. It is expected that the outcome of the Palliative Care Funding Review currently being piloted will impact on the development of National Service Specifications or Practice Frameworks. It would be expedient, therefore, to await these expected developments before making too many changes to the current SPC Measures.

*It is recommended to support the suggested “light touch” approach to 2013/2014 Peer Review process to allow time to align any revised measures with the new NHS framework.*

5. **The Position of the Voluntary Hospices**

The majority of the voluntary hospices have participated in the Peer Review Process and submitted completed the required Self-Assessments and Reports. There has, however been widespread concern expressed regarding the additional burden that participation in Peer Review creates. It was evident that many logistical barriers compounded the problems. These included lack of resources, lack of capacity and lack of integrated I.T. systems. In addition the ratio of cost to benefit was found wanting. It is clear from the self-assessment reports that the majority of hospices have extensive engagement in their locality, with partnership working and shared clinical posts being a frequent feature. Concerns were evident about compliance failure and the consequent potential for serious reputational risk. This could result in a misrepresentation and misunderstanding of the quality of hospice care.
It may be reasonable to consider a specifically designed incremental approach for hospice participation in SPC Peer Review which reflects the proportionate status of their statutory engagement.

*It is recommended to continue to encourage hospice participation in the SPC Peer Review Process but to acknowledge their limitations with regard to the required level of resource and capacity. Opportunity should be provided to demonstrate the impact of logistical or resource restrictions on compliance with the measures.*

6. **New Points of Reference for Specialist Palliative care**

The appointment of a new National Director for End of Life Care has provided an opportunity to establish Specialist Palliative Care in a broader context with reduced formal association with cancer specific services. Among other things this important new palliative care point of reference will strengthen the interface with commissioning and exert influence on the development of new national service specifications. It provides the potential to develop appropriate SPC Peer Review Measures which:

- Can be used to support commissioning decisions
- Will be accurately based on SPC practice in England
- Can provide realistic benchmarking
- Will drive up standards
- Will be developed in the context of a nationally agreed service specification and definitions of practice.
- Strengthen the position and status of SPC as an integral component of End of Life care
- Support the position of SPC within NICE Guidance

The National Director for End of Life Care will be an important influence on the application of the findings of the Palliative Care Funding Review which will in turn significantly impact on the new commissioning arrangements for palliative care services. *It is recommended that the new department of Improving Quality works closely with the National Director for End of Life Care in producing future SPC Peer Review Measures, particularly in relation to the development of a new National Service Specification.*
Focus on Outcomes
It was regularly remarked upon that the SPC peer review measures were geared towards measuring process and would benefit from an increased emphasis on desired outcomes. There was a general understanding shown that by their very nature measures need to be objective, measurable, verifiable and unambiguous.

This can result in measures being or appearing to be, prescriptive and inflexible. As previously stated there are instances where there is agreement with the overall aim of a measure but the given process for compliance is difficult to achieve. His inevitably results in feelings of tension and frustration which creating an exaggerated and unnecessary hostility towards the Peer Review generally. Moving, where possible, to a more outcome focused approach would more aptly serve the speciality of palliative care and induce greater confidence and credibility in the SPC Peer Review process. It is recommended that when the SPC Peer Review Measures are more fully revised that efforts are made to adopt an outcome focused approach to their design and development.