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Learning what high quality compassionate care means for cancer patients and translating that into practice

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Learning what high quality compassionate care means for cancer patients and translating that into practice

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Abstract

In 2010, UCLPartners, a partnership of health care providers and universities in North Central London, began a collaboration with local commissioners that aimed to think about cancer care and diagnosis differently. Understanding that a good patient experience can only be delivered by putting patients first and working together along their journey from symptoms to recovery, we brought clinical leaders together with patients to think about how to improve outcomes for patients, outside institutional barriers. From the very beginning this new network, an integrated cancer system, focused on understanding what mattered most to patients and organising how it worked and how it measured success around this. Co-designed by conversations and with contributions from over 1,000 clinicians and over 200 patients, *London Cancer's* ten things that matter most to patients are embedded throughout the continuing work of this organisation. In this article our work to develop these ten topics is described alongside how we used this to create a truly patient centred integrated cancer system for a population of 3.5 million people in London and Essex.

Keywords

Person-centred, patient and family centred care, patient experience, patient engagement, patient involvement, practice, integrated, London, United Kingdom, NHS, cancer, what matters to you, patient reported experience measures, measurement

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Introduction

The vision and need for patient centred care in the National Health Service has been stated consistently, but with increasing vigour, over the last 3 years. The Francis¹, Keogh² and Berwick³ Reports of 2013 all highlight the challenges posed by a health service that does not respond to the concerns of patients and their families and carers. While there are many varied definitions of patient or person centred care, we will use the National Voices simple definition of “organised around the needs of individuals”⁴.

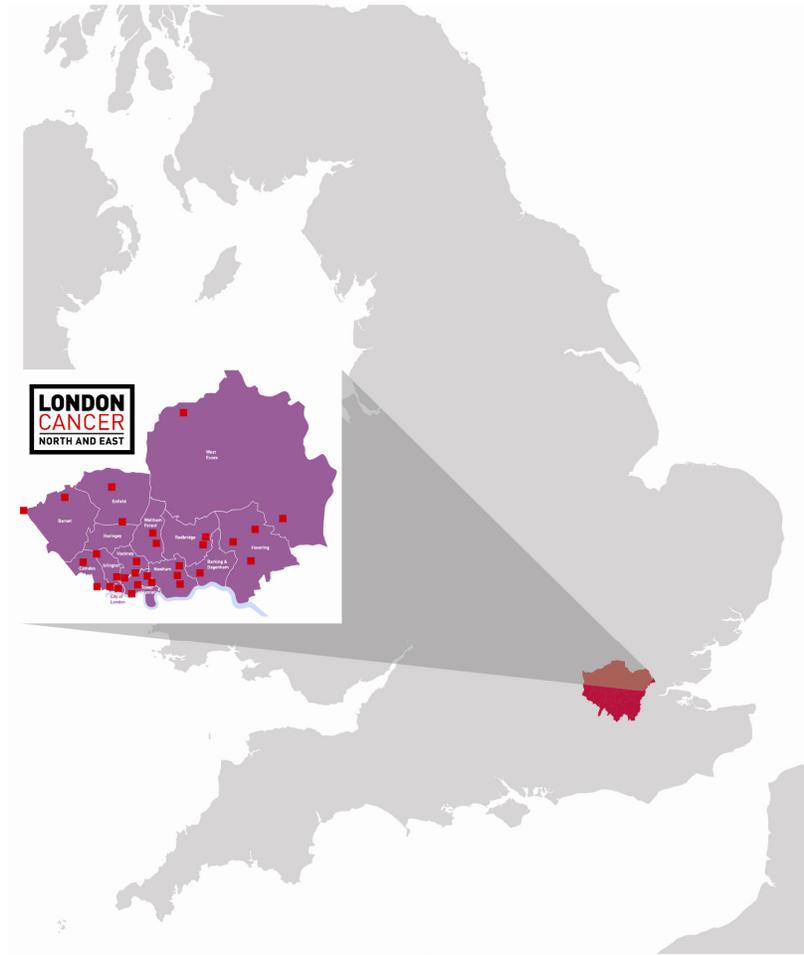
Turning patient centred care from rhetoric to reality is one of the greatest cultural challenges for health and social care organisations. This article outlines how a London-based integrated cancer system, *London Cancer* (Figure 1), a collaboration of patients, hospitals, charities and local General Practitioners (GPs) working along the patient pathway, assessed what mattered most to cancer patients

within its region. It describes the co-production of these priorities, championed by local clinical leaders who role-modeled these values, and how it has used this ‘what matters most’ framework to develop pathways of care and pathway measures that reflect that they treat people, not simply diseases.

In 2010, 67,713 patients responded to England’s National Cancer Patient Experience survey, which provided insights into the care experienced by cancer patients across England who were treated as day cases or inpatients during the first three months of 2010. Building on a previous survey undertaken in 2000 involving over 65,000 cancer patients and a smaller survey undertaken in 2004 involving 4,300 patients, the 2010 survey revealed that London patients were significantly more critical of cancer services in regards to:

- being told they could bring family with them to their appointment;

Figure 1. Map of the *London Cancer* integrated cancer system in the UK



- getting understandable answers to important questions from ward nurses;
- contacting their Clinical Nurse Specialist;
- the general organisation of NHS services, especially those “reaching” into the community and primary care.⁵

Many of the areas where London performed poorly related to fragmentation as patients moved between organisations, and not having all their questions answered. By engaging with existing and new patient audiences and local clinical teams, *London Cancer* set about defining priorities for local pathways through an integrated cancer system.

Background to London’s First Integrated Cancer System

In 2010, UCLPartners, at the time a fairly small partnership of health care providers and universities in North Central London, was asked, in partnership with local commissioners, to host and develop a cancer services provider network. This was envisaged to be fundamentally different from the previous English Cancer Networks’ way of working, with a primary focus on patients, rather than organisational performance, using their voice, through co-design and development, to change services for the better with clinicians and staff. The Cancer Networks worked through clinically led ‘Network Site Specific Groups’ with a separate patient advisory group, known locally as the Cancer Partnership Group, working alongside these groups. The new integrated cancer system proposed having patients embedded in co-design and co-production

throughout its work, and as ongoing partners. Initially the focus was a population of 1.5 million people in North Central London but this grew to 3.5 million with the inclusion of North East London (since April 2013 UCLPartners has expanded to include mid and South Essex, West Hertfordshire and South Bedfordshire, a population of over 6 million people).

Officially established in 2012 in partnership with commissioners of cancer care, *London Cancer* is now the integrated cancer system for North Central and North East London and the west of Essex in England. *London Cancer* is embedded within UCLPartners, an Academic Health Science Network (AHSN). UCLPartners' overall purpose is to translate cutting-edge research and innovation into measureable health and wealth gains for patients and populations by enabling strategic partnership working between hospitals, universities, primary and community care. For cancer patients, this means we aim to accelerate improvements in all aspects of cancer patients' care – from novel and quicker diagnostic pathways through reducing variation in both the quality of routine care, in access to 'state of the art' therapies and innovation, to streamlining research delivery so that more patients are offered access to clinical trials.

When six specialist providers and three local hospitals across North Central London came together in 2010 to develop the new integrated cancer system, there were several clinical indicators or proxies routinely in use to measure cancer outcomes (one year survival, five year survival, disease-free progression) but these were generally at a population level and not understood well by patients. For specific cancers there were no more relevant measures or parameters for improvement focused on what patients felt was most important for them. The lack of patient-defined outcomes, particularly around areas of patient experience, was a major concern to this area of London, where providers received much of England's poorest feedback through the now annual National Cancer Patient Experience Survey. It was crucial that the new system develop better insight into how it might influence improvement in patient experience.

Methods

Inherent to the change in focus on patient outcomes and experience was the emergence of a new type of clinical leadership, one driven by values and a desire for improvement, rather than process measures or institutional dominance. The conversion of Network Site Specific Groups, commonly known as Tumour Boards, to new Pathway Boards, reflecting through their membership all care settings (e.g. primary care, psychological support, rehabilitation) and with skilled patient advocates, flowed from the new direction of the integrated cancer system. Pathway Boards brought patients, primary care, carers and

allied health professionals to the table alongside surgeons, physicians, oncologists and other members of the multidisciplinary team. 11 Pathway Boards were set up with this diverse membership, alongside 5 Expert Reference Groups that provide knowledge and expertise of specialist staff working in the areas of chemotherapy, radiotherapy, nursing, psychosocial support and acute oncology. Many of the Expert Reference Group members also sit on a pathway board to bring their discipline-specific expertise to the tumour-specific discussions. Each Pathway Board or Expert Reference Group includes at least one patient or carer representative and meetings are considered not quorate without one.

Building on the work already started in the system to understand the experience of brain patients⁶, an initial task for these new Pathway Boards was to think differently about: 'what does great care look like?' and if we were to achieve it, 'how the system could know care was great? – what would have changed?' Pathway Boards were encouraged to think about what outcomes mattered and how they might be measured, what might need to change about the areas of activity and responsibility and membership to develop a whole-pathway perspective, and what kind of leadership would be necessary to ensure a full pathway perspective. In November 2010, following discussions with their membership, Pathway Board and Expert Reference Group Chairs submitted their collective responses to the following questions via a tool that asked them to outline stages of the pathway and articulate what great care would look like in this stage and how we might know care was great:

1. Which 3-5 outcome measures would the Pathway Board aim to measure for the whole pathway?
2. What might need to change about the Pathway Board remit [areas of activity and responsibility] & members when considering the whole pathways and its outcomes?
3. What might need to be different about the leadership of Pathway Boards when overseeing the whole pathway?
4. What might Pathway Boards need to do to improve education, benchmarking and dissemination across the system (and more widely)?

As may be expected when such an exercise involves such a large and diverse group, thinking about care through the eyes of patients was variably received by the various professional groups.

The team from UCLPartners was supported in the task of finding out what mattered most to patients by the North Central London and West Essex Cancer Partnership Group and the North East London Cancer Partnership Group, the service user advisory groups to the previous cancer networks. These groups brought together cancer patients, carers and healthcare professionals from across

the sector interested in improving local cancer services and the patient experience. With over 40 patients and carers engaged and involved at any time, it also had involvement of local and national charities, including Macmillan Cancer Support.

At a meeting in November 2010, the group were asked to think about ‘what does great care look like?’ and ‘how would you know?’ The Chair (a patient representative) had found work that they had previously done for the previous network looking at what measures patients and other users might care about for hospitals but others at their meeting had not yet had a chance to consider the questions. The group felt that they would like to revisit this for the whole pathway for patients and carers, and look at it in greater depth. Using the same tool as the Pathway Boards and Expert Reference Groups, with the questions detailed above, they focused on what a set of measures of achievement and progress, different to those traditional population and process measures inherited, might look like. The group provided a report to the Pathway Board Chairs in January 2011. Staff collated all the responses to this exercise and identified themes. A system of grouping the items via a thematic approach was agreed with the Cancer Partnership Groups, who also reviewed the final summary.

Results - What Matters Most?

The following summarises what our communities of professionals, patients and carers felt were the aspects of the cancer journey that most impacted on their outcome and experience. These are not in priority order, as this was not assessed, but are listed in what the Cancer Partnership Group of patients and carers felt to be the order that patients experienced care in their journey through our system. While many of these overlap in detail, we have presented these as ten distinct areas that matter most to *London Cancer* patients, alongside the context in which the discussions evolved.

1. Early Diagnosis

All involved felt earlier diagnosis of cancer was crucial. In North Central London and West Essex 22% of patients are diagnosed with cancer only when they arrive at hospital for emergency treatment. In North East London, the figure is higher at 28%.⁷

Patients and carers emphasised the importance of public information and guidance on healthy living and ways of minimising cancer risk and symptoms of common cancers and cancer screening programmes. They encouraged further guidance for GPs and suggested more rapid access to diagnostic services and associated outpatient consultation. Providing education for GPs, community care providers, and others such as emergency room staff was one suggestion as to how to improve early diagnosis

by raising awareness of suspicious symptoms to medical professionals. It was also apparent from the feedback received that raising and sustaining public awareness of both prevention, including public health interventions and campaigns for issues such as smoking cessation, and for cancer screening programmes, was essential. These themes were entirely consistent across respondees and led to earlier detection and diagnosis becoming one of the most significant streams of activity in the *London Cancer* integrated system.

2. Choice

Many of the suggestions relating to improving patient experience focused on patient choice as a key aspect of patient centred care. Patients should have a choice, and the ability to make an informed decision, as to what treatment to receive and where to receive it. Ensuring the equality of access to services for patients, particularly with regards to referrals to regional, national and international centres, where appropriate, is necessary to offer maximum patient choice and the best clinical outcomes. Some of the responses overlapped between choice and communication, detailing the need to better inform and communicate where and when choices might be made.

Research is a crucial element in the effort to improve patient care from early diagnosis to choice and communication. Providing all patients with the opportunity to take part in clinical trials was an aim for staff and patients, every patient can make a contribution and should be given the opportunity to be considered for innovative diagnoses and treatments. The suitability of individual patients to participate in clinical trials should be discussed at multi-disciplinary team meetings, and patients offered trials even if they are open at different sites across the system. Enrolment statistics should be reported and shared regularly to drive improvement, and the barriers to participation understood and addressed. These objectives formed a core, essential part of system-wide scorecards for cancer pathways.

3. Communication

Communication dominated the response from the Cancer Partnership Group, with focuses on a number of themes within this – breaking bad news; open discussion and shared decision-making around treatment options; keeping GPs informed throughout treatment; clear communication around treatment outcomes; and choice of when, and how, to receive information. The importance of bad news being delivered sensitively was stressed.

High quality, tailored information should be available to both patients and staff. This is essential to ensuring patients are able to make informed choices regarding treatment decisions, and that they feel supported throughout their cancer pathway. Patients felt they should decide what level of information is appropriate to them at

each stage of their pathway, but should be provided with a summary information pack detailing the contact details of their key worker, often an advanced practice registered nurse, when they first receive their diagnosis. *London Cancer* has focused on improving communication between patients and clinicians through a number of projects, including delivery of communications training with trained counsellors and clinical psychologists, use of the Holistic Needs Assessment (detailed below) and working with partners to improve written information provision.

4. Travel and Parking

Patient representatives and key workers also felt patients should be provided with information on travel and parking options, and the associated cost, prior to their appointment. There are several transport alternatives – driving; public transport; and patient transport provided by hospitals – for attending treatment and appointments in London but all have inherent flaws or problems for patients. *London Cancer* has been working with Macmillan Cancer Support and the other integrated cancer system in London to plan an assessment of the various options available to patients and then work with stakeholders, including Transport for London and the Mayor's Office, on how to improve.

5. Ethos – patients treated as individuals

Patients should receive holistic, empathetic, responsive and individualised support throughout their pathway. Patients and carers felt that clinicians needed to consider the implications of treatment options in terms of resultant quality of life and possible long term effects of treatment, as well more immediate issues of mortality and complications. It was felt that patient satisfaction and experience scores should serve as a measure of success for cancer services. *London Cancer* partners responded to this by committing to work together in a community of practice on those areas that could have most impact on improving patients' experience of services, using patient satisfaction and experience scores to demonstrate improvement.

6. Holistic Assessment of Needs

Patients felt they should specifically have access to complementary therapies and treatments, rehabilitation services, and if applicable, to palliative care at the earliest possible opportunity. Patients and clinicians felt there needed to be a more systematic way to assess the holistic needs of each individual patient. Funding from Macmillan Cancer Support provided assistance in the integration and rapid roll out of defined models of assessment and support for individuals living with, and beyond, cancer. Specific areas of focus have included provision of care plans, and the availability of information directly related to their needs, and web based information.

7. Support

Support for patients, through formal and informal mechanisms, was very important. Patients want to always have the option of being accompanied by partner/friend at outpatient appointments. Patients felt having a keyworker or clinical nurse specialist from the first appointment made a difference to how supported they felt, and suggested excellent care included information on support groups, counseling services, benefits entitlement, and returning to work. To better meet the needs of patients and carers, *London Cancer* has facilitated collaboration between partner hospital trusts and the non-profit and voluntary sector, who provide high quality information, guidance and support.

8. Carers

Carers should be welcomed, and supported throughout the cancer pathway, involved as early as possible in the patient journey, and factored into treatment decisions. Carers should be encouraged to be fully involved throughout the patient pathway. This should be seen as of benefit to both the patient and their clinical team. Support for carers and families was considered crucial throughout the patient journey but particularly around coping with advanced cancer and related to end of life care, so that there is less anxiety about supporting the patient at home. At a system-level, *London Cancer* has focused on encouraging the carer perspective in pathway development through a greater number of carer representatives.

9. Discharge

Patients and carers stressed the importance of a seamless and holistic care pathway, which starts and end with a General Practitioner, who should help facilitate patient discharge following an inpatient stay. GPs should provide information and advice to patients, and remain a central point of contact across the entire cancer pathway. Patients wanted to be given details of the keyworker who would be their first point of contact while at home recovering following treatment, and clear advice on what symptoms might necessitate further action. Appropriate pain relief needs to be provided at discharge, with the GP sent information on treatment, outcome, and ongoing medication and therapy needs.

10. Seamless (Integrated) Care

There was a strong consensus amongst patients and all clinical pathway directors that cancer care should be seamless, with patients managed closely during the whole pathway through a multi-disciplinary team approach. Creating a system whereby patients can follow an integrated care pathway between various organisations and services across the *London Cancer* locality was the main priority for patients. This extends, but is not limited to, creating and sustaining a positive dialogue and relationship with: primary and community care, diagnostics, specialist medical and surgical services, chemotherapy services,

radiotherapy services, pharmacy, psychological support, Allied Health Professional services including dietetics and physiotherapy, 'late effects' services, and palliative care.

Reducing delays within this system was another important point raised. Collaborative working and communication between the acute providers of cancer care was identified as the first step to ensuring this occurs. The ability for perceived delays and "gaps" in pathways to lead to anxiety and increased distress was noted by many. Reducing variation and bringing providers together across the healthcare system, and along the cancer pathway, were organising principles for clinicians joining up within the *London Cancer* Pathway Boards to redesign pathways and guidelines in partnership with patients.

Discussion

Taking the learning from what our patients had told us, aligned with clinicians' views, the partners within the *London Cancer* system together identified key themes for initial focused activity that would align with improving the most important aspects of the cancer care journey for local people. These key themes have focused on improvements in early diagnosis, integration of the care pathway, and improving holistic assessment of needs, all underpinned by strong partnership and leadership.

Assessing what matters to patients and those caring for them, ensuring that there is a shared goal that unites the interests and activities of all involved in care, to achieve value is fundamental to UCLPartners' programmatic approach, as exemplified in *London Cancer*. In order to ensure pathways were focused on what mattered most, a small set of key metrics were identified with the Cancer Partnership Groups for each *London Cancer* Pathway Board to monitor their progress in implementing integrated cancer care. We have followed Porter's ethos of: "Achieving high value for patients must become the overarching goal of health care delivery, with value defined as the health outcomes achieved per dollar spent."⁸

Value-based metrics were selected only if they were clinically useful, in line with the current work plan and improvement effort; were accessible on a recurrent basis and requiring minimal manual effort; made better use of existing data for understanding the entire patient pathway; and aligned with *London Cancer's* objectives in improving survival, patient experience, and access to innovation and clinical trials.

Pathway metrics are reported at a system level, reflecting the care for our local population, against measures that are important to them and will allow visibility of success. Current pathway metric development is constrained by the availability of meaningful data but local solutions including in-house questionnaires and surveys as well as peer

interviewing have seen a useful focus on attempting to measure and track these key items. The profile of those things that matter most has been raised within organisations across the partnership and underpinned by local effort. Alongside this Pathway Boards were encouraged to develop annual objectives that could each be tangibly related to the ten things, which mattered most to patients.

Examples of improvement projects in these areas are summarised below.

Early Diagnosis

London Cancer led an innovative evaluation in collaboration with emergency departments across all nine acute NHS hospital trusts and local GP practices in the *London Cancer* region, to understand the reasons why patients are diagnosed with cancer in this way.⁹ This has led to new and more responsive measures of emergency presentation that will help track this trend in real time.

London Cancer is working collaboratively to shorten the patient pathway to diagnosis. Doctor Ed Seward at Barts Health NHS Trust (Consultant Gastroenterologist) has developed a new service at Whipps Cross Hospital that opens up the referral pathway for patients with lower gastrointestinal symptoms beyond the strict criteria for urgent referral of suspected colorectal cancer. GPs and patients receive a definitive diagnosis more efficiently through a 'straight to test' model whereby a trained specialist nurse assesses patients by telephone. This enables most patients to go directly to the appropriate endoscopic investigation, according to symptoms and age, rather than attending clinic first. Clear benefits from the first 125 patients include faster diagnosis, a reduction in missed appointments (3% versus 7% on average), unnecessary clinic visits for the trust and cost savings across the whole pathway, which could be redeployed for capacity, communication with primary care or educational activity to aid further earlier diagnosis.¹⁰

Integrated and Optimised Care Pathway

Evidence shows that dedicated specialist centres, treating a high volume of patients, staffed by expert teams and equipped with the latest technology and research capability save lives and reduce complications.¹¹ Clinicians across *London Cancer* have been working closely with partners to ensure that we can achieve the best possible outcomes for every patient requiring a complex procedure for five rarer groups of cancers. Building on commissioners recommendations in 2010, clinicians came together to develop proposals to consolidate some specialist cancer services into a partnership of world-class specialist centres in a new connected system of care - including the best diagnosis, treatment and recovery care at local hospitals, primary and community care services - to provide consistently excellent services. Clinicians believe the

proposals would allow more rapid improvements in care, ensure every patient has access to the full range of treatment options and research opportunities and provide a consistent level of care no matter where a patient lives or first receives care. Now agreed by NHS England and local clinical commissioners, the changes, along with improvements across the whole care pathway, will save over 200 lives a year and significantly improve the safety and outcomes of surgery in many others.¹²

Clinical Trials and Research

Research studies and clinical trials allow patients to access the latest interventions not yet available as part of standard care, and help build the evidence base for changes in clinical practice that will improve outcomes for all patients. Our aim across *London Cancer* is for researchers at the cutting edge of discoveries to work with patients so that we can change lives, at a faster pace and at scale¹³. By working together as a coordinated network and linking up our clinical practice with leading medical research and innovation, we have a remarkable opportunity to give patients improved access to clinical trials. We are working closely with the newly formed NIHR Clinical Research Network: North Thames to improve information for staff and patients and access to a full portfolio of studies for our population.¹⁴

Improving Holistic Assessment of Needs and Ethos

With generous support from Macmillan Cancer Support, *London Cancer* is continuing its work to introduce the 'recovery package' for all patients. This package combines several interventions which, when delivered together, aim to improve care co-ordination and outcomes for individuals living with or after a cancer diagnosis. The recovery package consists of: holistic needs assessment, treatment summaries, cancer care reviews (conducted by GPs) and health and wellbeing events. Since the beginning of the project, nine trusts have introduced holistic needs assessments, five have implemented treatment summaries and six host health and wellbeing events. We have agreed a standardised treatment summary template, which informs the patient and the GP of the care and treatment received, for embedding in all pathways. This document includes possible treatment toxicities and /or late effects; symptoms that require referral back to a specialist team, an ongoing management plan, and any required GP actions to support the patient.¹⁵

Comment

While *London Cancer* has not yet achieved patient reported experience measures (PREMs) on all pathway scorecards, the work to galvanise the local health economy around the things that matter most is seeing all partner sites focus tremendous effort on improvement. The emphasis on what matters most to patients in *London Cancer* also requires patients and their carers to be active participants

in all of our work. To date, 65 patients are actively involved in our day-to-day work. In addition to participation in pathway discussions, patients have provided invaluable feedback and input into improving information provision and the quality of clinical letters, designing patient measures for scorecards, creating content for the *London Cancer* website, co-designing improvement initiatives with clinicians and staff, leading and designing innovative research, and assisting commissioners in significant service redesign. It is clear from our work, however, and the continued focus on this over four years, that significant time is required for a truly patient centred approach to gain traction and embed sustainably.

Conclusion

Patient centred care that really shifts outcomes not just on paper but in the perception of the people we serve requires us to understand what matters most to patients. We have worked from this base and with this focus to direct and prioritise improvement efforts that meet the needs of patients and their clinicians. In this article we have described an innovative patient-led and co-designed approach to service delivery, leadership and redesign, sustained through a new way of measuring for improvement. Our efforts to do this have been underpinned by the belief that if you start with the patient you have the best chance of keeping your work relevant, and making the biggest difference for your investment. Institutional alignment and traditional process measurement can have limited impact for change when patients actually experience care along entire pathways in multiple settings, each as individuals. Accepting this and looking to organise its work according to these principles, *London Cancer's* partnership continues to be focused on change created by combining patient voice with clinical leadership, underpinned by data for improvement. We have outlined the ten things we keep central to our vision and how this is enabling the partners within *London Cancer* to achieve significant redesign of health care that had not been possible before in this geography. It is the work of these committed clinicians, health care leaders, charities and patient partners that continues to make this possible.

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