Commissioner Events Summary Report June 2015

MAXIMISING CPES DATA TO DRIVE IMPROVEMENT

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Introduction

In 2014 NHS England (NHSE), NHS Improving Quality (NHSIQ) and Macmillan Cancer Support convened a national learning event with people affected by cancer, Trust leaders, senior clinicians, and patient experience leads which aimed to:

1. explore how best to present and act on data from the Cancer Patient Experience Survey (CPES) in order to improve patient experience
2. inform the content, presentation and publication of the 2014/15 CPES in a manner which would benefit key stakeholders who would be influenced by the findings.

Following on from the findings of the 2014 national learning event (see appendix 1), NHSIQ and Macmillan Cancer Support, in partnership with NHSE, held a further series of workshops aimed at commissioners and commissioning bodies.

The purpose of these workshops was to support commissioners and lead local improvements in patient experience. This included analysing local performance data derived from the CPES results, and to ensure that commissioners felt confident in using this analysis to respond to local variation and embed improvements that reflect the needs and complexity of the local context in which patients access services.

The end goal of these workshops was to provide a baseline understanding of the gap between where commissioners currently are with their plans (with regard to patient experience) and where they want to be, via the use of a more robust interpretation of local performance data.

Attendees included patients, providers, clinicians, as well as representatives from Commissioning Support Units (CSUs), Clinical Commissioning Groups (CCGs), and strategic clinical networks (SCNs). The workshops were held in conjunction with the Strategic Clinical Networks and took place across four areas: London; the South West of England; the East of England; and Yorkshire and Humber, between December 2014 and March 2015.

Each workshop focused on answering the following four questions:

1. Which information in the CPES dataset is most important and valuable to commissioners and commissioning bodies?
2. How can CPES results be best presented and used by commissioners to drive improvements?
3. How can CPES data align with other patient experience outcomes data across pathways?
4. What else do commissioners need to assist them using this data ie guidance, etc?

In addition, the workshops identified examples of good practice, as well as the challenges that were preventing commissioners and commissioning bodies from using CPES data to drive local improvements.

Summary of findings

The following summary includes an overview of the key findings from the workshops. These have been separated into two sections i) Data collection and presentation of CPES findings and ii) Driving improvements in patient experience. The summary concludes with a set of recommendations for action that commissioners can use to maximise the inclusion of CPES data in driving local improvements in patient experience.

This summary also provides a useful overview of the different ways in which CPES data is being used by commissioners to drive change, as well as identifying the opportunities to use CPES data more effectively in the future. Throughout the workshops, there was a consensus that CPES data plays an important role in driving improvements in patient experience at a local level, bringing together providers and commissioners. A number of questions, however, were raised in relation to how CPES data can be practically applied to support the following: application locally of national accountability frameworks; national strategies and priorities to improve patient experience; and the role of patients and the public in driving improvements.

Key themes that emerged overall include:
- significant variation in local interpretation of what ‘good patient experience’ means
- a poor articulation of what good patient experience means results in sometimes contradictory approaches to the analysis of the root causes of problems and the viability of potential solutions
- good presentation of local performance data provides opportunities to measure like for like, resulting in more sustainable and locally compatible ideas for improvement in patient experience.

i) Data and presentation of CPES findings

Key Questions:

Which information in the CPES dataset is most important and valuable to commissioners?

What else commissioners need to assist them using this data?

- The commissioners who use the CPES data regard it as a useful and well-established tool to support improvements in patient experience.

Commissioners and commissioning bodies were clear and constructive about which parts of CPES were most valuable to them, as well as how CPES data is used at a local level, highlighting the strengths of the CPES dataset. Commissioners agreed about the value of CPES in capturing broad information from patients. On this basis, a number of attendees thought that local CPES findings had been instrumental in initiating more conversations about improving patient experience between commissioners and providers. Workshop discussions also focused on the gaps and limits of CPES data and a range of suggestions were made about how to overcome these (see below), with an increased focus on local collaboration, and examples provided of what had worked well.

- Commissioners and commissioning bodies were in agreement across all four workshops about the importance of collecting cancer specific data in a systematic way. However, while commissioners welcomed the systematic approach to collecting data from patients, they were also eager for more data on patient experience that was not single disease focused. Commissioners acknowledged the value of CPES in making comparisons (both annually and locally, between Trusts) and emphasised that comparative data had led to greater attention of patient experience at a Board level.
- A number of commissioners mentioned the value of specific CPES data on the following: access to a GP; access to a CNS; and the experience of patients between settings in care along the pathway. Overall, commissioners were more likely to prioritise CPES data on areas that they felt could be improved directly through the commissioning process. Examples cited included access to healthcare professionals and making improvements to the time spent with patients at key points in cancer. All workshop groups discussed the nature and role of commissioners, particularly the method and practice of commissioning improvement.
- Commissioners felt that the current format of CPES data for CCGs is too complex. A number of participants commented on the need for greater granularity specifically within the CCG reporting tables and access to the raw CPES datasets.
- A recurring theme across all the events was the long delay between when CPES data is collected and when the results are published. It was felt that the lag between collection and reporting did not allow CPES to fully capture the efforts and improvements by Trusts and had led to a lack of confidence in the published data. Furthermore commissioners felt that the subsequent round of data collection took place in too short a window to effectively measure improvement over time. As a result, it was felt that Trusts were relying on outdated findings which, in some areas, had led to the inefficient use of resources, or providers and commissioners conducting their own “real time” data collection in order to capture a more accurate and current picture of patient experience.
- Mixed views were expressed about the length of the survey. Many commissioners agreed that the survey was too long, whilst others called for improvements to be made which would reflect a more accurate picture of wider health services (ie primary and community). Many attendees also felt that the cancer pathway

had changed significantly since the development of the survey and that changes to reflect this change were long overdue. The arguments behind this were as follows:
  - The survey takes too long for patients to complete, with one patient commenting that it took her three days to finish it.
  - The length of the survey means that analysing the data is equally complex and time consuming, making it difficult to identify key areas for local improvements or analyse key findings in depth.
- Understanding and awareness of the free text data was mixed across the groups, with half of the respondents unaware of its existence. Those who were aware of the data felt that it was difficult to use as it required deeper analysis to pull out trends, which they relied on Trusts to do for them. However, when this analysis was done, commissioners felt that the qualitative findings were valuable when read alongside the quantitative data. It was felt that this data should be made more freely available to commissioners, highlighting top quotes or trends. Attendees from patient groups were keen to provide support in analysing and presenting this data and working locally to develop the capabilities of local networks to generate qualitative data on patient experience (Healthwatch and Public Involvement Networks were highlighted as an example).
- While some commissioners found the RAG ratings useful to help them understand performance, many more felt that they could be easily misinterpreted and a national benchmark or score could be better used to drive improvements. Suggestions for improving RAG ratings are in section two below on 'driving improvements in patient experience'.

Challenges

1. **Timing:** Commissioners felt that the lag of a year in reporting meant that CPES data did not truly reflect current service and some felt that this had led to a misalignment between the direction of NHS resources aimed at improvements and the experiences of patients.
2. **Sampling and variation:** A theme that emerged at most of the events was the lack of data from traditionally excluded groups, for example; Black and Minority Ethnic, younger people, people who identify as Lesbian Gay Bisexual and Transsexual, those with rarer cancers and those living in rural areas. In some cases this meant that the data collected was not reflective of the respective CCG populations. During the events it was also acknowledged that the CPES dataset did not capture the local practice or context; the Yorkshire and Humber workshop participants thought that a greater level of understanding of the local context of service delivery would provide a better understanding of the causes of variation in results. For example, one attendee cited an example where a local freeze on nursing had led to a drop in CPES scores. Some felt that this lack of knowledge made it difficult to reflect an accurate, local picture.
3. **Comparability:** Despite the survey providing strong comparisons annually, commissioners and other attendees agreed that the survey

does not account for differences in demographics between CCGs and concerns were expressed about comparing small Trusts with larger ones, which many felt needed to be emphasised in reporting.

4. **Design and content:** The survey required improvements in order to add value to commissioners' work, with specific mention of length and the content of questions.
5. **Presentation and reporting:** The RAG ratings were largely considered unhelpful and commissioners had expressed difficulty in understanding how they were performing comparatively to the national average and to neighbouring CCGs. Monitoring trends over time was considered valuable, however commissioners expressed difficulty in doing this without the appropriate tools for aggregating and presenting data.
6. **Awareness:** Many were in agreement that in most areas the role of a local champion to raise awareness of the data had been fundamental in terms of commissioners using the data. Many cited the relationship with the local Trust in analysing and sharing CPES results as the most common way of finding out about CPES. Many attendees were concerned about the overall lack of awareness of the dataset as a key challenge, suggesting GPs as a key audience for greater engagement. Many felt that buy-in from Trusts was not sufficient and that more could be done to align and facilitate local action using CPES as a driver.
7. **Capacity:** Many commissioners said that time and resource to analyse data was a key challenge for them. There was a call for greater guidance and capacity to analyse data. It was also acknowledged that a change in attitude towards patient experience would be needed if CPES was to be used effectively to drive change in the future.

Suggestions for improvement

1. **Strategic Clinical Networks play an important role:** It was felt that commissioners have a tendency to focus on different parts of the cancer pathway, making it difficult to bring everyone together and focus on improvements to patient experience across the pathway as a whole. It was suggested that SCNs could play an important part in leading and facilitating improvements by bringing commissioners and other stakeholders together to plan action in line with annual CPES reporting.
2. **Adapt data collection methods to reach a greater diversity of people:** Suggestions for improving reach included piloting innovative engagement methods for reaching traditionally excluded groups (moving beyond postal surveys) and translating surveys to be multi-lingual. Commissioners in London were also particularly keen to capture socio-economic status within the survey as this information was considered to be particularly valuable for commissioning bodies working with deprived populations and for collaborating with Public Health.
3. **Enable the collection and reporting of data in real time:** Commissioners felt that a real time feedback collection for CPES would add value to them and to key partners ie providers and clinicians. Suggestions include working with

local Public and Patient Involvement networks and Healthwatch to co-design methods for capturing information on patient experience in real time.

4. **An interactive, online tool and simplify reporting:** Commissioners posed a range of suggestions for improving the presentation of data specifically to support commissioning practice. Many were clear that online access would be more beneficial than a report via email and access to the raw data would be fundamental. Many felt that reporting needed to be much clearer with greater emphasis on priority areas for local improvement. Direction and guidance from a national level in terms of "what good patient experience should look like" was also widely discussed and agreed as crucial to improving the use of CPES. It was also viewed that trend analysis per question/area year on year would help to identify areas for improvement. It was noted, however, that caution is needed when comparing Trusts of different sizes, due to the difference in the number of respondents.
5. **Theme free text data and make available:** Commissioners and patients were in agreement that free text should be made available and that a thematic analysis and presentation would add value to reporting. It was also suggested that greater collaboration with local Public and Patient Involvement networks should be supported to develop this analysis. Healthwatch inspection reports were cited as a good example where patients were directly involved in the analysis and presentation of data. One attendee also felt that these bodies would be well positioned to work with commissioners on this analysis as they would have access to wider evidence on patient experience across health and social care. It was suggested that these groups could present a local picture of patient experience by facilitating a wider conversation at a local level.
6. **Improve CPES:** Although the event was not a consultation about the specific questions within CPES, many felt that a review and refresh of CPES was needed, particularly in relation to its length and the questions asked. To reduce the length of the CPES it was suggested that questions where results are consistently 90% and over could be omitted, with some questions being clustered to create component statistics. This reduced survey could be sent annually with a longer survey distributed at key milestones (ie every 3 years) to allow for deeper trend analysis. Other suggestions included: identifying other means for capturing responses on particular aspects of patient experience; rephrasing questions with low response rate on transitions between settings; working with Patient and Public Involvement Groups and Healthwatch to consult on improvements to and language in the survey.
7. **Graphics and tables:** It was felt that the report structure and presentation of data could be improved by developing a number of user friendly readable versions, for example, developing separate specific reports aimed at commissioners, patients and Trusts; with consistent information and specific calls for improvement and action. It was suggested that infographics and graphs could be used to present the data.
8. **Collaboration:** Collaborative working was highlighted as an important way to enable improvements across primary and secondary care. Commissioners at the South West event felt a map of regional governance was needed (both for commissioning and delivery) to support organisations to work together in doing this.

Good practice examples

- **Collaborating locally:** South East London Trusts and CCGs, are working together via local clinical quality reviews to discuss CPES data and other public health items. East and North Hertfordshire CCG have also developed a strong relationship with their providers, reporting to a cancer forum, working with specialised commissioners and building up awareness within GP practices.
- **User involvement and excluded groups:** Yorkshire and Humber proactively engage their local public and patient groups and work with the equality and diversity team to engage specific groups, for example, working with the local learning disability partnership board on a cancer symptoms campaign to improve awareness of signs and symptoms. The CCG in Yorkshire and Humber also consult their existing community focus groups on issues of poor patient experience in cancer care.

ii) Data and presentation of CPES findings

Key questions:

How can CPES results be best presented and used by commissioners to drive improvements?

How can CPES data align with other patient experience outcomes data across pathways?

- The CPES was seen as a valuable tool when read alongside data from other quality and safety datasets. The examples most frequently used by commissioners include Friends and Family Test, the Inpatient and Outpatient survey, and the GP survey. Commissioners felt that more effort should be placed on presenting key datasets together via a tool or dashboard to allow for the triangulation and alignment of data by theme. Specific suggestions included linking improvements in primary care to q1-4 of CPES; linking q10 of CPES with a review of accident and emergency admissions; and linking national cancer registry data with CPES. South west commissioners were keen for national bodies to investigate how CPES data could link to financial metrics and demonstrate cost savings. Across two events there were good examples where individual patient or patient groups have played a pivotal role in analysing and triangulating CPES data for use by CCGs and Trusts.
- Commissioners are not held to account for improvements and many were clear that performance management was not viewed as the best tool for driving change. However, many felt that accountability was important in driving improvements in patient experience and discussions ranged from assurance frameworks to driving change via contracting.
- Many of the commissioners involved in the workshops felt that there was a lack of clarity on national priorities for patient experience, and specifically what to do with CPES data; which they felt in turn led to some areas “de-prioritising” the agenda. This issue was coupled with

challenges in the reporting of CPES, which many commissioners felt could make explicit suggestions on areas for improvement at a CCG level. Other suggestions included a summary of key points of action and including CPES data within commissioning packs. Discussions also focused on the role of regulators and more effective use of the RAG ratings to make improvements happen.

Challenges

1. **Resource limits:** Commissioners all felt that time and resources were key in driving improvements. However, many felt that they had little time to analyse and identify areas for action. Commissioners also stressed the difficulties caused by the split between specialised commissioning, the role of CCGs and the current commissioning structure for primary care. The pace of change in service delivery was also seen as a huge barrier to improvement.
2. **Parity of esteem:** Commissioners expressed concerns about how patient experience was considered as a low priority which, in turn, led to little action towards making improvements. A number of commissioners and some patients strongly believe that patient experience must be given the same parity of esteem as clinical effectiveness and safety.

Suggestions for improvement

1. **Present related data and themes together:** In all of the discussions commissioners suggested presenting data from CPES alongside data from patient surveys, complaints and audits. Commissioners discussed the value of understanding variation and consistency in services and agreed that data on care quality; generic quality; infection; incidents; complaints; and the friends and family test would make it easier to identify key themes and areas for improvements in patient experience. An online tool supporting commissioners to do this was suggested as well as including CPES data within commissioning packs. Greater involvement and engagement with patients and the public to identify key areas for improvement was also supported, with some areas already working closely with local Healthwatch. Commissioners valued the role of patient groups in both identifying areas for action and holding providers to account.
2. **Use reporting to suggest specific areas for improvement:** The current reporting structure for CPES was felt to be a barrier to improvements. Commissioners suggested that more support should be provided when results were published. Some suggested setting out the key priorities and areas where action was required in local data reports. This would support commissioners with little time to analyse the whole dataset and would make explicit reference to using the data to prioritise local improvements in patient experience; this was something that many participants felt was needed. Commissioners suggested a summary of key points for action, whilst others felt improvements to the RAG scores could be linked to a national average for patient experience.

3. **Drawing on best practice and celebrate success:** In addition to highlighting areas for specific improvements, commissioners also called for a greater need to share best practice between CCGs and facilitate learning. Many attendees would have welcomed an online forum for CCGs to compare examples and participate in a dialogue about improvements with CCGs of similar sizes and demographics. Peer support networks between CCGs aimed specifically at driving improvements were also suggested, with "high performing" or areas of success celebrated nationally.
4. **Some accountability is needed:** Although commissioners did not want to link CPES with performance management, a number of suggestions were made about how to strengthen the methods for making improvements. Suggestions included: making it a requirement for local organisations to publish a formal, jointly owned response upon the publication of findings; ensuring that local bodies were committing to take actions from the findings; specific action plans and reviews to specifically improve patient experience should be built into existing services; and action planning meetings involving patients and the public. Some commissioners did suggest scoping the use of financial incentives to drive improvements or the use of assurance frameworks to drive change, some commissioners also felt that regulators could play an important role in holding bodies to account on patient experience and greater efforts should be made to work with them.

Good practice examples

- Yorkshire and Humber discussed a range of ways they are using data to drive improvements in patient experience. When asked which data they use to drive improvements they mentioned the use of: acute and community provided data on patient experience; complaints and clinical incidents reporting; and specific feedback from people affected by cancer.
- Yorkshire and Humber told us that 2014 was the first year in which they were using data to drive change. They shared a number of ways in which they are using data locally. These included: reviews to pathways; working with secondary care and GPs to review two week waiting forms; GPs and consultants in secondary care working on clearer referral guidelines; improving the quality of information provided to patients; and reviewing and improving the communication between primary and secondary care.

Overall recommendations for consideration

- **Linking data:** Commissioners require greater access to the full data (including free text data) and a platform to link CPES data with other relevant datasets, including the Friends and Family test and the Inpatient survey. One way this could be achieved is through the development of an online tool which could be used by CCGs to identify key areas for improvement.
- **Survey improvements:** NHS England should conduct a wider review of the CPES survey and work with key stakeholders (CCGs, providers, patients and patient advocacy organisations, regulators and educators) to make improvements to the content, length and sample of the survey (particularly in relation to reaching traditionally excluded groups) to ensure it remains accessible and used to drive improvements at a local level.
- **RAG ratings and reporting:** A review of RAG ratings should be conducted to understand how these are currently used to inform improvements in patient experience and to understand where improvements might be required.
- **Facilitate learning:** Commissioners welcomed the dialogue and called for a platform or network bringing CCGs together to share best practice examples, discuss challenges and celebrate success. NHS England in partnership with Strategic Clinical Networks should consider the hosting a network or online forum for commissioners.
- **Accountability:** NHS England in partnership with the National Clinical Director for Cancer should consider investigating the use of assurance frameworks and incentives to drive improvements in patient experience, using cancer as an exemplar.

Appendix 1

Summary of key learnings from national event on 25 June 2014.

Key points

- Overall people were happy with the draft formats presented.
- Local area comparisons (or data in a format allowing this) would be particularly valuable.
- Access to free text comments alongside the quantitative data would improve interpretation and support more timely action.
- An executive summary (eg five key points) would be useful to aid tailoring to different audiences.
- Setting national goal posts and clear consequences to these is important.
- Improvement needed in the visibility and accessibility of the reports and other outputs as they are not easy to find on the Quality Health website.
- Patients would like to see where their hospital falls in a simple overall league table, a 'barometer was also suggested as a good national summary.
- Improvement infrastructure is needed and there may be gaps, for example, in resources and skills.
- Leadership, as well as team level ownership of results and improvement activity was essential to a culture of improvement.

Appendix 2

Breakdown of each event and attendees/results from webinar etc.

Regional Events – sample agenda

East of England Cancer Patient Experience Survey Event

Friday 20 March 2015, 10:00 – 16:00
Trinity Centre, 24 Cambridge Science Park, Milton Road, Cambridge, CB4 0FN

10:00	Registration	
10:30	Welcome and introduction to the day	Maggie Parsons Programme Manager, Cancer, Palliative and End of Life Care for NHS Great Yarmouth and Waveney CCG
10:40	Keynote Address	Charlotte Billington Macmillan Cancer Support
11:00	Local case study presentation	Dave Pitchers
11:15	Break	
11:30	Bringing patient experience data to life • Which information in the CPES data set is most important and valuable to commissioners? • How can this national data be aligned with other patient experience outcomes data across pathways?	Group work 1
12:15	Feedback on group work 1	
12:45	Lunch and networking	

13:30	Update from NHS England	Dan Wellings Head of Insight and Feedback, NHS England
13:50	Turning insights in to improvement • How can the CPES results be best presented and used by commissioners to drive improvements? • What are the barriers and how do we overcome these?	Group work 2
14:45	Break	
15:00	Feedback on group work 2	
15:30	An update from NHS Improving Quality	Alison Kirk NHS IQ
15:45	Reflections on the day and next steps	Maggie Parsons
16:00	Close of meeting	

South West Event 24 November 2014

(Attendee list not available)

London Event 02 March 2015

Attendees:

Job title	Organisation
Senior Patient Experience Officer	Macmillan Cancer Support
Macmillan GP Lambeth CCG	
Patient Experience Manager	Macmillan Cancer Support
Project Delivery Lead – Experience of Care	NHS Improving Quality
Head of Patient Experience and Quality (London Region)	
User Involvement and Patient Experience Coordinator	
Pan London Transformation Lead	Transforming Cancer Services Team for London
National Improvement Manager – Patient Experience	NHS Improving Quality
Clinical Adviser	Transforming Cancer Services Team
User Involvement and Patient Experience Coordinator	Transforming Cancer Services Team for London
Clinical Governance Lead SECSU	
Head of Patient Experience	NHS England
Cancer Commissioning Manager	

East of England Event 20 March 2015

Attendees:

Job title	Organisation
Project Delivery Lead – Experience of Care	NHS Improving Quality
Patient/Carer Representative	
Head of Insight and Feedback	NHS England
Patient/Carer Representative	
Patient/Carer Representative	
Patient Pathway Simulations	Pathway Communications
Macmillan Information and Support Manager	Southend University Hospital NHS Foundation Trust
Service Improvement Lead	EoE Strategic Clinical Network
Patient/Carer Representative	
Interim Senior Commissioning Manager-Cancer	Mid Essex CCG
Patient and Public Participation Lead	Strategic Clinical Network and Senate
Engagement Manager	NHS Norwich CCG
Nurse Consultant, Thoracic Oncology	Papworth Hospital NHS FT
Commissioning Development Assistant	NHS Corby CCG
Programme Manager, Cancer, Palliative and End of Life Care	NHS Great Yarmouth and Waveney CCG
Patient/Carer Representative	
Clinical Quality Specialist	West Essex Clinical Commissioning Group
Patient/Carer Representative	
Commissioning Manager	Basildon and Brentwood Clinical Commissioning Group
SCN Programme Manager	EoE SCN
Senior Quality Improvement Lead	Strategic Clinical Network and Senate

Yorkshire and the Humber WebEx Event 27 March 2015

The Yorkshire and the Humber Event was held as a WebEx rather than a face-to-face event.

Dialling in:

Job title	Organisation
Quality Improvement Manager	NHS England
Service Lead – Planned Care and Cancer	North East Lincs CCG
Head of Patient Experience	NHS England
Head of Long Term Conditions	Bradford City and Bradford District CCG
Project Delivery Lead	NHS IQ

Prior to the WebEx a short survey (Survey Monkey) had been sent out to all Commissioners and Cancer Leads in the Region to complete, based around the key questions asked in the previous three events. The WebEx included an introduction from Dr Matthew Day, PHE Consultant and an update from Charlotte Billington, Macmillan. The results were fed back as part of the WebEx content and formed a basis for discussion.

When you have cancer, you don’t just worry about what will happen to your body, you worry about what will happen to your life. At Macmillan, we know how a cancer diagnosis can affect everything and we’re here to support you through. From help with money worries and advice about work, to someone who’ll listen if you just want to talk, we’ll be there. We’ll help you make the choices you need to take back control, so you can start to feel like yourself again.

No one should face cancer alone. For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

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