

From surviving to thriving: cancer's next challenge

October 2015



We are entering a new era of health – New Health

Health matters. It matters to each of us as individuals and to society – it connects us all like no other. It lies at the heart of our economic, political, social and environmental prosperity and is one of the largest industries in the world.

Modern health systems can treat and cure more diseases than ever before. New technology such as mobile health and data analytics are bringing innovation to old treatments. Yet significant quality, access and cost issues remain and our health systems are at risk of becoming unsustainable.

But even as health executives and government leaders retool their systems – creating more efficiency and capability – the ones that matter most are often left out of the equation. Inclusion of patients and their caregivers in the dialogue on these solutions is key to achieving the ultimate outcome of efficiency and quality. These, together with current trends – changing demographics, the rise of chronic disease, depleting resources and the growing power of the consumer – are all impacting the high quality delivery and financing of healthcare.

As demographic, economic and geopolitical forces combine, a more dynamic and competitive environment is emerging. Technological advances, the emergence of a number of new entrants¹ into healthcare, new business models and partnerships, greater transparency and new funding models, all bring cause for optimism. These changes will provoke turmoil but will also create unprecedented opportunities.

This paper focuses on the need for health systems to find new ways of empowering people with cancer, the need to focus on outcomes that matter to them and encourage better models of care.

The transformation of health is upon us, with a new era of healthcare emerging.

Will you be ready?

¹ New entrant definition: A disruptive, recent arrival to a market or industry. These may include companies whose core businesses reside entirely outside of the new industry, or businesses expanding into new roles.

Imagine...

“...if you worked all your life, were not extravagant, saved your money and on the eve of retirement, there was a knock on your door and someone told you that you had lost all your savings. You are bankrupt and they are not sure why.

That’s cancer.

No dialogue. No preparation. No forewarning.

Just a decision from someone, somewhere that your number is up.”

This happened to Justin McLean, a PwC strategy partner in Melbourne, Australia who received that metaphorical knock on the door in late 2013. A highly motivated individual used to having control over his life, was suddenly thrown into a real-life scenario of the unknown. From the moment he was diagnosed with Stage 4 colorectal cancer, Justin’s quality of life began to decline (see ‘Justin’s journey’).

In the months that followed he went through a gruelling, often frustrating, journey as he navigated a fragmented health system whose priorities didn’t align with his needs. As Justin discovered, there is no roadmap for people to follow

as they go through their cancer journey. Instead, they must largely fend for themselves at a time of extreme stress and vulnerability.

In addition, he sensed that health systems are more focused on increasing a person’s length of life than on addressing the quality of life. Improved survival for people with cancer is one of modern medicine’s great triumphs. But people with cancer want more; a quality of life based on their priorities – not just living longer.



Executive summary

One of the great achievements of medicine is the improvement in survival of people with cancer. But people diagnosed with cancer, once the initial shock is absorbed, want to be able to make choices, receive personalised and coordinated care and have more control over what happens to them. They want to live as 'normal' a life as possible – to 'thrive'.

Influenced by the experience of cancer care of one of their partners in Australia, Justin McLean, PwC asked patients, caregivers and clinicians in Australia, the UK and US what is important to them.

Communication is critical – it is often done well, but more could be done

Initial diagnosis and communication of treatment is a key 'moment that matters'; it is where people want to understand everything that is going to impact them and the options they have.

- 88% of patients say it is extremely important to have information about their diagnosis presented clearly in a way they could understand but only 69% say they did.
- 81% of patients think it's extremely important to have all cancer treatment options and recommendations presented clearly, but results show only 65% feel they did.
- 74% of clinicians feel their responsibility includes setting patients' expectations about life while going through treatment, 21% do not feel accountable beyond diagnosis and treatment.
- 84% of patients and 74% of carers felt it was extremely important to have the opportunity to ask questions about their treatment; 71% and 55% respectively had that experience.

Being part of making key decisions is important – but there are gaps

People with cancer want more say in what treatment and care they have, and readily accessible information.

- 77% of those surveyed said they want to be involved in choosing a doctor, whilst 83% want to have a say in the decision of where they will receive treatment.
- 71% of patients expressed it 'extremely important' to have their personal preferences considered. Only 60% feel their preferences were considered.
- 71% of patients said they wanted a proactive healthcare team, 53% said their expectations were met.
- 59% of clinicians said they feel a sense of responsibility to serve as a resource to answer questions but patients and caregivers feel this is not made clear.

Co-ordinating care makes people feel safe and able to cope - but care can appear fragmented

Navigating the various systems, providers and payers is frightening at such a critical time in people's lives. People want care to be holistic and connected, not to have to think about it, and to focus on quality of life.

- 47% patients and 34% of caregivers said their care was not very coordinated.
- 35% patients and 49% of caregivers said their active healthcare team was not synchronised.
- Significantly more clinicians in the UK (86%) and Australia (70%) versus the US (43%) think providing a specialist nurse is very important.

So what does this mean?

The research shows that people want care and treatment that enables them to thrive through cancer; have a quality of life, as 'normal' as possible, whatever that might be. Fundamentally this means health systems need to:

- **Personalise** – focus on the outcomes that matter to the individual.
- **Coordinate** – provide coordination of care and easy navigation.
- **Go Digital** – to enable improved quality of life through the cancer experience.

Delivering a better experience for cancer patients is part of a larger challenge for the healthcare industry globally; to become more efficient and effective to ensure sustainability as well as economic viability. Countries can learn from each other, digital technology is already a major catalyst that traditional clinical systems need to embrace, or be left behind.

New funding and reimbursement models will be needed as well as new regulatory models and metrics. Policy makers will need to move quicker just to keep up, and partnerships with new entrants² as well as public and private investment will be key.

But are health systems ready and willing to change?

² Organisations pioneering into healthcare whose core business is outside the industry, such as retail, consumer products, telecommunications and technology companies. See 'Global health's new entrants: meeting the world's consumer', PwC March 2015. <http://www.pwc.com/us/en/health-industries/healthcare-new-entrants/assets/pwc-global-new-entrant.pdf>

Shifting the focus from surviving to thriving

This paper discusses the need for health systems to reassess their overall objectives: from helping people with cancer to survive, to enabling a better quality of life regardless of their prognosis.

“We need to let go of the word ‘survivor’. If that’s a value proposition then it’s a lousy one because not everyone will survive cancer. But you can still have a good quality of life and be enabled to continue doing the things that you enjoy. Things that enable you to flourish. Things that enable you to thrive. We need a change in mind-set”.

Justin McLean

People’s cancer experience will differ based on factors such as age, type of cancer and the stage at which the disease is diagnosed. So it may seem an impossible task to create a personalised experience focused on individual outcomes. However a significant proportion of the elements that make up cancer care are common across cancers, such as communication with health professionals, treatment requirements, and rehabilitation. By addressing elements that are common across all cancers – by better co-ordinating care and helping people navigate the health system – it may be possible to reduce costs and streamline the care processes.

To enable people with cancer to thrive, health systems and clinicians must address quality of life issues and recognise that people suffering with cancer have other objectives that, at first glance, may conflict with traditional clinical goals.

Eric Dishman, director of Proactive Health Research at Intel Corporation struggled with cancer: “I finally realised some years ago that all my medical teams were optimising my treatment for longevity,” recalls Dishman. “It’s like a badge of honour to see how long they can get the patient to live. I was optimising my life for quality of life, and quality of life for me means time in snow. So on my chart, I forced them to put, ‘Patient goal: low doses of drugs over longer periods of time, side effects friendly to skiing.”⁷

Atul Gawande, the prominent surgeon, writer and public health researcher, says his experience shows that “[I]n medicine, in society it seems we have failed to recognise that people have priorities to serve, priorities they want us to serve besides just living longer... and people have priorities that can range from... wanting us to help (them) spend more time at home than in the hospital or wanting to make sure that they can just be with their dog”, echoing Dishman’s view. Dr. Gawande adds “...the most reliable way to learn is to ask. And we don’t ask.”⁸

In recent years, health systems have made great strides in developing medical treatments for cancer, including personalised medicines that target specific gene mutations.

Yet cancer still places a significant burden on economies. According to Franco Cavalli, chair of the World Oncology Forum, “Every year cancer drains an estimated \$2 trillion from the world economy in terms of lost output and the cost of treatment, equivalent to around 1.5% of global GDP”.³

Compounding this issue are global challenges of lack of access to quality care, affordability and an ageing population, meaning more people will have cancer. Cancer touches a huge proportion of the global population and is among the leading causes of death worldwide.

In 2012 alone, there were some 14 million new cases diagnosed and more than 8 million cancer-related deaths.⁴ According to one projection, the number of new cases of cancer will increase 70% over the next two decades.⁵ Because of the enormity of the impact, for the first time the topic of cancer was placed on the World Economic Forum agenda in January 2015, where world leaders faced calls for bold action to address this critical health issue.⁶

3 Franco Cavalli, Chair of the World Oncology Forum, Press Release January 14, 2015. <http://www.asco.org/press-center/world-leaders-gathering-davos-face-calls-bold-action-turn-tide-cancer>

4 Bernard W. Stewart and Christopher P. Wild, editors, World Cancer Report 2014, World Health Organization International Agency for Research on Cancer. <http://www.iarc.fr/en/publications/books/wcr/wcr-order.php>

5 World Health Organization fact sheet. <http://www.who.int/mediacentre/factsheets/fs297/en/>

6 ‘World Leaders Gathering at Davos Face Calls for Bold Action to Turn the Tide on Cancer,’ American Society of Clinical Oncology, Press Release January 14, 2015. <http://www.asco.org/press-center/world-leaders-gathering-davos-face-calls-bold-action-turn-tide-cancer>

7 Eric Dishman, ‘Healthcare should be a team sport,’ TED talk. http://www.ted.com/talks/eric_dishman_health_care_should_be_a_team_sport/transcript?language=en

8 The Reith Lectures 2014: The Future of Medicine. Atul Gawande, ‘The Problem of Hubris,’ 09 Dec. 2014. http://downloads.bbc.co.uk/radio4/open-book/2014_reith_lecture3_edinburgh.pdf



Justin's journey

It started with the diagnosis nobody wants to hear: *You have cancer.*

It started with the diagnosis nobody wants to hear: You have cancer.

When his doctor delivered the news that he had Stage 4 colorectal cancer, Justin McLean and his family realised there was no option but to beat it. For his partner, his children, himself, he had to live. There was no plan B, which quickly became a mantra – an aspiration not just to survive, but to thrive.

As a fit 40-year-old, in the prime of his corporate career as a global strategy partner at PwC, facing mortality was daunting. There was no history of cancer in his family, and now, suddenly he was having a conversation with a doctor about the probability of his living or dying.

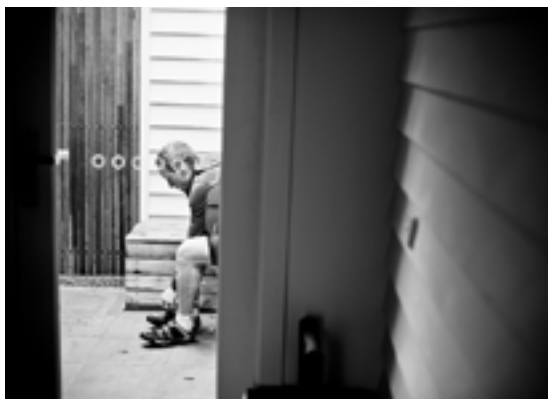


Accustomed to consulting with clients and offering options, McLean was stunned to find that the health system was dictating decisions to him rather than giving him choices. He took charge anyway, interviewing and choosing clinicians, documenting his journey of surgery, radiation and rehab and recording his observations from the viewpoint of a strategy consultant as well as a person with cancer. What he observed was a fragmented system that focused on medical outcomes and on meeting the needs of specialists more often than patients.

Most importantly, he learned there was no roadmap for people to follow. “I was simply at a loss that there was no clear path for me to follow from the time of diagnosis for something so personal, confronting and time-consuming in one’s life,” says McLean.

In response to what he encountered, McLean co-founded ‘thrive’, an organisation that will advocate for the needs of cancer sufferers, families and caregivers, putting them in the best possible position to thrive throughout the cancer experience, regardless of their prognosis. He also documented his experience in a film and enlisted the support of PwC, which sponsored research to explore how to improve the quality of life of people diagnosed with cancer.

“I was simply at a loss that there was no clear path for patients to follow from the time of diagnosis for something so personal, confronting and time consuming in one’s life.”



From Cancer to Corsica

In October of 2014 Justin, his wife and a group of friends all went to Corsica on a bike ride that would close a chapter on a dark place in Justin’s life, and celebrate what lay ahead. At the top of every mountain, they would pause and kiss the ground to rejoice in the beautiful, but oh-so-temporary, gift of life.

Our research

Inspired by Justin McLean's journey and committed to tackling important global health challenges, PwC explored the current experience of people diagnosed with cancer, identified the 'moments that matter' and determined where change is needed.

The research was conducted among a wide range of cancer 'patients', 'caregivers' and 'clinicians' in Australia, the United Kingdom (UK) and the United States (US) – (see 'Research methodology'). Here we highlight some of the results of the research and offer insights that healthcare players can apply to improve the experience of cancer patients.

Overview – the desire for a coordinated, flexible and personalised system

Results show that people with cancer want care that is coordinated, flexible and personalised. They want a health system that involves them in the decision-making on their treatment and care, taking into consideration their personal outcome preferences.

But according to our research, their needs and desires do not always match their experience.

Whilst a large number of patients reported positive experiences and good relationships and communication with their oncologists and other care providers, almost 40% of said they weren't fully satisfied with the care and resources they received during their cancer journey. An even higher proportion of caregivers (53%) expressed dissatisfaction.

After going through cancer one individual said they became a different person, not as confident or positive, whilst another said they would have liked to be treated as a person, not a tumour.

Three consistent themes emerged where improvements could be made: communication; the making of key decisions; and care coordination.

The need for better two-way communication

Diagnosis is the moment that matters most. This is true for all audiences surveyed – patients, caregivers and clinicians. It is also the moment when the research shows the biggest gap between what people with cancer need and what they experience.

The majority of patients say it is extremely important to have information about their diagnosis presented clearly in a way they could understand but that their experience shows that not all of them do (see Figure 1).

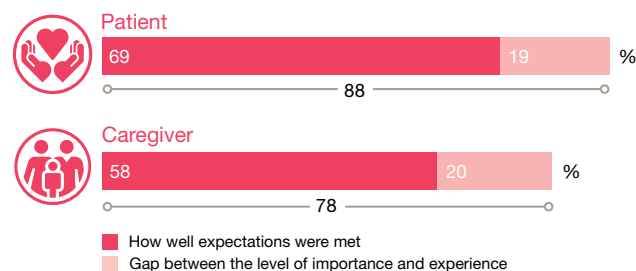
In fact over 80% of patients think it is extremely important to have all cancer treatment options and recommendations presented clearly to them but again, this is not necessarily what they find. Interestingly enough, the results for caregivers were lower still.

One critical question that people diagnosed with cancer want answered is how their lives will change.

Fig 1: Clear communication is essential, especially at the time of diagnosis

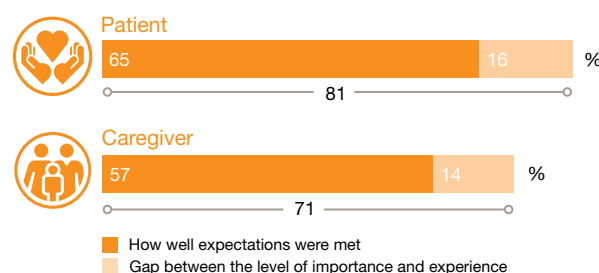
Diagnosis

Having information about my diagnosis presented clearly by my healthcare team in a way I could understand.



Treatment

Having all cancer treatment options and recommendations presented clearly.



Source: PwC Analysis

And although three quarters of clinicians feel their responsibility includes setting patients' expectations about life while going through treatment, one in five do not feel accountable beyond diagnosis and treatment. Significantly, almost a third of clinicians in Australia said they do not feel accountable beyond diagnosis.

Too often, this leaves cancer patients without a clear sense of what to expect and having to resort to finding alternative sources of information. With the growth of digital and global communication tools, the information people have at their fingertips is enormous and certainly overwhelming, but not necessarily accurate.

People who have been told they have cancer want to ask questions about their diagnosis and treatment, to understand their options and to maintain at least some sense of control over what is going to happen to them.

However the research shows that there are still gaps regarding the opportunity to ask questions and engage in a meaningful dialogue (see Figure 2).

In fact, of the high percentage of patients who felt it was extremely important to have the opportunity to ask questions about their type of treatment, not all of them were able to and indeed there was an even bigger gap for caregivers.

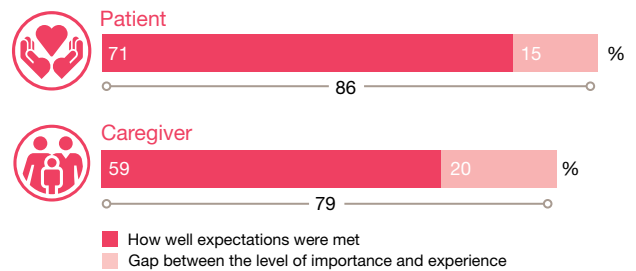
The research also shows a disconnect between communications that clinicians believe are most important and those that are most valued by patients.

For instance, whilst patients and caregivers value communication with their family more than any other interactions in the first 24 hours after they are told of their diagnosis, some clinicians believe that communicating with the doctor is the most important interaction. This is especially true in the US, where 29% of oncologists ranked the patient's communication with them in the first 24 hours after diagnosis as most important, and only 13% cited communication with family as the top priority.

Fig 2: Patients and caregivers want the opportunity to ask questions about diagnosis and treatment

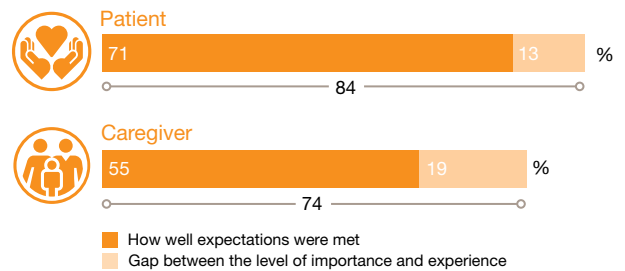
Diagnosis

Opportunity to ask questions about diagnosis



Treatment

Opportunity to ask questions about treatment



Source: PwC Analysis

Making key decisions

In addition to clear communication about diagnosis and treatment options, patients also want to have a say in decisions about their care.

For instance, 77% of those surveyed say they want to be involved in choosing a doctor, whilst 83% want to have a say in the decision of where they will receive treatment. But too often, people with cancer are not given the chance to be part of these decisions.

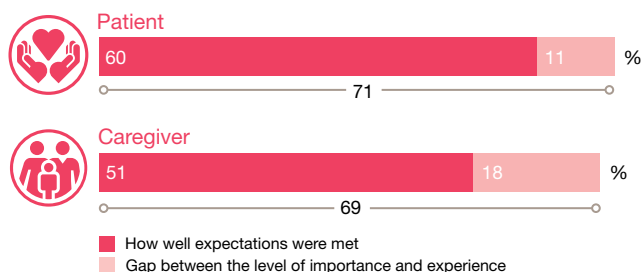
Patients also expressed the desire for a personalised approach to cancer care: as you can see in Figure 3, the research found that although many felt it ‘extremely important’ to have their personal preferences considered, not all feel it is taken into consideration.

In addition, patients indicate they wanted to have a healthcare team that is proactive in addressing their future needs and challenges, but not all of their expectations are being met.

Fig 3: Patients and caregivers want to have their personal preferences considered, and a healthcare team that is proactive in addressing future needs and challenges

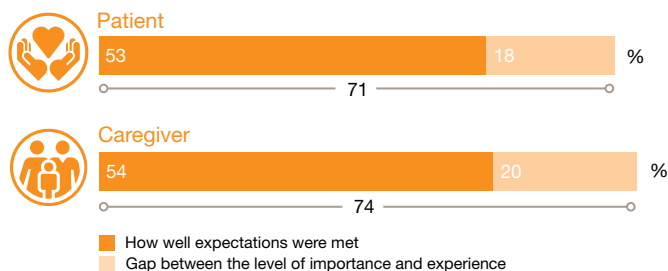
Diagnosis

Having my personal preferences taken into consideration when being presented with treatment options.



Treatment

Having a healthcare team that is proactive about future needs and challenges I may face.



Source: PwC Analysis

And although almost 60% of clinicians say they feel a sense of responsibility to serve as a resource to patients and help answer questions they may have, patients and caregivers feel this is not made clear.

Clinicians acknowledge that there are communication, social and emotional barriers to overcome.

Indeed, comments were made during the research that the emotional, social and physical well-being of the patient are all important but that cancer doctors are not always well equipped at dealing with all three. Clinicians also said that more needed to be done to provide support to ensure the patient is emotionally and psychologically stable.

A particular key barrier consistently identified was not having enough time to spend with patients to address their needs.

In treating cancer, health systems must enable clinicians to be able to treat the whole person, not just the disease, and go beyond tests and treatments to address the non-medical aspects of cancer. By doing so, they can help patients to thrive, regardless of their prognosis.

David Kerr, professor of Cancer Medicine at the University of Oxford in the UK, concurs: “I’m not a trained psychologist, I’m busy, I’m rushing around the ward, I’m giving chemotherapy. I think that if we had more psychological support, that would make a difference to the mental wellbeing of our patients; a number of whom are depressed, a number of whom are anxious. But we just don’t have the time to provide that sort of support”.

This echoes the findings of the research, illustrating that clinicians see the benefit of thriving, but that the demands of the health systems do not allow it.

Gaps in care coordination

The research also showed that care coordination continues to be a significant challenge for health systems, with the consequence of a fragmented cancer service.

Clinicians believe a multidisciplinary care team helps coordinate efforts across departments, supports the continuity of care, avoids confusion for both patients and providers, and helps them feel more in control of care decisions.

Yet despite the fact that 95% of clinicians say they participate in multidisciplinary teams, almost half of patients said their care was not very well coordinated (see Figure 4). Not only that but over a third of patients and almost half the caregivers felt active members of their healthcare team were not synchronized.

Patients cited that they often spend a lot of time setting appointments, changing treatment times and co-ordinating between departments.

They refer to systems being fragmented and often not 'talking' to each other. All this can leave patients feeling like a 'pinball' being bounced around from one department to the next and having little sense of control or confidence over their experience.

Among the three countries included in our research, significantly more UK caregivers (60%) said care was very coordinated with a specialist nurse to contact. In contrast, only a third in Australia identified their care as coordinated.

Indeed almost twice as many patients in Australia versus the US and UK say they were extremely unclear about their main point of contact for information and support. In fact in Australia the person responsible for managing patient care was also more likely to change at almost all milestones (e.g. after diagnosis and when starting treatment) compared to the US and UK.⁹

It has to be pointed out however that the majority of clinicians in both the UK and Australia think providing a single point of contact as a specialist nurse is very important.

So why is this not happening?

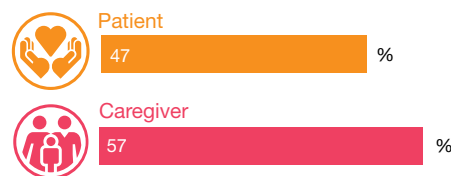
Fig 4: While 95% of clinicians say they participate in multidisciplinary care teams, almost half of patients and more than half of caregivers report that care was not very coordinated

Clinicians' participation in multidisciplinary care teams

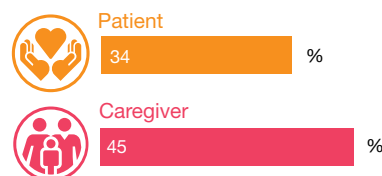


Organization of care

Care not very coordinated



Care not very synchronized across members of healthcare team



Source: PwC Analysis

⁹ While the research focused on coordination of cancer services, it did not focus on coordination between providers of cancer care and the general practitioners who refer people to oncology specialists. Such coordination is significantly lacking in the UK.

Patients must be able to navigate through the health system with ease. They must be able to access the information and resources they need to help them maintain a good quality of life and achieve their desired outcomes.

So what does this mean?

The research shows that people diagnosed with cancer want care that is personalised, flexible and coordinated, that recognises there are needs that go beyond the provision of medical treatment and services and that gives them a greater say in what their outcome might be.

Clinicians say it is important for them too: to give a more bespoke service to individuals who have cancer; to treat the whole person; to give them a quality of life and to enable them to thrive. However, it appears that it is the health systems themselves that do not always allow this to happen. And although there are multidisciplinary teams in place, they still appear fragmented to the person with cancer.

There seems to be a disconnect.

Health systems across the world need to re-look at how they are organised around three particular areas to help people with cancer thrive:

- Personalise – focus on the outcomes that matter to the individual
- Coordinate – provide coordination of care and easy navigation
- Go Digital – to enable improved quality of life through the cancer experience

Personalise – focus on the outcomes that matter to the individual

Everyone agrees, to some degree or other, that a more personalised system of care is needed. What seems to be the barrier is resource, including time. Going digital and improving coordination, described below, might bring the opportunity to release some resources through streamlining care delivery and reducing duplication and unnecessary steps.

But imagine a world where every clinician, especially lead oncologists and surgeons, understood and promoted personalisation, where they could turn to colleagues (perhaps lay people, former cancer sufferers indeed), who could coach and advise people newly diagnosed with cancer on thinking about and articulating what outcomes they wanted. It is clear that families and other carers should be at the heart of this process, and that most health systems do not involve them enough – they are not an extra burden but a resource that would be only too happy to help the person with cancer get what they want. Where problems arise with families is where they do not really understand what it is the person really seeks. The process of exploring and articulating outcomes will overcome that (see ‘What this means for your organisation’).

Alongside this, the process of activation¹⁰ would further motivate people with cancer to seek the outcomes that matter to them and to further personalise care. Evidence shows activated patients not only get better outcomes, through more personalised care, but that they use fewer resources. Whilst there is less evidence in people with cancer, there’s no reason to suspect any difference.

¹⁰ ‘Supporting people to manage their health: an introduction to patient activation’ by Judith Hibbard & Helen Gilbur, May 2014.
<http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health>

Personalisation is often seen as burdensome and costly, and yet the evidence base from shared decision making is that people with health conditions are more parsimonious than clinicians when faced with the pros and cons of treatment.¹¹ Faced with another course of expensive chemotherapy, or a trip to the slopes, we know what Eric Dishman would do.

Atul Gawande sums up the evidence in his BBC Reith lecture in 2014: people who are activated to express their outcomes live longer and use fewer resources. So, a personalised system focused on outcomes that matter to patients will likely be more efficient, more effective and be more satisfying for the person with cancer and their caregiver.

Coordinate – provide coordination of care and easy navigation

Justin, a motivated and high achieving individual, used to determining his life, was lost when it came to cancer care. This means that people with cancer are unnecessarily frightened, which can make their overall experience of cancer worse. While some people seem to be helped to navigate through the system through the provision of navigators, it is not consistently seen as a basic component of care.

Care also means so much more than the medical aspects: it means travel, finances, childcare, the intimate life. Put together they define the cancer experience – the definition of coordinated care.

Coordination not only improves the experience, but also reduces duplication or wasted steps. It prepares people better, they are more able to cope with the demands of treatment. And at its best, coordination can also help people adopt strategies that keep them as well as possible; a good diet, exercise when possible and stress reducing measures like mindfulness. Care

coordination should therefore also include partnerships with new entrants; aggregating non health services to deliver a more holistic care experience.

Support does not exclusively need to come from an individual coordinator; virtual communities of people with like cancers or treatments provide guidance on the best ways to cope, and pointers in what to expect and what to do.

Our research shows that coordination and navigation should be a core, not an optional, component of cancer care and can come in many forms (see ‘What this means for your organisation’).

Go digital – to enable improved quality of life through the cancer experience

As we thought through the implications of the research, and in particular spurred on by Justin McLean himself, we realised that there was a single unifying theme that could be the solution to many of the issues identified. That theme is digital, which we believe is the thread that runs through many of the needs for patients.¹² Digital can:

- equip people to navigate their cancer experience seamlessly – provide information in a range of forms so people with cancer, their families, friends and carers can access it at all times;
- help guide them to make smart decisions about treatment choices that will best deliver the outcome they are seeking;
- connect them to people with similar conditions nearby, or around the world;
- help navigate people through the system, preparing them for the next step, helping them understand what will happen at their next appointment or treatment session;
- help people with cancer, their families and carers make choices about care providers;

- get feedback on the last step of care, allowing for tailoring next time round; and
- enable them to make contact with a specialist at a time and in a place that works for them.

Digital, in the form of ‘health wearables’ can also play a part in monitoring their condition, either as a means of keeping as well as possible, or to provide feedback to clinical teams.

But research programmes, like those at University of Wisconsin which developed CHES¹³ showed that too much unfiltered information can be a bad thing. Patients with managed access to information, linked to online support groups and access to a specialist via email benefitted on a number of fronts, whilst those with free rein over the internet, and the plethora of information it contains (good and bad), were more anxious and less likely to do well.

On the other hand, having the ability to ask a question of a fellow sufferer, or a cancer expert was very positive. In the US in particular, this is leading to the desire for a ratings culture in the healthcare sector as well as the consumer sector.¹⁴

And digital can, of course, provide an integrated record, for people with cancer and their caregivers to share, wherever or whenever.

But the adoption of digital technologies is slow in healthcare compared to other sectors, making it likely, in our estimation, that a new digital entrant, working with a cancer centre, will very likely disrupt the way cancer care is provided.

11 ‘Partnerships with Patients: The Pros and Cons of Shared Clinical Decision-Making by Angela Coulter’, 1997. King’s Fund Development Centre, London, UK. <http://hsr.sagepub.com/content/2/2/112.short>

12 The PwC Health Research Institute (HRI) series of papers on how the healthcare sector is using data and technology to improve healthcare, 2014. <http://www.pwc.com/us/en/health-industries/top-health-industry-issues/healthcare-technology-and-innovation.html>

13 University of Wisconsin website, (July 2015) https://chess.wisc.edu/chess/projects/about_chess.aspx Comprehensive Health Enhancement Support System (CHESSM) is designed to ‘help individuals cope with a health crisis or medical concern.’ Among other things, the system, which patients can access from their computers, can provide timely, personalised information and support.

14 The PwC Health Research Institute (HRI) explores how, as they spend more money on health and wellness, consumers are beginning to search for rating systems to guide their decision making. <http://www.pwc.com/us/en/health-industries/publications.html>

The question is, is there an appetite for change?



Thriving with cancer will lead not only to more fulfilled lives and healthy communities, but also to efficiencies and continued contribution to business; ultimately bringing significant benefits to broader national and global economies.

Not all changes can be made at the level of individual health systems.

Delivering a better experience for people with cancer is part of a larger challenge for the healthcare industry globally; to become more efficient and effective in order to ensure sustainability.

And it is naive to believe that solutions will come solely from health systems. It means key players and new entrants will need to collaborate together, as well as with people who have cancer and their caregivers, to better understand what is needed in order to thrive.

Countries can learn from other countries' health systems challenges, successes and efficiencies. Developed countries can learn from developing countries which may have less barriers such as historic healthcare structures and systems that can be inhibiting to rapid change.

It will require policy makers, private enterprise and regulators to do things differently if we are to make progress.

A well coordinated cancer care service, focused on the individual's desired outcome, could also enable many to remain active in their communities and potentially to stay in employment.

Thriving with cancer will lead not only to more fulfilled lives and healthy communities, but also to efficiencies and continued contribution to business; ultimately bringing significant benefits to broader national and global economies.

To help make this change we need to evolve our language from **'surviving'** to **'thriving'**.

What this means for your organisation

Incremental change is not enough; to significantly improve the quality of life for people with cancer, bold steps must be taken to shift how we have traditionally done business to new models of care that integrate all components in the system, and some outside the system.

At a time when the industry is under significant cost pressures, an investment in helping people to thrive could pay dividends in terms of increased quality, efficiencies, reduced waste and cost, and strengthened brand loyalty.

Following are some of the key steps we recommend to help move cancer patients from 'surviving' to 'thriving'.

For providers



Focus on the individual

1. Instill a culture of asking what people diagnosed with cancer want as their desired outcomes, encourage discussion with family and former cancer sufferers (e.g., quality vs. longevity of life, specific goals, activities etc).
2. Provide a single point of contact – a cancer nurse/patient navigator – to filter communications and give real time responses, guidance and support.
3. Give clear information at the time of diagnosis, and allot time for additional sessions after the individual has had time to take in what it means to their life as they know it.
4. Give people with cancer an option to be involved in decisions affecting their care (e.g. choice of doctors, treatment, rehabilitation venue, timing of treatments etc).
5. Give people with cancer clear information about what to expect as they go through cancer treatment, including how it will affect their daily lives.

6. Partner with other providers if it will get patients a better result.
7. Partner with new entrants to offer payable services that will help individuals to thrive.
8. Measure results via patient feedback, social media.

Improve processes and technology

9. Map the current individual experience. Examine how care is delivered, from diagnosis through completion of treatment and beyond. Analyse where there are there redundancies, process bottlenecks or other forms of inefficiencies and eliminate these over a period of time.
10. Determine whether and how digital technology can be leveraged to improve the individual cancer experience (e.g. by using face-to-face media to enable in-home/remote consultations).

Clinical practice

11. Enable physicians to treat the whole person, not just the disease by addressing the non-medical aspects of cancer through technology and partnerships.
12. Give incentives on quality and outcomes, not just volumes.
13. Measure the results on an annual basis through patient feedback and time studies.

For payers



1. Review and design new reimbursement and funding models that reward outcomes rather than volume of activity: pay for thriving and surviving.
2. Establish conversations with lead providers to drive single organisation integration.
3. Develop, with providers, but driven by individuals and their carers, a set of outcome measures that include 'thriving'.
4. Encourage innovation and the adoption of digital solutions by sharing savings through their introduction and use.
5. Consider reimbursing for alternative treatments that could bring benefits; massage therapy and non-traditional, more convenient forms of care delivery, such as telemedicine visits that allow patients to consult with their doctors from home.
6. Make the investment not only to enhance the quality of a person's life as they go through cancer, but to reduce the number of costly hospital readmissions.
7. Monitor and measure effectiveness.



“In my field, gastrointestinal cancer, there’s evidence emerging that patients who exercise and who take care of themselves have a reduced chance of the cancer coming back... I’m becoming much more interested in the concept of prescribing exercise, of setting goals; 5,000 steps a day, building up to 10,000 steps and that sort of thing.”

Professor David Kerr

For policy makers



1. At a national level implement regulatory frameworks and legislation to include 'thriving and surviving'.
2. At a global level, liaise with other countries and regions to see what works and what doesn't. Share best practice to create a global standard.
3. Ensure regulatory and inspection regimes look at integration and are aligned to rewarding treatment of the 'whole person'.
4. Remove barriers and consider incentives for the adoption of innovative digital solutions.
5. Set up systems for monitoring compliance with 'thriving and surviving' frameworks and legislation.
6. Learn from developing countries particularly around digital and technological innovation where there has not necessarily been historic health systems creating potential barriers.

Research methodology

In 2014, PwC wanted to explore the current experience of people going through cancer and identify what could be changed to enable them to thrive.

A series of hypotheses were devised to understand what happens from cancer diagnosis through treatment to recovery. To test these hypotheses, PwC commissioned a research survey in three key countries: Australia, United Kingdom (UK) and United States (US) – three countries that are representative of cancer challenges faced by the developed world. The survey was conducted among more than 1,400 cancer patients, caregivers (relatives) and clinicians.

Definitions:

Patients – aged between 18-65+ (average age 50+) at all stages of cancer, predominantly in remission

Caregiver – aged between 18-65+ (average age 50+) helping their loved one

Clinician – in community practice/academic/teaching in medical oncology

The objectives of the survey:

- Identify critical ‘moments that matter’ to oncology patients and how they differ from what matters most to health systems.
- Reveal specific disconnects between patients, caregivers and providers (and to some extent between people with cancer and health systems).
- Gauge similarities and differences among countries, and establish benchmarks that can be used for cross-country comparison and for tracking over time.
- Monitor attitudes, preferences and priorities related to care, care coordination, information and communication, costs and progress.

The methodology consisted of 30 minute online qualitative surveys.

The sample consisted of 1,456 responses, research was conducted from November 2014 to February 2015.

Audience	n-size	MOE
Patients	705	+/-3.7%
Australia	100	+/-9.8%
United Kingdom	169	+/-7.5%
United States	436	+/-4.7%
Caregivers	349	+/-5.3%
Australia	50	+/-13.9%
United Kingdom	83	+/-10.8%
United States	216	+/-6.7%
Clinicians	402	+/-4.9%
Australia	100	+/-9.8%
United Kingdom	101	+/-9.8%
United States	201	+/-6.9%
TOTAL	1456	+/-2.6%

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