



**USING CANCER
PATIENT
EXPERIENCE
SURVEY DATA
TO DRIVE IMPROVEMENT**

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Our thanks to all the staff and patients who shared their learning to develop this document.

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OVERVIEW

Executive summary

Macmillan commissioned Transforming Health to develop a number of case studies that demonstrate organisations using patient experience data to improve service experience. In particular, we looked for the ways that trusts are using measures that allow comparison over time. This demonstrates leadership and organisational commitment, as well as dedicating resources to the tasks of capturing, understanding and improving patient experience.

The national Cancer Patient Experience Survey (CPES) provides a snapshot of approximately 70,000 patient voices every year. It is an important resource in terms of understanding and improving patients' experience of cancer care.

The aim is that the CPES results can be used to drive local quality improvements, by trusts and commissioners.

The benefits of a national survey

A key benefit of the survey is its breadth – 153 acute NHS trusts, providing cancer care, took part in the survey in 2013. Compared with some other national postal surveys, for example the in-patient survey, there is a relatively high response rate. These response rates indicate many people's willingness to comment on the care and treatment they received.

The survey's longitudinal nature is also a benefit, as organisations are able to assess their progress in making improvements over time. It would appear that the survey is helping to drive improvement, or at least it enables organisations to see where there are improvements in the way people score their experience.

Issues with a national survey

This report also highlights a number of challenges with the CPES from trusts' perspectives including:

- data analysis and timing
- moving from data to information
- patient journeys
- response rates
- public understanding
- quality improvement capability
- developments in questions over time.

Defining features of organisations using the CPES data for improvement

The case studies in this report describe how innovative organisations have used the CPES data to drive improvement in the way patients experience cancer services.

We have found that there is no 'one size fits all' approach. Trusts are developing individual approaches to improving cancer patient experience that fit with their existing systems, structures and ways of working.

In line with the elements we would expect to find in a service experience improvement programme¹, the case studies expose the following common themes:

- 1** The desire to deliver a positive experience is central to the organisation's vision and culture.
- 2** Leadership understands and embraces the value of improving patient experience
- 3** There is recognition of the importance of staff experience and the organisational culture that supports it.
- 4** The organisation maximises the value of listening and responding to the patient voice.
- 5** Measurement mechanisms and other systems are in place to ensure clear accountability and effective reporting.

In summary, these organisations:

- see CPES as an important element for beginning to understand the experience of cancer patients (all case study sites)
- ensure feedback contains positive aspects as well as areas for improvement (all case study sites)
- try to work collaboratively with the data across the patient pathway (all case study sites)
- link CPES results to training and development (all case study sites)
- spend considerable time on analysing the free text to help them understand more about patients' experience and feed this back to the relevant tumour groups (see Royal Marsden and Guy's and St Thomas' for more on this)
- consider when/how to feedback, and have a clearly defined process with named people responsible for managing and working with the CPES results (see Portsmouth and Basildon)
- give consideration to under-represented groups and consider how to bridge this gap (see Guy's and St Thomas')
- use the data for improvement year on year rather than judgement – work in 'quality mode' rather than 'research mode' (see Dorset and Gateshead)
- ensure that patients and carers are engaged in the CPES process, from results through to improvements (see Ashford and St Peter's, Royal Marsden, and Dorset).





The National Cancer Patient Experience Survey

The national Cancer Patient Experience Survey (CPES) provides a snapshot of approximately 70,000 patient voices every year. As such, it is an important resource in terms of understanding and improving patients' experience of cancer care.

The CPES is administered on behalf of NHS England. The survey began in 2010 and is designed to monitor national progress on cancer care. The aim is that the CPES results can be used to drive local quality improvements by trusts and commissioners.

This report features a number of case studies that describe how innovative organisations have used the CPES data to drive improvement in the way patients experience cancer services.

Origins of the national survey

The Cancer Reform Strategy, published in 2007, set out a commitment to establish a new NHS Cancer Patient Experience Survey programme. Feedback from commissioners and providers was that they sometimes found it difficult to give sufficient weight to actions that improve patient experience in comparison with demands for new technologies. The NHS Cancer Patient Experience Survey programme was designed to give commissioners a mechanism to track the extent to which improvements were being delivered in this area.²

The NHS developed the survey programme to provide an assessment of various factors. These are whether patients feel supported throughout their cancer journey, the extent to which their care is coordinated and the impact cancer nurse specialists have on patient care. The survey aims to provide data for:

- people to make informed choices about their care
- commissioners to ensure improvements in care through strong contract management
- local service providers to identify where improvements are most needed
- local services to compare their performance with other services.

Over the four years it has run, the CPES has driven improvements with scores on over half the measures surveyed (46 questions) improving between 2010 and 2014. Success is often attributed to local ownership of the results, and local direction and support to use the findings to deliver improvements.

Evidence – what supports making improvements in patient experience?

What we know from other studies.

What do we mean by patient experience?

People tell us that they care about their experience of care as much as clinical effectiveness and safety. They want to feel informed, supported and listened to so that they can make meaningful decisions and choices about their care. They want to be treated as a person not a number, and they value efficient processes.³

There are two aspects of the experience of care that need to be considered. The relational aspects of care, such as dignity, empathy and emotional support are significant in terms of overall patient experience. The functional aspects, sometimes referred to as transactional aspects, include access, waiting, food and noise. It is clear that the quality of relationships between NHS staff and patients is of great importance to patients and a key indicator of patient experience.

The dimensions of a patient experience have been set out in NHS Experience Framework.⁴ The National Institute for Health and Care Excellence (NICE) also published a Quality Standard and Guidance for Patient Experience in Adult Services⁵ which includes 14 quality statements.

Patient experience and the move towards person and family-centred care

It is important to consider the Cancer Patient Experience Survey in the context of the wider movement towards health services that deliver

patient and family-centred care. We should also look at the increasing emphasis on considering patient experience evidence, and subsequent improvement activities, alongside safety and clinical effectiveness.

As the Beryl Institute have commented: 'Embedded within patient experience is a focus on individualised care and tailoring of services to meet patient needs and engage them as partners in their care. The patient experience is strongly tied to patients' expectations and whether they were positively realised (beyond clinical outcomes or health status).'⁶

A recent evaluation of the national and international evidence for person-centred care concludes: 'Person-centred care is a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome.'⁷

The review also states: 'In order to be more person-centred, health services need to know what is most important to people. Person-centred care can focus on people's individual health needs, but it is also about involving people in planning and evaluating services. Words such as 'co-production' and 'co-design' have been used to describe involving people in developing services and assessing their quality.'

Why is measuring and improving patient experience important?

The imperative to measure and improve patient experience is described in a recent Patient Experience Journal article.

'In recent years, perceptions of performance and quality of healthcare organisations have begun to move beyond examining the provision of excellent clinical care alone, and to consider and embrace the patient experience as an important indicator.'⁶

The business case for improving the experience of people using healthcare services includes the:

- evidence of the impact of experience on organisational reputation
- impact of patient choice and increased control of care and treatment on health outcomes
- link between a positive experience and health outcomes
- link between experience and cost of care
- relationship between staff and patient experience.³

The policy imperative

Many aspects of current NHS policy and practice³ centre on 'the importance of a good patient experience as a cornerstone of high quality health and social care and reinforce the need for patient centred care.'⁸

The NHS Constitution⁹ establishes the principles and values of high-quality healthcare and sets out the rights to which patients, public and staff are entitled. One of the seven key principles is that the NHS aspires to the highest standards of excellence and professionalism. 'In the provision

of high-quality care that is safe, effective and focused on patient experience; in the planning and delivery of the clinical and other services it provides; in the people it employs and the education, training and development they receive; in the leadership and management of its organisations; and through its commitment to innovation and to the promotion and conduct of research to improve the current and future health and care of the population.'

Putting Patients First (NHS England Business Plan 2013–16)¹⁰ described collecting feedback from patients on their experiences as an essential part of the drive to ensure high-quality care is available to all.

Measurement methods

Understanding patient experience in hospital settings can be achieved through a range of activities that capture direct feedback from patients, service users, carers and wider communities. These include ward-level surveys, interviews, focus groups, informal feedback to Patient Advice and Liaison Service (PALS), complaints, comments on websites (such as Patient Opinion and NHS Choices) and 'real-time' data collection.

A central tenant of the NHS Business Plan is the introduction of the Friends and Family Test (FFT). The FFT was launched in 2012 and intended that all NHS services will eventually be required to ask patients and staff the same question. 'How likely are you to recommend our service/ward to friends and family if they needed similar care or treatment?'

The CPES is an annual survey and, as such, many trusts view the results alongside other data sources, including real-time feedback, FFT, PALS, complaints and local survey data.



There are advantages and disadvantages to all feedback and measurement techniques and it is important to view the CPES in this context. National surveys, in particular, enable data to be gathered from a large number of people and if outsourced can provide independence. The disadvantage of a survey is question bias, accessibility (language/literacy etc) and they don't provide an opportunity to explore further feedback. Many case study sites found the CPES

free text extremely useful, but note the additional resource required for analysis.

Increasingly, NHS trusts are using real-time data collection to measure experience. The advantage is that the data is timely, easy to read and enables services to track service quality across time. However, this data-capturing method can be expensive, does not always offer anonymity and questions can vary making comparisons difficult.

'Using patient experience information requires that organisations have the capacity to collate and analyse the data. It is also important to have good systems for managing and tracing the data collected. The most important issue is how patient experience information leads to change.'⁷³

Case studies – exploring the benefits of a national survey

Macmillan commissioned Transforming Health to develop a number of case studies that demonstrate that organisations use the Cancer Patient Experience Survey (CPES) to improve service experience. We selected case studies that gave us a mix of geography, CPES performance and type of trust.

In particular, we looked for ways that trusts:

- demonstrate leadership and organisational commitment to improve cancer experience
- dedicate resources to the tasks of capturing, understanding and improving patient experience
- triangulate data from different sources to share a detailed view of cancer experiences
- use CPES to identify priorities for improvement work
- capture insight from under-represented groups.

To do this, we reviewed systems, processes and literature and conducted a number of interviews with a range of staff and patients in a range of settings. In addition, we looked for evidence relating to the main attributes we would expect to find in a successful service experience improvement programme.¹ We used the NHS Institute and Ipsos MORI Service Improvement Self-Assessment (2012) domains as follows:

- the desire to deliver a positive experience is central to the organisation's vision and culture
- the leadership understands and embraces the value of improving experience
- the importance of staff experience and the organisational culture that supports it is recognised
- the organisation maximises the value of listening and responding to the patient voice
- measurement mechanisms and other systems are in place to ensure clear accountability and effective reporting.

Raising the profile of cancer patient experience improvement

The case studies in this report demonstrate that innovative organisations are using CPES data as baseline data for improvement.

A key benefit of the survey is its breadth with 153 acute NHS trusts that provide cancer care taking part in the survey in 2013. This covers every trust providing cancer care in England, though some specialist trusts are excluded due to low numbers. The survey included all patients over 16 with a primary diagnosis of cancer, who were discharged between 1 September and 30 November 2013.

Compared with some other national postal surveys, for example the inpatient survey, there is a relatively high response rate. The response rate to the 2011/12 CPES was 68% (71,793 completed questionnaires), compared to 67% in 2010 (67,713 completed surveys). These response rates indicate many people's willingness to comment on the care and treatment they received. The survey's longitudinal nature is also a benefit, as organisations are able to assess their progress in making improvements over time. In addition, many questions remain the same every year so there is a high degree of comparability from one year to the next.

It appears that the survey helps to drive improvement, or at least it enables organisations to see where there are improvements in the way patients score their experience. In 2013, patients reported improved scores on 31 out of 63 survey questions. This follows significant improvement in scores in the 2012 survey over those achieved in 2010. It is clear that specialist cancer teams have used the CPES to inform their quality planning activities, and that this work has borne fruit in many NHS trusts across England. The 2013 survey also shows that care and treatment in some tumour groups has advanced significantly, especially in respect of some of the rarer cancers.

Despite some difficulties in using the CPES data for improvement (outlined later in this report), this is undoubtedly important time series data. It helps boards focus on patients' experience and is leading to improvement. For example, the results

of the 2011/12 survey¹¹ demonstrate that there have been significant improvements on a wide range of scores, compared with the 2010 results. Also, on over half the scored questions in the 2011/12 survey, there are statistically significant differences compared with the 2010 results.

The survey also helps indicate what is most important to patients and their families. For example, the scale of the differences between those with a clinical nurse specialist and those without is substantial and has been maintained since the 2010/11 survey. The findings are the clearest possible indication of the quality of care given by specialist cancer nurses and the impact that they have on the services given to cancer patients. They also show the substantially improved understanding of treatment options and prognosis, which flow to patients from contact with their clinical nurse specialist.

Case study emerging themes – using CPES data to drive improvement

We have found that there is no 'one size fits all' approach to improving cancer patient experience. Trusts are developing individual approaches to improve cancer patient experience that fit with their existing systems, structures and ways of working.

The context in which cancer teams work is relevant, in particular the organisational culture and whether improving experience is valued and resourced. The skills and experience of the teams administering the CPES results, along with the

improvement activities, varies enormously, as does the budget. So too does access to additional capacity to support the process of collecting, analysing, sharing results and engaging staff and patients in the resulting improvement activities.

The CPES aims to provide data for:

- people to make informed choices about their care
- commissioners to ensure improvements in care through strong contract management
- local service providers to identify where improvements are most needed
- local services to compare their performance with other services.

Based on the explorations for this report, we conclude that there is more progress with points three and four. These are that, using CPES, trusts are able to easily identify areas for improvement and make comparisons over time and, to a lesser extent, with other organisations. There is wide variation in the extent to which commissioners and patients are engaged with the CPES results.

Raising the profile of patient experience and the CPES alongside other data sources

A number of case study sites cited the CPES as a useful tool for cementing the value of patient experience alongside safety and clinical effectiveness. The way that CPES is analysed – and results shared and used – varies enormously from trust to trust. Often, the value of this work lies in the sense of local ownership and relevance. However, trusts struggle with the range of feedback, as well as an inability to make comparisons across pathways, services and organisations and over time.

Case study sites reported that they found value in comparing patient experience data from different sources to get a more complete picture. These included patient stories, local and national surveys, complaints, PALS data, compliments, incident reports, general feedback and suggestions for improvements. It is clear from the case studies that teams collect information about patient and carer experience in a variety of ways rather than relying solely on a national survey. Many also noted that quantitative and qualitative data are equally important and should be considered together.

However, the ways in which these comparisons take place and the use of the data for information varies. At Guy's and St Thomas', there was a particularly integrated approach, regularly comparing trust-wide data with other data such as complaints. However, many case study sites report that this triangulation is problematic. This is because the CPES focuses on multidisciplinary teams and tumour groups, whereas the trust real-time data is ward and outpatients department based.

The CPES is seen as a useful basis for comparisons over time. The majority saw this as being more important than comparing across organisations.

Impact of capturing insight from under-represented groups

The CPES is sent to all cancer in-patients and daycases over a set time period and there are no opportunities for additional work with under-represented groups as part of this national survey process. Guy's and St Thomas' has done some important work to explore the breast cancer care experience of black African and African Caribbean women, as they report a poorer service.

The team used experience-based co-design methods to help understand the emotional journey through the service. To do this, they went out to the local community, using Peckham Library as a meeting venue and ensuring people were individually invited by someone they knew. Films highlighted the key themes. Local hospital and community staff worked with black African and African Caribbean breast cancer survivors to explore the Moving Forward literature. They helped them look at how to cope with and adjust to life after treatment, and how the literature could be more culturally appropriate and accessible. This resulted in a number of changes to the information. The trust will build on this activity when co-designing and developing new post treatment self-management interventions.

How CPES is used to identify priorities for improvement work

There is no consistency in approach to using the CPES and other feedback information to identify areas for improvement. Trusts have designed local ways of working to fit their existing feedback mechanisms. These systems have evolved over time and are seen to support a number of processes – governance, monitoring, performance and quality. The peer review programme offers an opportunity to make comparisons against a quality standard and patient experience is an element of this. In addition, a number of sites recruit patient representatives to support the peer review process.

The majority of case study sites follow an action planning process, whereby improvement activities are owned by teams and specialties. At Ashford and St Peter's the process of identifying improvement opportunities is patient and carer-led. The results are carefully considered by the patient and carer group, and recommendations made to cancer teams about where to focus their work.

We found evidence of a range of improvement techniques in case study sites and in particular use of Plan, Do, Study and Act cycles, and experience-based design. A recent introductory guide¹², published by NHS Improving Quality, will help cancer teams and professionals at all levels of a trust to drive continual improvement in patient experience.

By exploring the domains of successful experience improvement programmes¹ it was possible to identify a range of evidence present in case study sites.

1 The desire to deliver a positive experience is central to the organisation's vision and culture.

Evidence from case study sites included:

- trust-wide systems and processes that encourage ownership of the CPES results and support local survey-to-improvement initiatives
- a clear organisational vision and values for delivering a positive patient experience
- improving patient experience projects built into business plans
- CPES complimented by other ways of collecting feedback throughout the year
- skilled analysis of CPES results, in particular the free text, enabling teams to fully understand the data
- outreach with 'seldom heard' groups to help bring insight and real involvement
- improvement approaches that involve emotional mapping to understand more about patient and staff experience and facilitated support to achieve this.

2 Leadership understands and embraces the value of improving patient experience.

Evidence from case study sites included:

- a board that is committed to patient experience improvements
- developing an 'improvement culture' and fostering strong leadership that is focused on improving the care patients' experience
- mandating evidence-based practice and supporting people to access research and continuously develop their practice
- strong proactive leadership in patient experience with an emphasis on learning and improvement shared with and involving the multidisciplinary teams.

3 The importance of staff experience and the organisational culture that supports it is recognised.

Evidence from case study sites included:

- staff engagement activities, especially when feedback is negative
- an open and enabling culture that supports staff
- opportunities to celebrate success.

4 The organisation maximises the value of listening and responding to the patient voice.

Evidence from case study sites included:

- an organisational strategy to support patients' ongoing involvement.
- embrace feedback and offers of support from patient and carer groups
- a carefully established patient reference group can be of great value
- evidence of people participating in improvement and co-design activities.

5 Measurement mechanisms and other systems are in place to ensure clear accountability and effective reporting.

Evidence from case study sites included:

- a small number of consistent measures to provide a comprehensive picture that staff and patients can easily understand, share and use to inform improvement work
- comprehensive action planning, regular reporting and challenge
- a dedicated resource for analysing data and implementing quality improvements
- reporting feedback linked closely with clinical services and involving clinical teams.

In summary, the organisations featuring in this report:

- see CPES as an important element of beginning to understand the experience of cancer patients, often with strong leadership from one individual or team
- ensure feedback contains positive aspects as well as areas for improvement, especially where results are negative and there is a need to engage frontline staff in improvements
- try to work collaboratively with the data across the patient pathway, although all sites report difficulties with using CPES to do this
- link CPES results to training and development, in particular clinical nurse specialist networking and development
- work in partnership, across staff groups, with patients and carers, and across the cancer patient pathway.

In addition, some trusts commit additional resource so that they can:

- spend considerable time on analysing the free text to help them understand more about patients' experience and feed this back to relevant tumour groups (see Royal Marsden and Guy's and St Thomas' for more on this)
- consider when/how to feedback and have a clearly defined process with named people who responsible for managing and working with the CPES results (see Portsmouth and Basildon)
- give consideration to under-represented groups and consider how to bridge this gap (see Guy's and St Thomas')
- use the data for improvement year on year rather than judgement – operate in 'quality mode' rather than 'research mode' (see Dorset and Gateshead)
- ensure that patients and carers are engaged in the CPES process from results through to improvements (Ashford and St Peter's, Royal Marsden, and Dorset).

Some challenges with the CPES

It is clear that trusts face a number of issues when using the CPES data to drive improvement.

Data analysis and timing

Data analysis – quantitative and qualitative – appears to be a challenge in many organisations. This is in terms of the time it takes to analyse the data, particularly the qualitative material, and the skills needed to do so. The PDF format the qualitative data arrives in compounds the situation in terms of data manipulation. In addition, the quantitative data comes first then there is a time lag of a few weeks before the qualitative data is shared.

Organisations are often asked to respond to the first data set by the media, as it is in the public domain. But, at this point, they have not seen the qualitative comments which would help them provide a more comprehensive picture. Planning processes often begin immediately and are well underway by the time the qualitative data arrives in the trust. This means that opportunities to make the data more meaningful to frontline staff and patients may be missed.

The fact that this is an annual survey means that the data is always one year out of date. Trusts note that this can cause staff to feel demoralised by the results. In many cases a trust will have implemented a number of service improvements since the last data capture date but these aren't visible in the current year results. In addition, teams are under pressure to analyse and report on results, plan improvement activities and support the next year's survey all in the same quarter. This puts additional pressure on already stretched teams.

Moving from data to information

Data requires analysis and interpretation. It is this process that turns data into information and enables organisations to understand the key issues

patients face and to prioritise their improvement initiatives. There needs to be careful interpretation along with attention to detail. The scoring system currently used is: red lowest scoring 20%; green highest scoring 20%; amber remaining 60%. However, statistics can be misleading. For example, an organisation may fall into the 'green' rating but the scores for this question could be very low meaning most organisations do not do this well. But this may still be an area that warrants attention.

The patient journey

The survey relates to a single organisation and patients are asked to complete their response for the trust named on the covering letter. However, patients report on parts of their journey that would have been provided elsewhere. These results are suppressed when this shows up in trusts without a radiotherapy or chemotherapy unit. However, anecdotally, staff provide examples of where patients have provided answers that cannot relate to their trust. Patients are asked about primary care but the mechanisms for feeding back to primary care are based on existing mechanisms for feedback.

All case study sites reported regular meetings with commissioners but it is clear that the onus to share and engage primary care in the CPES is on acute trusts. Trusts also report that commissioners appear to be more interested in single trust results rather than trying to make sense of the patient pathway.

Response rates

The CPES is a postal questionnaire accompanied by a freepost envelope for replies. The initial questionnaire is followed up with two reminders. There appears to be an under-represented response rate for those who may experience poorer care and poorer outcomes. All covering letters are sent out on trust headed paper and signed by a member of the trust's staff, often the chief executive. A leaflet offering translation services is also enclosed. Quality Health also runs



a national free-phone helpline for patients, along with supported completion of the survey through text-phone and language translation facilities. However the take-up of this service is low.

Of those who do respond, women are generally less positive than men. Younger people are less positive than older people. Black and minority ethnic groups are less positive than white groups. Those who are bisexual, gay, lesbian or of other sexual orientation are less positive than heterosexuals. Those with a long-term condition are less positive than those without one and London still has the lowest reported figures.¹³ The absolute numbers of black and minority ethnic respondents to the survey is quite low (2,665 in 2013 including respondents of mixed heritage) which is around 3.7% of the whole respondent group. This is substantially less than the proportion estimated to be in the UK population generally by census returns.

It is also the case that response rates vary significantly between patients with postcodes in the least deprived area to most deprived area based on the Index of Multiple Deprivation. This effect is not unusual and follows the general pattern of participation in public life and civil society. However, it nevertheless indicates that we need more innovative methods to gain insight into patient experience from under-represented groups and individuals.

Public understanding of CPES

Public understanding of the national survey and the results is limited. Macmillan publish data on the top and bottom 10 organisations and the 10 most improved. Some organisations that appear in the top 10 treat very small numbers of cancer patients which may not be clear to patients.

Quality improvement capability

In addition to the data analysis skills required to interpret the results, quality-improvement skills are needed to support change to happen. There needs to be a defined process that supports the way data is fed back to multidisciplinary teams and, in turn, the way improvements are prioritised, tested, measured and sustained. These processes take time and skills that not all organisations have or assign to this work.

CPES developments over time

The CPES has changed and developed over time and new questions introduced each year. Often, knowledge about why new questions are introduced is not widespread. Increased knowledge about why the questions are asked can lead to improved results because the staff making the changes understand the impact.



Conclusion

It is clear from the case studies that the annual CPES has provided a platform for cancer services to explore how they can improve the experience of care. It appears that CPES has raised the profile of service experience alongside clinical effectiveness and safety monitoring. However, the CPES is not viewed in isolation – it is one element of a mix of service experience improvement activities that continue throughout the year.

The trusts interviewed described a range of ways to manage the analysis and sharing of results. This is a resource-intensive activity and the capacity and capability for understanding the results in detail varies from trust to trust. The CPES qualitative text is proving to be an effective way of bringing the quantitative data to life for frontline staff. However, extensive evaluation of this data is not always possible and the timing of its release, a few weeks after the quantitative data, is challenging.

There is no consistent approach to using the CPES and other feedback information to identify areas for improvement. Trusts have designed local ways of working to fit their existing feedback mechanisms. These systems have evolved over time and are seen to support a number of processes – governance, monitoring, performance and quality. In addition, the peer review programme offers an opportunity to make comparisons against a quality standard – patient experience is a small element of this.

The case studies provide a rich source of evidence – there are stories from patients and staff, along with many examples of innovative ideas. These illustrate a range of well-tested techniques to help trusts make the most of the CPES, work more closely with patients to understand their experience and use CPES to improve services.

Recommendations based on case study site experience include:

- ensure strong leadership and organisational commitment to improving experience
- dedicate specialist resources to the tasks of capturing, understanding and improving patient experience
- try to work collaboratively with the data across the patient pathway
- link CPES results to training and development.
- work in partnership across staff groups, with patients and carers, and across the cancer patient pathway
- consideration under-represented groups and how to bridge this gap
- use the data for improvement year on year rather than judgement – operate in ‘quality mode’ rather than ‘research mode’
- ensure that CPES is integrated with clinical effectiveness and safety monitoring and improvement
- ensure patients and carers are engaged in the CPES process – from results through to improvements
- celebrate success and engage all staff in improving services.

CASE STUDIES

Working in partnership – Ashford and St Peter's Hospitals NHS Foundation Trust

Read this case study for examples of: **Patient engagement, partnership working.**

Partnership working with service users and carers, along with GPs and commissioners, helps the trust prioritise and focus service improvement activities.

Setting the scene

Ashford and St Peter's is the largest provider of acute hospital services in Surrey. The trust serves a population of over 380,000 people across north-west Surrey, parts of Hounslow and beyond. Across two hospitals – Ashford in Middlesex and St Peter's in Chertsey – they provide a range of clinical and medical oncology treatments including chemotherapy and radiotherapy.

The way they work

The Improving Cancer Care Action Group (ICCAG) is a committed group of current and former patients and carers, trust members and staff. The group meets monthly and is chaired by a patient and carer representative. The lead cancer nurse and a clinical nurse specialist always attend meetings. The group invites external and internal speakers to present and join the conversation on relevant topics. In the past, this has included the trust chief executive, chief nurse and chair, and representatives from the local Healthwatch, the clinical commissioning group, Macmillan and NHS England.

ICCAG's aim is to support, develop and promote improved cancer services at Ashford and St Peter's Hospitals NHS Foundation Trust and to:

- be a source of advice to the hospital's cancer services team
- identify specific areas where improvement is needed and make recommendations
- work with the relevant health providers to make the changes happen

'The Improving Cancer Care Action Group (ICCAG) are fantastic – they give us local intelligence, know lots of people and can feedback on our service experience. They remind us what it's like to be a carer or patient.'

Sarah Burton

Lead Cancer Nurse, Ashford and St Peter's Hospitals NHS Foundation Trust

- improve communication between cancer patients, carers and health professionals
- have a say in the development of new initiatives.

ICCAG views the CPES results along with trust proposals. They use this as a starting point for discussions about improvement projects and developing an action plan for the cancer team.

ICCAG is represented on a number of groups, including the Cancer Steering Group and peer panel reviews. Members have been invited to share their experiences of care with the chief executive and hospital board. In addition, ICCAG is a source of advice and insight to funders such as Macmillan.

'It is good to celebrate the things that we are doing well. It's helpful to staff to know what they are doing well.'

Wendy Kimber
Secretary, ICCAG

Service improvements made as a result of CPES feedback

'This initiative was very forward thinking and patient focused. Even though it was difficult to achieve, those involved never lost sight of the desire to make things easier for patients. I found it really refreshing.'

*Dr Chrissie Clayton
Macmillan GP, North West Surrey CCG*

GP information

ICCAG raised the issue of information about cancer and cancer services, especially before and after treatment, being provided to GPs. This resulted in work to update and develop the GP Centre on the trust website. This now includes information on all clinical nurse specialists so that GPs can contact them directly if they have a question about a particular patient.

Green bracelets

Appraising CPES results led to discussion about patients at risk of lymphoedema, as well as identifying the fact that some non-cancer specialists did not have enough understanding of the risks. With the trust, the group gained funding from the League of Friends to purchase lymphoedema green bands from the Lymphoedema Association. Those at risk can now wear the band so that they're easily identifiable when in the hospitals. To complement this initiative the lymphoedema nurse delivered training in the risks and management to staff.

Patient resources room at St Peter's

CPES data indicated that improvements were needed in providing information to patients. ICCAG agreed that comprehensive information should be provided in the right way and setting. The group helped the trust source and facilitate a dedicated resource room, which provides information for cancer patients, with supporting funding from Macmillan. The resources room is also used by staff as a private area where they can discuss treatment with patients and their

families in a relaxed non-clinical environment. Feedback from patients has been very positive. Staff also appreciate having a less formal setting to meet with patients and share information and guidance.

Communication

ICCAG has provided recommendations to staff about how to ensure people are supported effectively when receiving a diagnosis. ICCAG has also supported the development of revised information leaflets and systems to ensure patients know who their clinical nurse specialist is, and that their GPs are aware too.

New chemotherapy service for breast cancer patients

As part of a joint project between Ashford and St Peter's and the Royal Surrey County Hospital, patients living around Ashford Hospital are now able to receive chemotherapy locally. This is rather than having to travel to specialist centres. The project's aim is to provide a better patient experience while reducing costs for clinical commissioning groups. Traditionally, patients from the Ashford area had to travel to Guildford or London for their treatment. The new suite is a purpose-built facility with the latest high-tech equipment needed to deliver complex treatments.

The ICCAG and cancer team felt that facing long journeys when receiving chemotherapy was extremely tough and wanted to be able to offer the same service locally that is provided at a specialist cancer centre. This joint service brings together expertise from the specialist oncologists at the Royal Surrey County Hospital with support from the Ashford Hospital specialist nursing team. The project has started with breast cancer patients, with plans to widen the service out to other tumour groups, starting with lung cancer.

Specialist oncologists come to Ashford to do their follow-up clinics. There has been positive feedback from patients who appreciate being able to see the specialist oncologists at their local hospital, with the added support and continuity of our specialist nurses.

Key learning points

Theme 1 – Staff engagement is vital, especially when feedback is negative

'It can be demoralising when a great deal of work has gone into improving things and then the CPES results from the previous year aren't good. The clinical nurse specialists work so hard.'

*Pat Morrison
Chair, ICCAG*

'We are working hard to re-energise and re-focus. The clinical nurse specialist group have come together to explore challenges and solutions.'

*Sarah Burton
Lead Cancer Nurse, Ashford and St Peter's
Hospitals NHS Foundation Trust*

Theme 2 – Embracing feedback and offers of support from patient and carer groups

'As a trust they are very open to the suggestions from ICCAG. I really want to be part of the next great thing they do.'

*Dr Chrissie Clayton
Macmillan GP, North West Surrey CCG*

Next steps

Dedicated cancer ward/beds

As the hospital has no dedicated cancer ward or beds, the ICCAG is working with them to look at how this can be addressed.

Support and wellbeing day for cancer patients and their carers

The cancer team at Ashford and St Peter's wants to offer practical and emotional support to people living with cancer after treatment. Exploratory sessions will help to identify what people need, and offer an opportunity to provide advice on healthy eating, exercise, emotional support, social services and benefits. There will also be stalls organised by the local voluntary and charitable sector, that offer support to people with cancer. ICCAG hope to use this opportunity to recruit more members too.

Cancer training and education days for hospital and community staff

These sessions are designed to educate and further develop staff's skills in breaking bad news, advanced communication, cancer treatment and dealing with emergencies.

Acute oncology service

The service is now open five days a week, with work underway to extend this to seven days to allow patients greater access to these important services.

Thank you to the staff and group members who supported the development of this case study:

Pat Morrison, Chair, ICCAG

Wendy Kimber, Secretary, ICCAG

Sarah Burton, Lead Cancer Nurse, Ashford and St Peter's Hospitals NHS Foundation Trust

Dr Chrissie Clayton, Macmillan GP, North West Surrey CCG

Rapid improvements – Basildon and Thurrock University Hospitals NHS Foundation Trust

Read this case study for examples of: **Culture change, engaged leadership, staff engagement.**

Over the past two years, the trust has undergone rapid improvements, with a strong focus on leadership, governance and creating a positive and caring culture. The confidence of those who work there is growing and there is an emphasis on supporting planned and emergent service improvement activity. Within an emerging framework for improvement, staff and service users are encouraged to try new ways of working and share the learning. This work has included a focus on improving patients' experience of cancer care at the trust.

'There has been a huge change for the positive. We were the first trust to be taken out of special measures. The changes have had a positive impact on staff morale and patients' perceptions.'

*Emma Elliott,
Macmillan Lead Cancer Nurse*

Setting the scene

Basildon and Thurrock University Hospitals NHS Foundation Trust serves 400,000 people across south-west Essex covering Basildon and Thurrock, with parts of Brentwood and Castle Point.

The trust has undergone a huge transformation in the past 18 months, after being put into special measures by Monitor in July 2013. This was following the Keogh Review into hospitals with

higher than average mortality rates. In June 2014, Monitor removed Basildon and Thurrock University Hospitals NHS Foundation Trust from special measures after the trust improved its services for patients.

The trust has made a number of improvements, including recruiting more than 200 additional clinical staff including nurses, nursing support staff and consultants. In addition, the number of patients who would recommend Basildon and Thurrock University Hospitals NHS Foundation Trust to their friends and family has risen by over 10%.

Cancer services sit with integrated core services such as pharmacy, imaging and pathology. This enables a cross-organisation view of cancer that acknowledges the multi-setting cancer patient pathway.

The trust was one of the 20 most improved in its CPES scores in 2014.



Cancer services

The trust provides a wide range of cancer diagnosis and treatment services for adults, children and young people. These are provided across a few sites with most chemotherapy and radiotherapy treatment delivered at Southend Hospital. All cancer referrals are centrally managed by the cancer services team to help minimise avoidable delays for patients.

Every patient has a named clinician and a trained specialist cancer nurse who is their keyworker. The keyworker provides continuing support, liaises with the patient's GP and community team, and provides patients with information about their condition and treatment. They can also give general information about living with cancer.

Macmillan Information Point

There is an information point in the outpatients department at Basildon University Hospital. This provides information about different cancers, treatments and services. The trust has also recently introduced a mobile information service that takes information to the wards.

The way they work

Comprehensive CPES analysis and reporting

The trust's Macmillan lead cancer nurse takes a lead on CPES across the trust. The role was developed with the notion that there is a need for change. This is a pivotal position, involved in continuously improving care, monitoring and reviewing results, and feeding back to multidisciplinary teams, user groups and across the hospital. The lead cancer nurse also supports the cancer nurse specialist group which has a strategic and operational role.

Analysis starts with an initial review of the data to compare scores and make comparisons with previous years. This is then shared with the trust's chief executive, chief operating officer and lead cancer clinician. The team has realised from previous years that there is a need to work more closely with the analytical department to pull data together and present in an engaging way. The next step is to produce more in-depth comparisons and charts for example.

'It is about putting the patient first, asking them what they want, rather than thinking that we know.'

*Jennie Deeks,
Head of Patient Experience*

Dissemination and action planning then takes place with the:

- Cancer and Palliative Care Nurse Specialist Forum
- cancer board which includes the medical director and tumour group leads (the patient user is deputy chair)
- divisional board – integrated care services manager and senior managers
- quality and patient safety group – board members included, chaired by a non-executive director
- cancer user group – used the same questions to delve deeper and take part in face-to-face interviews in the outpatients department.

The team also look at core tumour sites (lung, colorectal, breast, urology, haematology) and meet multidisciplinary teams to look at breakdown by question. CPES is included in the multidisciplinary team work programme. There is an annual report for each team, with a patient experience section. CPES and peer review both feed into the multidisciplinary team work programmes. Some teams use their own local surveys and are able to compare results with the national programme.

Rigorous action planning and reporting – Patient Experience Group

The Patient Experience Group is pivotal to the CPES process. Survey results go to the group who develops, reviews and finalises the action plan. The group is attended by all hospital divisions. There is a monthly experience report to enable teams to share everything that they are doing and pull together findings from the various surveys.

A culture of service improvement

'We look for the stars, find them and help them to shine. People start to notice that good people and good care get positive attention. But, it is still important to balance this with an atmosphere where it is okay to be upfront and honest and raise concerns.'

*Rebecca Myers,
Director of Integrated Care*

There have been a number of improvements made in the past two years and it is widely acknowledged that new ways of working are accepted at senior level. The hospital leadership is more visible and approachable, which staff have welcomed. One of the ways this has been achieved is via the 'stepping up meetings' which are held at 8.30am, every day, in the hospital cafe. These meetings are an opportunity for a general discussion about how things are developing in the trust. They're also a forum for anyone to raise concerns and challenges and for risks to be discussed. It is proving to be an effective way of bringing people together and making senior management more visible and accessible.

The stepping up meeting complements other ways of raising concerns and planning improvements. Also, there is a strong governance team with clearer expectations and reporting systems.

Work has been done to ensure that the right data gets to the right people, with complaints and stories forming an important part of board and performance meetings. There is a combination of informal and formal mechanisms for change.

Opportunities for reflection via the Schwartz programme

'Schwartz is an opportunity to talk about what it's really like to work here, to normalise the emotions involved in caring for others and build a sense of community amongst staff at all levels.'

*Rebecca Myers,
Director of Integrated Care*

Supported by the Point of Care Foundation, the Schwarz programme is a structured, monthly one-hour forum for staff from all disciplines to discuss difficult emotional and social issues that arise in caring for patients. The discussions are confidential and take place in a safe environment. Their purpose is not to solve problems, but to explore the human aspects of delivering care and the challenges staff face.¹⁴ The Basildon Schwartz meetings are themed and everyone who attends,

from porters to the chief executive, are encouraged to share their stories.

'The culture has changed dramatically.'

*Diane Sarkar,
Director of Nursing*

Service improvements made as a result of CPES feedback

Infospace

CPES highlighted issues about access to information and cancer but also benefits and other related issues. Infospace is a collaborative project with the local hospice, St Luke's. This partnership enables access to additional support services such as therapeutic groups, writing, complementary therapies and support for bereaved children.

The environment, opening times and recruitment of volunteers have been given careful consideration, as well as audited by the user group. The development of the Infospace has also enabled general cancer information throughout the hospital.

As things have developed, the Infospace steering group has started to consider how to use the space on traditionally quieter days, for example when there are no cancer clinics. As a result, the group has developed bite-size cancer information sessions for staff. Evaluation before and after sessions reveals that staff confidence has increased and those who took part were clearer on when to refer to cancer services.

Clinical nurse specialists' away day

Support for clinical nurse specialists was also highlighted as an action from CPES, resulting in an away day to provide professional development and networking opportunities. The event was facilitated and enabled attendees to consider the non-clinical aspects of their role, their part in improvement and what professional support may be needed on an ongoing basis. Everyone took part in and had an opportunity to reflect on their Myers Briggs assessment.

Support in difficult times

There has been a focus on providing people with additional support, for example by providing health and well-being clinics. This has been facilitated by dedicated professional time to get ideas off the ground.

Macmillan Specialist Palliative Care team

The team works alongside ward staff to provide support in to people with cancer and life-limiting illness in a range of issues including pain and complex symptom control, emotional support, family support and advance care planning. The Macmillan cancer nurse specialists provide seven-day cover, ensuring specialist palliative care advice and support are available every day of the week.

Acute Oncology Service

This is embedded within the Macmillan Specialist Palliative Care team, and staffed by the Macmillan clinical nurse specialists seven days a week. The service is nurse led. It ensures that any patient admitted to the hospital with problems related to their cancer, or treatment, is seen and assessed by a clinical nurse specialist within 24 hours.

A consultant oncologist is onsite from Monday to Friday to see patients with the clinical nurse specialist, including those seen by the nurse at the weekend. Three of the Macmillan clinical nurse specialists are non-medical prescribers. This enables prompt access to advice and guidance around symptom control but also the timely prescribing of appropriate medications.

Cancer of Unknown Primary (CUP) service

The service was launched in November 2013, and the trust has a dedicated Macmillan cancer of unknown primary nurse specialist, based within the Specialist Palliative Care team. The nurse specialist, working closely with the consultant oncologist, is the keyworker for patients with a CUP diagnosis. A CUP multidisciplinary team meeting is held once a week, in conjunction with Colchester and Southend hospitals. By embedding the acute oncology service and cancer of unknown primary service within the Specialist Palliative Care team, seven day cover is provided to all of these patient groups.

An audit carried out in May 2014 highlighted that 35% of patients seen by the acute oncology service also required specialist palliative care input. Analysis of the CUP patient caseload over a period of six months revealed that 37% of people had received specialist palliative care input. These audits highlight the benefit of running acute oncology, cancer of unknown primary and specialist palliative care within the same team.

The recent Care Quality Commission (CQC) inspection of the trust highlighted the work of the Specialist Palliative Care team as 'an area of outstanding practice'. It also shortlisted the Macmillan Specialist Palliative Care team as 'Cancer Team of the Year 2014' in the Quality in Care Oncology Awards, because of this integrated approach to cancer care.

Education and training

The trust makes a variety of training around cancer and palliative care available to staff within the trust. This includes study days, short courses and degree pathways for staff working in relevant areas. They have created an e-learning module in end of life care, which is now mandatory for all frontline staff. Each ward within the hospital is assigned a 'Macmillan link nurse' – a clinical nurse specialist within the Specialist Palliative Care team. They are responsible for ongoing cancer and palliative care education on that ward, and any training is tailored to the specific needs of the ward.

One nursing team within the trust is working closely with the Macmillan Specialist Palliative Care team in piloting the Macmillan Values Based Standard® programme on their ward. Developed by Macmillan, the programme provides a framework for improving patients' experience of healthcare. This framework focuses on the positive behaviours that promote dignity and respect, helping to improve the experience of patients and their families.

End of life strategy group

The group meets monthly to discuss the trust's end of life care strategy. Every division within the trust is represented, and any areas of concern or good practice are discussed, and fed back to board level.

Patient user group

This group is trialling carrying out face-to-face audits in outpatients departments. The Patients Association is supporting listening events across the trust.

Key learning points

Theme 1 – An open and enabling culture that supports staff

'There is an expectation that anyone can get involved in improvement, hear what's going on and feedback good practice as well as challenges.'

*Emma Elliott,
Macmillan Lead Cancer Nurse*

'We don't want to stifle energy and enthusiasm in its early stages.'

*Rebecca Myers,
Director of Integrated Care*

Theme 2 – Engaging staff in making improvements and celebrating success

'We asked, "What's really good about this place?". There was a fear that, "If we shout about the good we will get shouted down." So, we had to find a way to get that confidence back.'

*Rebecca Myers,
Director of Integrated Care*

'It is also about celebrating what we do well. It's a boost to morale – we can feel proud to do this job and benefit patients and families.'

*Emma Elliott,
Macmillan Lead Cancer Nurse*

Theme 3 – Comprehensive action planning, regular reporting and challenge

'The experience group has a radar on CPES actions so that there are no surprises.' *Diane*

Sarkar,
Director of Nursing

'Cancer sits everywhere, so it needs to be a trust-wide approach because it impacts everywhere.'

Jackie Gibson,
Cancer Services Manager

'It's about doing the right thing and doing it right, stripping out the variation where it isn't needed and doesn't help patient experience.'

Gavin MacDonald,
Deputy Chief Operating Officer

Next steps

The next step is to raise the profile of the survey results and celebrate improvements, sharing five key messages from CPES results on posters around the hospital.

Four cancer task and finish groups are underway, and include staff, patients and other key stakeholders such as GPs and commissioners. These will focus on:

- Diagnostics – speeding up time from request to report (currently measure request to test, but report is vital stage)
- Multidisciplinary teams – exploring how the multidisciplinary team can be standardised and includes information collection, peer reviews and tumour group objectives
- Information and reporting – examining what is and isn't measured and how information is reported
- Patient choice – are patients given the information to make an informed decision and do GPs know how to refer?

Thank you to the staff and group members who supported the development of this case study:

Diane Sarkar, Director of Nursing
Rebecca Myers, Director of Integrated Care
Emma Elliott, Macmillan Lead Cancer Nurse

Jackie Gibson, Cancer Services Manager
Jennie Deeks, Head of Patient Experience.
Gavin MacDonald, Deputy Chief Operating Officer

Experience-based design – Dorset County Hospital NHS Foundation Trust

Read this case study for examples of: **Staff engagement, co-design, measurement systems.**

Dorset County Hospital has focused efforts on two aspects. One is fully understanding the CPES data implications, the other is sharing the results in an engaging and meaningful way so that teams can work on making improvements. In addition to CPES data, the trust also encourages regular consideration of real-time experience data.

'We are a friendly, compassionate hospital with a loyal local community. We seek out innovation and like to try bright ideas. There are strong links between our board and wards.'

*Sarah Silverton,
Patient and Public Experience Lead*

The trust has done work to change attitudes towards complaints. Using an emotional mapping tool, staff can learn from the complaint and its implications for care and compassion more easily. The trust fully supports experience-based design programmes. In addition, it enables partnership working with staff, patients and their families, so that the design and ongoing delivery of an improved patient experience are considered in detail.

Setting the scene

Dorset County Hospital was established in 1991 as part of a long-term project to bring together all the local services for acutely ill

patients on to one hospital site. The new hospital, just outside Dorchester town centre, was completed in 1997. The trust was awarded Foundation Trust status in June 2007.

The hospital provides a full range of district general services, including an accident and emergency department, and links with satellite units in five community hospitals.

They are the main provider of acute hospital services to a population of around 210,000 living within Weymouth and Portland, west Dorset, north Dorset and Purbeck.

The trust's 3,000 staff work in GP surgeries, schools, residential homes and people's own homes, as well as Dorset County Hospital and the community hospitals.

Dorset County Hospital has approximately 400 beds, seven main theatres and two day theatres, and has been designed with a major commitment to Public Arts in Hospital. Related services are grouped into three connected wings: North, South and East.

Cancer Services

Cancer patients are treated throughout the trust and services include:

- Acute oncology
- Haematology
- Investigation and diagnosis of cancers
- Care and treatment of patients with solid tumours
- Chemotherapy services including community outreach chemotherapy
- Palliative care and end of life care

Clinical nurse specialists:

- three Macmillan breast care nurses are included within the Cancer Nurse Specialist team across the cancer service teams. Their primary role is to provide information and guidance to women and men with breast disease. Although the main focus of the work centres around patients with breast cancer
- a Macmillan-sponsored dietitian works predominantly with patients treated for upper and lower oesophageal cancers
- a new Macmillan-sponsored associate cancer nurse post spans Lung, Upper GI and Cancer of the Unknown Primary teams.

There are five breast cancer support groups within the area, which are self-managed and include a young persons' group. All the groups meet monthly, with the breast care nurses regularly attending meetings. In addition, there are local support groups for colorectal, head and neck, urology and skin.

Macmillan Patient Experience team

The Macmillan Patient Experience Team is running an innovative project at Dorset County Hospital. They are working with cancer care services to put patients and staff at the heart of service design. The team does this using a process called experience-based design. In essence, this is a means of collecting the thoughts, feelings and experiences of people who use and deliver services, and using this information to shape or co-design service improvements.

The project is all about building great relationships with patients, doctors, nurses, service designers and all the other 'stakeholders' involved in Dorset cancer services.

'We are focused on innovation and looking at different ways of working. For example, we helped establish the chemotherapy service in the community.'

Anita Thomas,

Associate Director for Cancer and Access Services

The way they work

The associate director, cancer services manager and lead cancer nurse work closely together to manage the cancer services across the trust and also to promote improvement. Though they do not line manage the clinical nurse specialists, they work closely with them and are informed by the results of the CPES. They also work with the Patient and Public Experience team and have been involved in the experience-based design programme where this has focused on cancer specific areas.

CPES data

There is a full-time cancer information manager who receives the CPES data first. They then feed this into a data platform that enables comparison with previous years and drills down into specific tumour groups.

This information is then presented in an engaging way using infographics and statistics are discussed and shared with multidisciplinary teams. The cancer services manager or the lead cancer nurse helps facilitate these discussions. The CPES results are then fed into the multidisciplinary teams' annual general meetings and incorporated into their workplans. The results form part of the performance framework for multidisciplinary teams along with waiting time, clinical audit and outcome data. This information informs the individuals and the whole team on improvements and areas for further development.

The survey results, including the free text, are then used to assist in the design of local surveys. This is to better understand the poorer performing areas and why some tumour groups have a different experience to others.

The CPES and experience-based design work formed the basis of the cancer services' strategy days, held every six months. This means that the strategy remains patient focused and alert to new concerns.

Each multidisciplinary team has an annual general meeting where they will discuss operational policies, work plans and peer review together, as well as any pathway changes under consideration. Patient experience data informs all of these discussions. This data may come from several sources including CPES, experience-based design work and local data, for example from the breast service which runs their own specific local survey annually.

Teams also have access to the raw data and use this to further their understanding. They can also find their own comparators, which may sometimes be other local providers, but could also be similar services in other parts of the country.

The cancer teams are also supported by the patient and public experience lead and team. To make service improvements, they promote understanding of the patient, carer and staff experience across the trust. The team uses NICE and Care Quality Commission quality standards to measure patient experience, also focusing on learning from complaints and compliments using human factors and experience-based design. In doing so, they have reduced complaints about compassionate care across the trust by over 50% in a year.

Service improvements made as a result of CPES feedback

'Having seen the general themes from the CPES data, we realised we needed a much more detailed analysis to really understand what the problems were and therefore what the solutions might be.'

*Sarah Silverton,
Patient and Public Experience Lead*

The first year of the CPES exposed a need for a deeper exploration of some services. This was to determine what patients and their families need and want from the service and what it is like for staff to work in that service. It was with a view to using this to 'co-design' service improvements, with staff and patients working together.

In addition, the CPES highlighted a need to monitor experience at regular intervals to ensure that changes are made throughout the year. As a result, Dorset County Hospital focused on two key activities: the experience-based design approach and the use of real-time data.

The experience-based design approach

Dorset County Hospital takes an innovative approach to improvement and patient experience, with an emphasis on a proactive approach to making improvement happen.

An example of this innovation is the way the trust analysed the CPES data and drilled down into specific areas using an experience-based design approach to improve patient and staff experience. There is also a culture of learning, especially from complaints.

The trust chose five cancer sites in the first round of experience-based design work. It held an improvement event which prompted ideas for service improvement, followed by co-design to explore the detail of what needs to change. The upper GI experience-based design programme involved a whole system approach. It looked at the patient journey beyond the trust, involving Bournemouth and Poole hospitals.

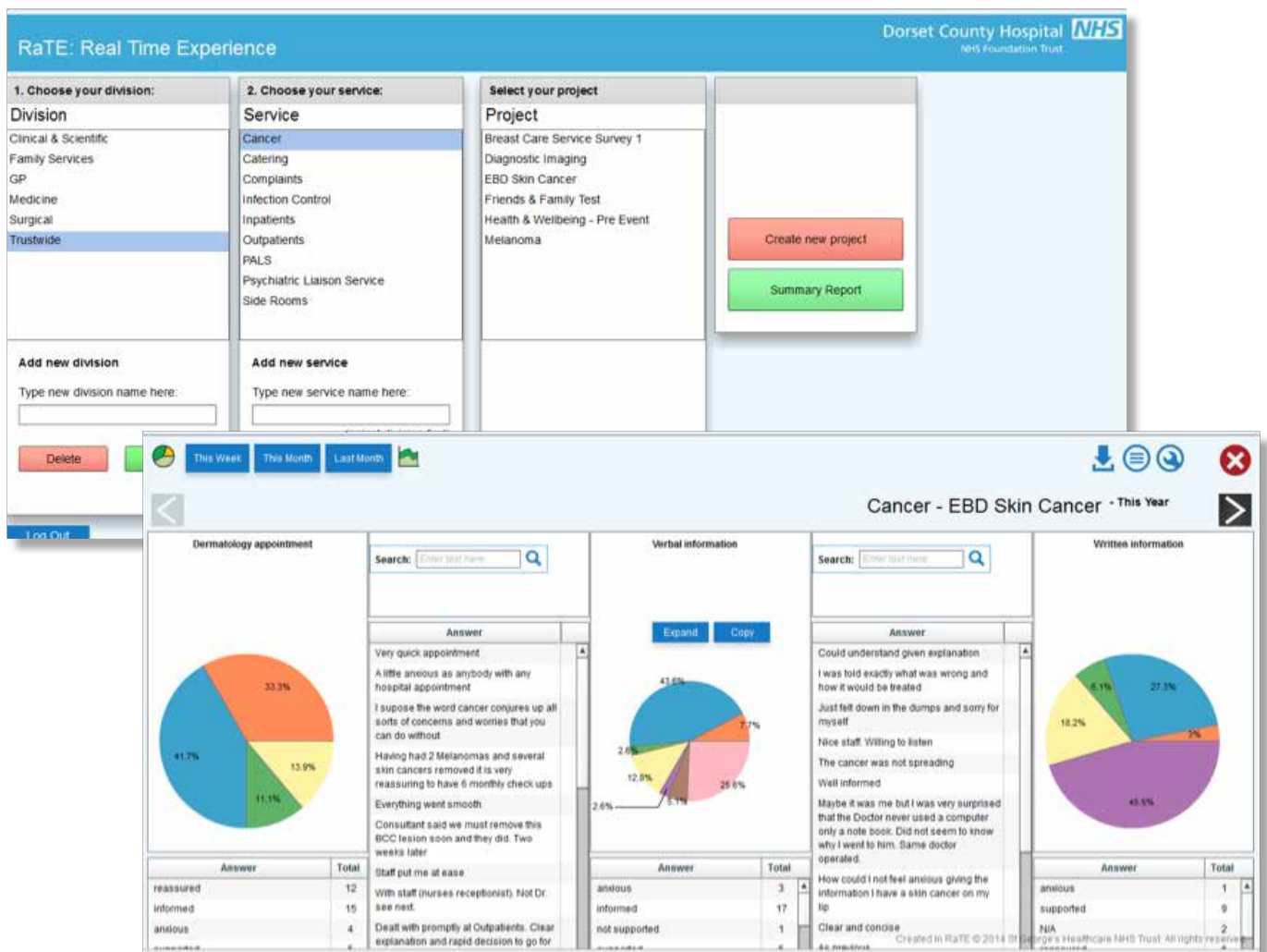
Other disease sites are using a similar approach to promote a better understanding of the whole patient pathway and where service improvements should be focused within that. There is an emphasis on facilitation and enabling staff to gain the confidence to use the experience based-design tools to understand and improve patients' experience of care on an ongoing basis.

A number of improvements have resulted from this work and we include some here:

- a volunteer is being recruited to start early in the morning and meet and greet cancer patients undergoing surgery
- a microsite is being designed for lung cancer patients which, if successful, will be rolled out to other cancer services
- the Macmillan Values Based Standard has been launched with the allied health professionals.

Using real-time data

There is some 'bespoke' measurement as part of the experience-based design work and the annual national data from the CPES. However, the trust believes it is important to keep a range of consistent measures on an ongoing basis. This will allow for regularly recording progress over a longer period of time. The focus at Dorset is on complaints, compliments and a real-time data system. The trust use the Real Time Experience (RaTE) 2013 website, which was created by St George's Healthcare NHS Trust, to map the emotions to the contact points.



CASE STUDY 3

'In our trust, as in most health services, the same complaint themes emerged year on year, indicating that we were not doing enough to learn from complaints.'

*Sarah Silverton,
Head of Patient Experience*

Complaints data and emotional mapping

The trust also places emphasis on learning from complaints to bring about improvement, in addition to the experience-based design programme of work. The trust's data suggests that nearly half of NHS complaints relate to patient interactions with healthcare staff. So, improving compassionate care as a response to complaints requires a culture shift in seeing every complaint as a learning opportunity.

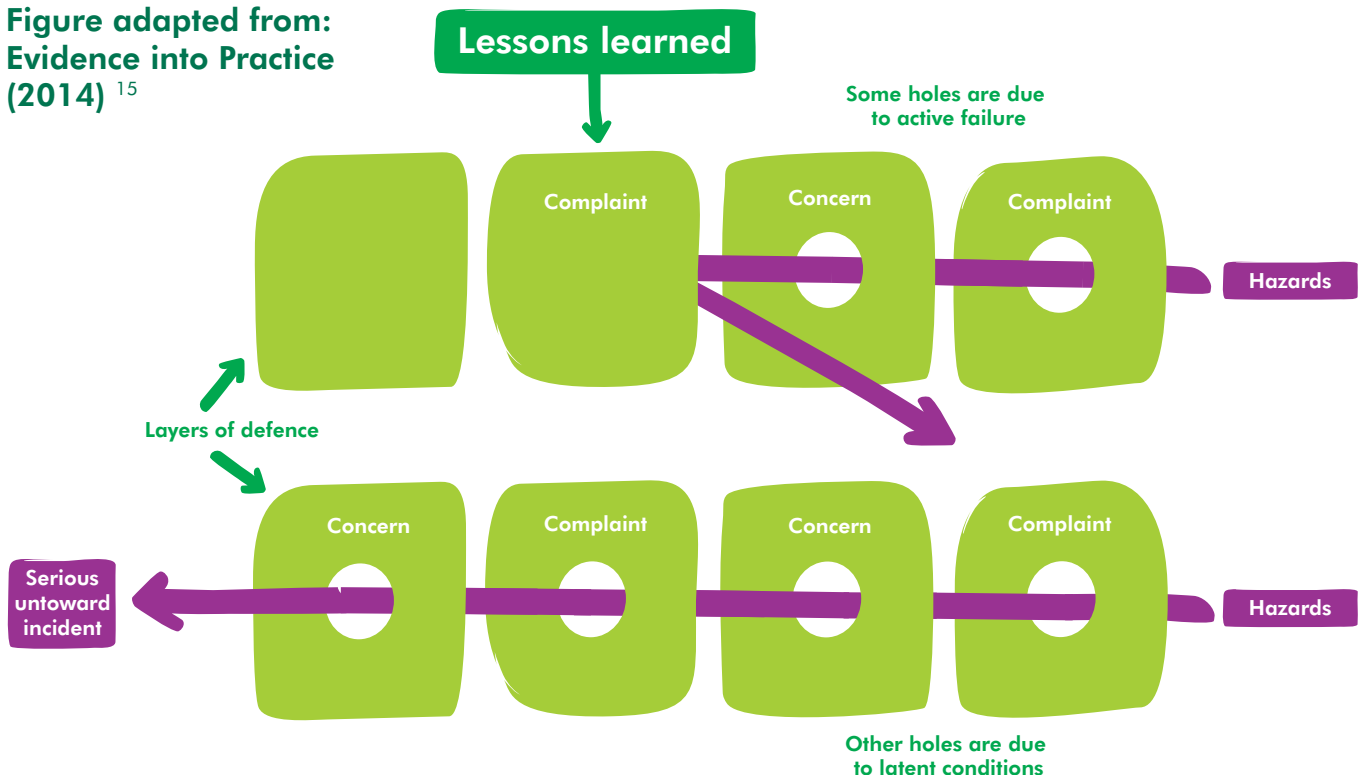
All the complaints during 2013–14 were coded according to QS15 NICE quality statements in adult inpatient experience. The trust then focused on learning from complaints coded to QS15 NICE Statement 1: 'Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.'

Workshops with staff helped to encourage a more analytical response to complaints. This involved emotionally mapping the complaint from patient and staff perspectives, and using the Swiss cheese model in clinical human factors to promote understanding (see figure below).

These emotional mapping exercises take place with all the staff throughout the Trust, clinical and non-clinical, using 'live' complaints about compassionate care from their own departments. Staff from across the trust reflect on complaints and their emotional map in ward rounds, at divisional and departmental meetings, junior doctors' training, porters' and housekeeping briefings, and at sisters' and matrons' meetings.

This process resulted in a 61% decrease in complaints about compassionate care by quarter three 2013/14, which was sustained in quarter four. There was also an 87.5% decrease in complaints referred to the parliamentary and health service ombudsman in 2013/14 from the previous year.

Figure adapted from: Evidence into Practice (2014)¹⁵



Key learning points

Theme 1 – Strong proactive leadership in patient experience with an emphasis on learning and improvement shared with and involving the multidisciplinary teams

Theme 2 – Improvement approaches that involve emotional mapping to understand more about patient and staff experience, and facilitated support to achieve this

Theme 3 – A small number of consistent measures to provide a comprehensive picture that staff and patients can easily understand, share and use to inform improvement work

Next steps

The trust will continue to roll out the experience-based design approach across cancer services and other specialties within the trust. This means that it will continue to be embedded as a trust-wide approach to using patient experience to inform service improvement.

The Macmillan patient information project is using patient and carer experience to improve information provision across Dorset.

The trust is using patient experience to plan for future services, particularly to support the trust strategy of integrated care.

The NCPES and other experience-based design work raised the profile of patient experience and how fundamental it is in all elements of care and service we provide. It helps staff focus on the quality aspects of the service, not just on efficiency.

Our Macmillan allied health professionals are working on a number of projects around the Macmillan Values Based Standard.

Thank you to the staff and group members who supported the development of this case study:

Sarah Silverton, Patient and Public Experience Lead
Abigail Orchard, Lead Cancer Nurse
Anita Thomas, Associate Director for Cancer and Access Services

Gill Faley, Macmillan Patient Experience Project Lead
Tom Magill, Senior Analyst, St Georges Healthcare NHS Trust, London (for use of the RaTE website for data capture and analysis)

Measurement Systems – Guy’s and St Thomas’ NHS Foundation Trust and King’s College Hospital NHS Foundation Trust

Read this case study for examples of: **Engaged staff, patient voice, use of free text and Measurement systems.**

Skilled analysis of free text enables teams to gain a greater understanding about what the CPES data means for their service. Methods such as experience-based co-design are used to engage staff and patients in service improvements. Extensive patient involvement, including outreach work with seldom heard groups, adds value and raises the profile of patient experience.

‘We aim for our cancer services to be internationally recognised, patient centered and focused on people’s needs, as well as clinically excellent and underpinned by groundbreaking research.’

*Catherine Dale,
Programme Manager for Cancer*

Setting the scene

Guy’s and St Thomas’ NHS Foundation Trust and King’s College Hospital NHS Foundation Trust is part of King’s Health Partners.

Cancer Services at Guy’s and St Thomas’

The trust runs the largest NHS cancer service in London and all radiotherapy for patients across south-east London. Research and education activities help give patients the latest treatment and innovations, including robotic surgery and new methods of directing radiotherapy. Where complications arise, patients can be fasttracked

through the acute oncology assessment unit rather than waiting in A&E. There are special cancer wards run by specialist staff. The focus is on the whole person – staff aim to look at how cancer affects patient’s emotional, social and family life too. In addition, there is an emphasis on emotional and psychological wellbeing – with psychological teams offering support to help patients cope with their cancer journey.

The Dimpleby Cancer Care Service

Dimpleby Cancer Care is a support and information service for patients and their carers from south-east London and west Kent. There are drop-in centres at the Guy’s site and at St Thomas’. Staff work closely with the clinical teams to ensure people have all the information and support they need while having cancer treatment at Guy’s and St Thomas’.

Cancer Services at King’s College Hospital

King’s College Hospital at Denmark Hill is a specialist centre for haemato-oncology (cancer of the blood and circulatory system), neuro-oncology (cancer of the brain and central nervous system) and liver cancer. King’s is also a regional centre for breast and bowel cancer screening.

Macmillan Information Centre

The Macmillan Information Centre is in the Cicely Saunders Institute on the Denmark Hill site of King's College Hospital. The centre provides help and support to those living with cancer or who have had cancer or any other long-term condition. The drop-in centre also assists carers, relatives and friends.

'Our improvement aim is to engage and skill up our staff to enable them to focus on patient experience, engage patients, run their own groups and go beyond individual projects.'

*Catherine Dale,
Programme Manager for Cancer*

The way they work

Catherine Dale is the programme manager for Cancer for King's Health Partners. Her post covers strategic change management that specifically relates to cancer patient experience across King's College London, Guy's and St Thomas', and King's College Hospital.

While each organisation takes a separate approach to improving cancer services, the aim of the organisations together is clear. This aim centres around being internationally recognised for cancer services in terms of clinical outcomes and person centeredness, and groundbreaking in terms of clinical research. There is a specific focus on trying to meet people's needs.

There are some similarities between Guy's and St Thomas' and King's College hospitals in terms of their clinical and academic reputations. This is in that they both try to meet the needs of London's diverse communities. They are complex organisations dealing with complex cancer cases as well as tertiary referrals. This complexity plays out in their CPES results. Guy's and St Thomas' have made significant improvements in the past, featuring in the list of 10 most improved organisations. Whereas King's College Hospital continues to feature in the bottom 10 providers in England in CPES results.

In terms of a 'culture of improvement', both organisations see patient experience and continuous improvement as a core value. Guy's and St Thomas' chooses to put substantial resources into service improvement. Historically, though, this has been more in the field of efficiency than in robust methodologies that seek to improve patient experience. Kings College Hospital has worked to implement the Macmillan Values Based Standard in a number of areas across the hospital including chemotherapy outpatients, haematology and an acute medical ward.

CPES data

'Sometimes, trust-wide issues arise from the CPES data. This is where my role as lead cancer nurse is to coordinate how we respond across the whole trust.'

*Mairead Griffith,
Deputy Chief Nurse and Lead Cancer Nurse*

Processes exist at Guy's and St Thomas' and Kings College Hospital for analysing the data led by the patient experience teams. This is followed by a more detailed analysis which is fed back to multidisciplinary teams. At both trusts the process is top down and bottom up – the board take the survey seriously and there are discussions in the multidisciplinary teams). The data is sent to multidisciplinary teams by tumour group and they draw up actions plans which become part of their peer review process.

Once the data comes into Guy's and St Thomas' it is presented at a 'safe in their hands' staff meeting attended by a wide range of clinical and non-clinical senior staff. Detailed analysis then takes place, which is fed back via tumour groups with slide packs prepared to help teams understand what the data is telling them. Teams are asked to triangulate the CPES data with the trust-wide patient experience data and complaints to help draw out themes. However, triangulation is problematic because the CPES focuses on the multidisciplinary teams and tumour group whereas the trust real time data is ward and OPD based.

Real-time experience data tends to provide a much more positive picture than the data from the CPES. However, all those involved in the process at the trusts believe the data sent out to multidisciplinary teams succeeds in getting people talking about patient experience and thinking about how they might respond.

Where there are themes that arise from CPES that are trust-wide, the lead cancer nurse will direct work in this area. For example, the CPES highlighted a theme around poor communication. In addition to making advance communication courses available, the trusts rolled out Sage and Thyme. They also trained the members of each directorate to facilitate future courses to retain the skills on site.

For themes that arise from CPES that are multidisciplinary teams or tumour group specific, the improvement areas are the responsibility of the relevant group. These are picked up through their peer review process. A new approach this year is to engage the cancer committee members in brainstorming solutions that they then take forward. The cancer committee is made up of the cancer management team, multidisciplinary team leads, trust directors and GP representatives. There is an emphasis on the process of sharing CPES results. This is to communicate a clear message that the data needs to be owned by all and that the improvements and actions needed must not fall solely on the nurses.

Service improvements made as a result of CPES feedback

'While the CPES data does not drive all our improvement work, there are examples of specific changes that have come about because of the survey data.'

*Catherine Dale,
Programme Manager for Cancer*

There are a number of complexities in analysing the CPES data but there is also a challenge in using the data for improvement. There is such a small window between one set of data being fed back

and a new set of questionnaires being sent out. This means that it is difficult to drill down and focus on specific areas and then know the following year whether these led to an improvement.

This suggests that there needs to be a process in place that bridges the space from the CPES data to an improvement methodology such as Plan, Do, Study and Act. Nevertheless, there are examples of specific changes that have come about because of the survey data.

The clinical nurse specialist workforce

The CPES continuously shows that where patients are able to access a clinical nurse specialist, their experience is more positive. Together, the 16 organisations that make up the London Cancer Alliance mapped the current and vacancy rates of advanced and specialist nursing workforce. Future work will focus on succession planning and workload analysis.

At Kings College Hospital, people were reporting difficulty in contacting their clinical nurse specialist. The hospital set up a phone helpline, with trained administrators answering calls. This enabled the caller to have a discussion about what they felt was needed. Since the helpline has been in place evidence shows that often the right course of action is not direct communication with the clinical nurse specialist. Issues are resolved without encroaching unnecessarily on their time and patients are still able to access a clinical nurse specialist when this is what is required.

Analysis of the free text

'Analysis of the free text comments helps us to better understand patients' experience of care and highlight areas for improvement. When teams can clearly understand what patients are saying and what the real issues are, change can happen.'

*Jerrina Eteen,
Lay Member, Cancer Clinical Academic Group (CAG)
Executive Board*



Both trusts experience high volumes of free text in the CPES data and do not have an in-house analysis team. Guy's and St Thomas' was fortunate in the fact that a volunteer with expertise in this area offered to help with the analysis. (This is Jerrina Eteen, a lay member of the Cancer CAG Executive Board).

Qualitative analysis is used to theme the data. This is a laborious process because the data is sent in a PDF format and cannot easily be interrogated or manipulated. This analysis takes about a week but the trust believes that it is a vital process to allow sense to be made of the data. Teams report that this is a valuable source of information about how patients and families experience the service.

The pathway approach

Both trusts are keen to try and explore patient experience across the pathway. However, there are limitations on how the CPES data can provide a useful picture across a pathway. This particularly applies in the sense that patients come from at least six boroughs across London and therefore experience a multitude of other services. Nevertheless, some work is progressing at Guy's and St Thomas' in one clinical area. This is one where there is evidence that the relationships between primary care and the trust mean that when patients move between the organisations they're not being as well managed as they could be. The trust is looking to forge new relationships with practice managers, which it is hoped will ease the transition between services. In addition, the trust is also providing training for practice nurses around psychological support.

Patient and family involvement

Guy's and St Thomas' encourages patients' and families' involvement in improving cancer services. It has a strong cancer patient reference group for developing and designing the new cancer centre at Guy's with 25 plus members. (King's, too, is now introducing this approach). Chaired by a patient since its inception, the Guy's group has been able to encourage positive and ambitious changes in cancer services.

The trust put detailed work into designing and recruiting the reference group. It also looked at moving people from focusing on 'my story' to 'our story' so that individual agendas do not dominate. The success of this model is now being replicated in other places. Catherine Dale, Programme Manager for Cancer, sees it as part of her role to help equip staff with the confidence to support patient involvement and reference groups such as this. Catherine emphasises the need to build 'energy' around patient involvement and experience rather than only focusing on 'infrastructure'. It is an interesting distinction, and one that aligns to connecting people and helping secure relationships as well as empowering staff.

Under-represented groups

CPES reporting exposed that the surveys do not always capture everyone's views. The trust was interested in working more with communities who may be under-represented. This resulted in some work across specific service areas.

This included a project with Breast Cancer Care which targeted black African and African Caribbean women, as they report a poorer service. The team used experience-based co-design methods to help understand the women's emotional journey through the service. To do this, the team went out to the local community, using Peckham Library as a meeting venue and ensuring that people were individually invited by someone they knew.

Films highlighted the key themes. Local hospital and community staff worked with the women to explore the Moving Forward literature. They helped them look at how to cope with and adjust to life after treatment, and how it could be more culturally appropriate and accessible. Changes were made to the information including:

- lymphoedema – to include information on long-distance travel to hot countries, as some may need advice about travelling to their country of origin
- healthy eating after breast cancer – to include culturally relevant African/Caribbean food and where to find healthy alternatives
- understanding breast cancer treatments and managing side effects – to include information on how to manage side effects on black skin, nails, and hair loss and regrowth
- adjusting and adapting after a diagnosis – to emphasise that it's ok to ask for help, as many may feel the need to be strong and get through it by themselves. Also to include information on how to access group and one-to-one counselling
- intimacy and relationships – information to take account of different family contexts, for example, lone parents; the taboo of talking about sex and sexuality.

The trust will build on these discussions when co-designing and developing new post-treatment self-management interventions. In addition, experience-based co-design workshops are planned with cancer survivors from an Asian background. People who have had had cancer and stakeholders welcomed being consulted in a more inclusive and culturally appropriate way.

'It is really important to go out to people where they are – don't always ask them to come to you and try to use venues they know. You also need to think about how they are invited and by who. These things make a real difference.'

*Catherine Dale,
Programme Manager for Cancer*

Key learning points

Theme 1 – Skilled analysis of free text enables people to gain more understanding about what the data means

Theme 2 – You cannot move from CPES data straight into improvement areas – you need to drill down more into services and methods such as experience-based design help with this

Theme 3 – A carefully established patient reference group can be of great value

Theme 4 – Going out to harder-to-reach groups of people can help bring insight and real involvement

Thank you to the staff and group members who supported the development of this case study:

Catherine Dale, Programme Manager for Cancer
Jerrina Eteen, Lay Member, Cancer CAG Executive Board

Mairead Griffith, Deputy Chief Nurse and Lead Cancer Nurse, Guy's and St Thomas'
Anne Duffy, Lead Cancer Nurse, King's College

A patient-centred culture – The Royal Marsden NHS Foundation Trust

Read this case study for examples of: **engaged leadership, patient engagement, partnership working.**

The Royal Marsden strives to create a culture of evidence-based practice where staff feel valued and patients are listened to. They endeavour to extract as much value as possible from the CPES alongside other experience and patient participation activities. An in-depth analysis of the free text brings the CPES data to life. This, along with processes to encourage ownership of the results, places the emphasis on continuous improvement. Positive changes are rewarded and celebrated.

Setting the scene

The Royal Marsden opened its doors in 1851 as the world's first hospital dedicated to cancer diagnosis, treatment, research and education.

Today, together with its academic partner, the Institute of Cancer Research, it is the largest cancer centre in Europe. The Royal Marsden employs over 4,000 staff and treats more than 50,000 NHS and private patients every year. It is a specialist centre enjoying close partnerships with local research and education institutions. The Royal Marsden has two hospitals: one in Chelsea, London, and another in Sutton, Surrey. It also has a chemotherapy medical daycare Unit at Kingston Hospital. The Royal Marsden also provides community services in the London boroughs of Sutton and Merton and has an academic partnership with Mount Vernon Cancer Centre in Middlesex.

The Royal Marsden is a founder member of the London Cancer Alliance (LCA). Established in 2011,

the LCA is the integrated cancer system across west and south London, serving a population of over five million. The LCA aims to work collaboratively across the integrated system to deliver safe and effective care, improve cancer clinical outcomes and enhance patients' and carers' experience and quality of life.

'It's a great place to work: well-resourced, staffing levels good. We are relatively small, people know each other and we know our patients.'

*Sarah Wemyss,
Clinical Nurse Specialist, Medical Oncology*

'We are a learning organisation and one of our core values is continuous improvement. We set the bar high for recruitment and for staff wellbeing, because good staff who are valued will improve patient care.'

*Dr Shelley Dolan,
Chief Nurse*

The way they work

Valuing staff and engaging them in improvements

‘One of the ways to raise experience of patients is to raise the knowledge of nurses.’

*Suzanne Chapman,
Clinical Nurse Specialist, Pain Management*

CPES data is shared widely in the trust with a view to encouraging ownership of the feedback and ideas for improvement/actions required as a result. The CPES results are disseminated and discussed in a range of settings, via existing meetings, including the clinical nurse specialist monthly meeting, team and division meetings, open meetings and the senior nurses’ away days. Action plans are developed and regularly reported on. The patient experience group meets monthly to monitor and maintain momentum.

Nursing is incredibly valued within the Royal Marsden, both by patients and other staff. There is also a shared belief that the leadership style of the chief nurse) has had a significant impact on the organisational culture. This is with specific reference to her credibility, knowledge of cancer and personable approach. All senior nurses are involved in ‘back to floor Fridays’ and work directly with teams to improve services.

The Royal Marsden has made efforts to have a higher-than-average number of staff, as well as skills mix. This strategy came from a range of feedback mechanisms and reports, including CPES and the Francis report. In early CPES free

text analysis, comments relating to poor care indicated a link to staff numbers, the use of agency staff at weekends and nights, and communication skills. This has resulted in few/no bank staff being used at weekends, matrons carrying out regular staff to patient ratio checks, and a general increase in staff ratios. In addition, other support staff, such as porters, security and ward clerks are often employed directly, which has helped with recruiting and retaining the right people. Efforts are made to recognise and reward compassionate practice, for example a porter who was buying one of the patients an Arabic newspaper on the way to work.

The Royal Marsden has a policy around supporting continuous learning by offering study leave and access to higher education. They have the highest number of nurses working clinically with a PhD.

As a result of CPES, among other feedback mechanisms, an audit was carried out across the London Cancer Alliance. This was about how clinical nurse specialists spend their time along with self-reflection on their role and career progression. As a result, the Royal Marsden is introducing a clinical nurse specialist development plan.

Values-based practice

‘It’s really changed the way we recruit.’

*Keetje Gull,
Clinical Nurse Lead, Critical Care*

The Royal Marsden is shaped by a distinct set of values. These 16 values were developed over five years ago by staff from all areas of the organisation and levels of seniority:

Characteristics (what we are)	Attitudes (how we act)	Relationships (relating to others)	Emotions (how we feel)
Pioneering	Determined	Collaborative	Compassionate
Knowledgeable	Open	Trusted	Calm
Aspirational	Confident	Supportive	Positive
Driven	Resilient	Personable	Proud



The critical care unit wanted to re-launch these values as they felt they had lost sight of them over the years. Through a process of thematic analysis and testing, they have developed their own set of core values: compassionate, open, personal and supportive.

The trust organised a high-profile launch for the CCU values via a reception on the unit attended by CCU staff, the chief executive, other site sisters, matrons, directors, former patients and relatives. One relative was asked to unveil the values plaque for CCU and spoke about what the values meant to her and her husband during his stay at the critical care unit. Pin badges and flash cards were produced for staff and a special values screen saver montage ran for 24 hours on CCU computers.

Recruitment now involves a values-based assessment, tailored to the post and seniority. The core values are used in appraisals and are being used to shape performance management. In addition, the CCU introduced the monthly 'Above and Beyond Award' whereby they celebrate a member of the team who has demonstrated the CCU values in their work. Staff are nominated by colleagues and the team use family and patient thank you cards to identify excellent care. This work is leading to other similar initiatives around the hospital.

In-depth analysis of CPES free text

'It really makes a difference when people can hear the patient voice. The comments really illuminate the ways in which things could be better – they show you what you need to do differently.'

*Dr Theresa Wiseman,
Lead for Health Service Research*

Working in partnership, the London Cancer Alliance (LCA) and London Cancer commissioned the Health Service Research team at the Royal Marsden to analyse the free text in the CPES. This free text analysis was completed for both 2011/12 and

2012/13 data, allowing for some comparisons. Using Framework Analysis (Ritchie and Spencer 1994, 2004), the group was able to analyse the data and present findings by trust and tumour group. By comparing the data they are able to see that the number of comments has increased by 75% (8,862 in 2011/12 and 15,603 in 2012/13). They also saw that there has been a shift by 5.5% in a positive direction for London.

The free text analysis is fed back widely, internally and across the network, and informs the working groups including tumour groups. Specifically at the Royal Marsden, the free text results are shared in the nursing and allied health governance group, the medical group, the patient and carer advisory group, and by service specific routes.

Engaging patients in the improvements – Patient and Carer Advisory Group (PCAG)

'PCAG is about identifying opportunities to make things better, giving the patient perspective on new initiatives and being able to ask questions and give feedback on survey results and action plans.'

*Fiona Stewart,
PCAG Member and Patient Governor, the Royal Marsden*

PCAG is for patients, carers (partners, relatives or friends) and members of the public. The group meets regularly to collaborate on a wide range of issues. Minutes of meetings are available on the trust website. The group reviews the CPES results, including free text analysis and action plans, and gets involved in a range of improvement initiatives. They also carry out direct observations and conduct surveys with patients.

PCAG reps attend other groups to advise on service improvements, for example safety, consent, clinical audit and an arts forum. They also speak at conferences and share stories. All members sign a comprehensive good practice declaration that sets out the expected behaviours and values of the group. The Royal Marsden hosts regular

PCAG away days, facilitated by Macmillan chairing workshops which are not just for chairs, so all have an opportunity to understand the role, among other opportunities. The group regularly considers their mode and practice, reviewing and injecting new energy when required.

You Said, We Did posters are displayed in the hospital. These highlight specific improvement projects and demonstrate the Royal Marsden is an organisation that listens to feedback and makes changes, however small, to improve experience.

A culture of improvement

'At every point, it is everyone's responsibility to make experience better – learning from incidents, surveys, following through on action plans. Everyone buys into it and knows what's expected.'

*Craig Mortimer,
Quality Assurance*

There have been a number of improvements made as a result of the CPES. However, it is also important to consider CPES in the context of quality reporting, governance and accreditation. In addition to CPES data, the trust collects experience feedback in a range of ways and is able, as much as possible, to review the data for common themes including:

- PALS reports
- complaints and compliments
- Viewpoint (a PCAG initiative to encourage people to feedback via postboxes in the hospital)
- Listening Post (a PCAG initiative whereby members collect feedback in person rather than written form)
- friends and family test
- local surveys
- Care Quality Commission national inpatient survey
- Customer service excellence standard (annual inspections).

Evidence-based practice

'Do the best you can. Research the evidence. If the evidence has changed, we change.'

*Dr Shelley Dolan,
Chief Nurse*

'We don't do anything without evidence. We have to take responsibility – it doesn't come on a plate but we work hard to get results.'

*Justine Hofland,
Divisional Clinical Nurse Director*

In addition to a culture of evidence-based practice, there is extensive staff involvement in the process of business planning across the trust. Decision-making, information and feedback routes are clear throughout the organisation, with an emphasis on providing evidence for decisions.

Service improvements as a result of CPES feedback

'We get feedback straight from the patient and are able to do something about it – this means less complaints and a better experience.'

*Andreia Fernandes,
Clinical Nurse Specialist , Gynaecology*

The trust has implemented a range of improvements in recent years, many a result of the CPES in conjunction with other feedback mechanisms.

Badges

Patients fed back that they couldn't read the badges because of the colours and the size of the font. All badges have been changed so that they are easy to read with a large font.

Information

Patient feedback led to a re-design of the keyworker contact card, including new colours and information on out-of-hours contact.

Purple folders

New patient packs have been developed, highlighting the role of the team secretary, multidisciplinary team and cancer nurse specialists.

Admissions letter

CPES identified that patients weren't aware they could bring a friend or relative with them to their appointments. A review of all letters followed the CPES and resulted in every trust letter being updated to include a line letting people know that they can bring a support person with them.

Clinics that overrun

Timings are now announced so, for instance, if a particular consultant is running 20 minutes late the reception staff announce this to the waiting room.

Outpatients

Waiting times were highlighted as an issue. The clinic timings have been changed to fit with a more realistic day and an appointments clerk recruited to set future appointments with people there and then. The environment was highlighted as an issue in outpatients and has resulted in a cafe run by Friends of the Royal Marsden, a fishtank, new chairs and colour coded zones.

Phone clinic

The hospital has introduced a system where nurses phone patients after their first round of chemotherapy. This service is found to be especially important for those who are living alone or who have had problems in the past. It enables the team to pick up problems that may need further investigation before they become urgent.

PAIN assessment tool

The various pain scales are now available in one tool, which includes numerical rating, faces, a thermometer and ratings for people with dementia who cannot verbalise pain.

Examples of suggestions made by the PCAG that have been implemented:

'We are very involved in work in lots of areas of the hospital.'

*Anita Gray,
PCAG Chair*

'The hospital does take notice of suggestions made by the PCAG; the hospital wants to provide its patients with the best experience possible.'

*Fiona Stewart,
PCAG Member and Patient Governor, the Royal Marsden*

- there is a better choice of magazines in the chemotherapy suite and waiting rooms
- patients are able to wear their own clothes for a CT scan, when it isn't clinically necessary to change into a hospital gown
- there is a new option of one-stop or two-stop chemotherapy. For some patients it is easier to have blood tests one day and appointments the next to avoid waiting at the hospital between the two. For other patients, having everything in one day is preferable
- patients reported that wards are noisy at night when people make mobile phone calls. The hospital immediately made the rule of no mobile conversations after 10pm, only silent mobile use
- for those who have to travel a distance to the hospital, repeat prescriptions are now available locally.

'People want to do well. They are interested and motivated.'

*Dr Theresa Wiseman,
Strategic Lead of Nursing Research*

Key learning points

Theme 1 – Evidence, research and continuously learning

'We are absolutely committed to quality improvement. If we are falling short we want to address that quickly in a suitable way.'

*Dr Isabel White,
Clinical Research Fellow in Psychosexual Practice*

'It's our job to ensure that the impact of our decisions is positive for patients. Even when we are making financial decisions we need to consider the impact on patient experience.'

*Justine Hofland,
Divisional Clinical Nurse Director*

Theme 2 – Valued staff

'There isn't anyone I couldn't ask for advice.'

*Justine Hofland,
Divisional Clinical Nurse Director*

'Staff feel supported – there are opportunities to ask advice, leaders are visible, communication is two way. We can share good things that have happened.'

*Suzanne Chapman,
Clinical Nurse Specialist, Pain Management*

Theme 3 – Listening to feedback, and improvement culture

'There is a clear message that patients are at the centre of everything we are doing.'

*Suzanne Chapman,
Clinical Nurse Specialist, Pain Management*

'No matter what the job is, patients are the thing that drives us. They are our customers – they deserve the best service possible. It's a human life, so even more important.'

*Justine Hofland,
Divisional Clinical Nurse Director*

Theme 4 – Working across a network and bringing data to life

'The free text is very useful and helps us to pick up some fascinating and useful information.'

*Craig Mortimer,
Quality Assurance*

'The quotes give us more depth, tell us how it feels.'

*Sarah Wemyss,
Clinical Nurse Specialist, Medical Oncology*

Next steps

All senior nurses will be involved in 'back to floor Fridays' and work directly with teams to improve services.



Thank you to the staff and group members who supported the development of this case study:

Fiona Stewart, PCAG Member

Anita Gray, PCAG Chair

Dr Shelley Dolan, Chief Nurse

Theresa Wiseman, Strategic Lead of Nursing Research

Amrit Sangha, Research Assistant

Grace Lucas, Research Assistant

Justine Hofland, Divisional Clinical Nurse Director

Sarah Wemyss, Clinical Nurse Specialist, Medical
Oncology

Craig Mortimer, Quality Assurance

Andreia Fernandes, Clinical Nurse Specialist,
Gynaecology

Dr Isabel White, Clinical Research Fellow in
Psychosexual Practice

Suzanne Chapman, Clinical Nurse Specialist,
Pain Management

Keetje Gull, Sister, Critical Care Unit

Elaine Parr, Head of PR and Communications

Maintaining consistent high standards – Gateshead Health NHS Foundation Trust

Read this case study for examples of: **Improvement culture, engaged leadership, measurement systems.**

Gateshead scores consistently high in the CPES and has used the results to inform their service experience improvement work. Well-thought through systems and processes encourage shared ownership of the data and resulting actions. The CPES is embedded in and supports peer review, and a range of experience measures are used to complement the national survey.

You said:

'It's too hot here, there is poor air conditioning'

We did:

The air conditioning was adjusted to make the environment more comfortable for children on that ward.

You said:

'We could do with some music at Bensham physio'

We did:

There was already a radio in the department so it was repaired and now it is working properly.

You said:

'It's difficult to find the outpatients department with the roads and entrances blocked off'

We did:

Improved the information on appointment letters to show better directions while building work continues.

'The trust has got a really good patient-centred culture. Staff are developed. There is a can-do attitude.'

*Alison East
Nurse Consultant, Acute Oncology*

Setting the scene

Gateshead Health NHS Foundation Trust runs Gateshead Hospital, Queen Elizabeth Hospital, Dunston Hill Hospital, QE Metro Riverside and some services at Bensham Hospital, all within Gateshead. It also runs services from Blaydon Primary Care Centre and Washington Primary Care Centre, as well as a specialist 12-bedded unit in Houghton-le-Spring for patients who require rehabilitation care.

As well as a full range of local hospital services, the trust provides breast screening services for Gateshead, South Tyneside, Sunderland and parts of Durham. It is also the north-eastern hub for the National Bowel Cancer Screening Programme. This covers an area east of the Pennines stretching from the Scottish border to Humber, a population of around seven million people.

Gateshead was one of the first foundation trusts in the country, established in 2005. It employs more than 3,000 people and is the second biggest employer in Gateshead.

The cancer services based at the Queen Elizabeth Hospital, Gateshead, are delivered by tumour site multiprofessional teams. They serve the city of Gateshead and the surrounding area in the South of Tyne & Wear PCT with a population catchment of 230,000. Common cancers are treated within the cancer unit at Gateshead hospital. However, some treatment pathways can span across hospitals known as cancer centres, such as the Royal Victoria Infirmary & Freeman Road Hospital. The Queen Elizabeth Hospital, Gateshead hosts the Northern Gynaecological Oncology Specialist Centre (NGOC), which treats all gynaecology cancers. Children's cancer's referrals are usually made directly to Newcastle Hospitals Cancer Centre.

Gateshead was ranked first in the national CPES 2012–13 and has consistently sat in the top five performing trusts nationally.

The way they work

Patient, carer and public involvement

This is a key focus within the trust, with ongoing learning from PALS, NHS Choices and patient surveys. The trust also strives to work closely with local voluntary and patient groups. The patient, carer and public involvement group produces an annual report including information and results from a range of patient experience measurement and monitoring systems. These include:

- 15 steps challenge
- friends and family test
- PALS (Patient Advice and Liaison Service)
- NHS Choices
- Care Connect
- local inpatient and outpatients surveys
- listening posts.

There is an emphasis on further development in the trust. Everyone is given an opportunity for postgraduate study and encouraged to carry out leadership training.

The cancer teams analyse the CPES results and share them with key groups across the trust including:

- trust board and senior management
- cancer unit meeting
- GP cancer leads and clinical commission groups
- Monday morning senior nurses meeting
- Director of Nursing –senior line managers and matrons
- clinical nurse specialist meeting
- patient partnership panel.

CPES results are integrated with peer review processes. Each multidisciplinary team produces an operational report, annual report and work plan. This is subject to internal validation, which also involves service users.

CASE STUDY 6

The CPES is viewed in the context of a range of experience measures and improvement mechanisms which are highlighted on the trust website. Most cancer teams carry out their own local surveys, using some of the CPES questions among others to elicit real time/in-year responses. For example, in the lung service local surveys have revealed challenges with diagnosis, breaking bad news and providing information. These in-year surveys are shared with the team and enable improvements to be made on an ongoing basis. As a result there are never any surprises in the national survey.

Patient, carer and public involvement

The trust vision places patients firmly at the centre of all activity. There is an emphasis on asking, listening and understanding patient needs and expectations in the approach to planning services as well as delivering them. This involvement operates on three levels:

- **Individual participation/involvement**
This is about an individual being involved in discussion and decisions relating to their own care and treatment, and their personal experience of care, and respecting a patient's right to be in control of their care.
- **Public participation/involvement**
This concerns the wider public, patients and carers being involved in discussions and decisions about health and care services, which may be more strategic in nature, involving the planning and delivery of services.
- **Patient experience**
Patient experience measures the experiences of patients in receiving care and treatment in services with a focus on improvement.



Service improvements made as a result of CPES feedback

'We can learn from each other and everyone is approachable. There is no such thing as a daft question.'

*Pauline Connelly,
Breast Care Nurse Specialist*

Clinical nurse specialist professional development

The trust has introduced a clinical nurse specialist and senior nurse personal development plan. In addition, Gateshead has set up mechanisms for reflective practice, a huge drive for leadership development and supported postgraduate and practice-related development.

Breast team

There is an emphasis within this team on developing supportive relationships with patients, with the same keyworker maintained all the way through a patient's journey. There is also close working within the team, a collegiate atmosphere with regular communication and information sharing. Sometimes these relationships last beyond the treatment period and patients are known to get in contact. For instance, they may get in touch when new research is published, to discuss the implications with their keyworker. The team room is filled with thank you cards from patients and their families and there is a real sense of pride about the services they are providing within the nursing team.

A few years ago, the breast team created an information pack, referred to as the green folders. These contain core data on the trust and hospital, breast team, support groups, trials, information centre, surgery information and follow up. There is a facility to add information to the folder over time, following feedback that people did not need or want all the information in one go but to receive it in sequence. Patients have consistently given positive feedback about the green folders –

'It's my bible!' – and the practice has spread to other cancer teams within the trust.

The breast team has traditionally asked questions about daily living and mental health issues early on in the patient journey, and knows that this has had a positive impact on people. The team carries out a number of local surveys throughout the year and looks carefully at PALS, complaints, compliments, and the friends and family test results.

The team has focused recently on care after treatment and offered information sessions in a range of venues at different times of the day. They have received extremely positive feedback about the introduction of dual trained oncoplastic surgeons, which gives some patients the option of reconstructive surgery at the same time as a mastectomy.

Chemotherapy service

Electronic diary system

This has transformed the chemotherapy department. The electronic diary system enables staff to see when people have arrived, automatically link notes and records, immediately book the next appointment, schedule treatment, and allocate staff.

A full blood analyser

This was been purchased for the department and all staff are now trained, meaning patients spend as little time as possible in the unit.

Induction visits

Each patient is invited to an induction visit where they meet the team and are shown around the department. This helps people know what to expect and do if they experience any problems during treatment, particularly when they are at home, at night and at weekends. People tend to be booked by specialty, which provides an opportunity to bond with other patients experiencing a similar cancer. There is a kitchen for friends and family to use during treatment.

CASE STUDY 6

Time to care

Gateshead offers art therapy and counselling to all patients. Patients and staff have created all the art work displayed in the department.

Support for patients out of hours

A mix of feedback and internal audit highlighted the fact that people undergoing chemotherapy who were waiting in A&E were not easily identified. They needed to notify staff themselves which wasn't always happening. Work has been carried out to ensure that there are now alerts on file which flash up the patient's relevant diagnostic and treatment status if they're seen in A&E. The chemotherapy unit, specialist nurses and acute response team use the Oncology Nursing Society (UKONS) triage process for chemotherapy patients and are fully trained in this risk management assessment tool.

The trust has introduced a second alert. This means the acute oncology and chemotherapy teams and others know that a person has been to A&E and can be contacted for follow up. This has the added advantage that wherever a person is seen in the hospital the team are aware of diagnosis and can act appropriately in organising the patient's follow-up and management.

Key learning points

Theme 1 – Continuous improvement – teams own their own local survey process which encourages ownership of results and improvements

Theme 2 – Comprehensive cancer service planning and implementation by specialty

Theme 3 – Trust-wide systems and processes that support local initiatives

Next steps and plans for sustainability

- Continue report review with clinical nurse specialist team and in particular patient comments, positive and negative. Link directly with area matrons – feedback and work with areas appropriate to comments. For example, work has begun with a patient partnership panel who have carried out the first part of a 'five senses' study about the outpatients' department, where negative comments focused on the environment. The initial visit report identified issues with chair arrangement and paintwork which is now being changed.
- Address areas highlighted in the survey that demonstrate a less positive experience for patients, for example benefits advice. Work with Macmillan to explore models to improve patient access to this advice.
- Maintain a connection with the trust's ongoing work with patient experience, linking with the patient, public and carer involvement, and experience strategy.

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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. How to talk to those close to you. What to do about work. How you'll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything.

So when you need someone to turn to, we're here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we're always here for emotional support when things get tough.

Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

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](https://www.macmillan.org.uk)**