

THE DIVIDING LINE IN CANCER CARE FOR 2030

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CANCER SUPPORT**

Exploring the effect of
inequalities on four million lives

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Foreword: Four million reasons

Jagtar S Dhandra

Jagtar has worked at Macmillan Cancer Support since 2007. Having started as the lead for user involvement he then went on to set up and head Macmillan's Inclusion Department, leading the organisation's work on Patient Experience, Inequalities, Peer to Peer support and User Involvement. Jagtar is also responsible for developing Macmillan's Pan London Strategy which will further support the organisation develop and enhance its portfolio of service improvement and development initiatives across the capital.

Prior to joining Macmillan, Jagtar was the Director of Policy at a leading Human Rights and Equalities organisation. He has also taught social policy as a lecturer at the University of Kent for three years. He is a current member of the National Cancer Equality Initiative, a member of the Dignity Council and has also been involved in the London Health Commission.

Foreword: Four million reasons

Jagtar S Dhanda

Recent years have seen remarkable improvements and innovations in the treatment of cancer and in the delivery of care. However, these co-exist alongside significant inequalities that, at their most extreme, dictate the prospects of survival. The net result is that the UK as a whole lags behind the European average for cancer survival rates¹.

The reality of pioneering innovation in cancer care is that we focus so much on the future that we may neglect to understand the present – surely the efficacy of any future innovations in treatment and care will be pre-determined by a set of conditions in ‘the now’. These conditions have set in motion inequalities that will underscore the dividing line between those who will benefit and those who never will. This dividing line will be ever more pronounced in 2030 when the UK population affected by cancer will double to four million.

Or, to put it another way, the future impact of innovations in cancer care and treatment will be decided now. We need to be alive to the challenges inherent in delivering greater cancer equality at a time of rapid change, increasing pressure and rising costs.

But this doesn't have to be seen as wholly negative. We can be bolstered by a sense of optimism and ambition as there are no inequalities in cancer care that we do not have the capacity to reverse.

This might seem like a bold statement; but if a focus on tackling inequalities and understanding its root causes imbues our thinking, planning and commissioning of cancer care and treatment, then we could truly achieve outstanding cancer care services for all, not

simply for the lucky few. With even more rapid and profound change on the horizon, we need to act now to ensure that everyone affected by cancer is able to benefit from improvements and that no one is left behind.

This is why Macmillan Cancer Support commissioned this series of essays that explore the impact of cancer inequalities on the UK of 2030. All experts in different aspects of health, the contributors have approached the issue of equality in cancer care from very different perspectives, but consistent themes emerge.

As Ara Darzi and Ryan Callahan write, a discussion about cancer care in 2030 may sound like a conversation in a foreign language, so profound will the change be. The adoption of new technologies can exacerbate inequalities if only some in society are able to access them, so we must take action to ensure that the benefits of medical progress are funded and spread so that everyone can benefit from them.

David Welbourn argues that the inequalities of the future may be in unexpected parts of cancer care, occurring in the areas of services that have less ability to adapt to profound change. The challenge will therefore be to enable services to respond to change in a way that meets the needs of the people who use them.

Pam Garside and Parker Moss point out that as pathways and cancer information become more complex, there is a risk that only a select few patients will have the available resources and support to confidently interpret and act on this degree of complexity. As Jo Bibby and Ben Gershlick describe, those most capable of self-managing and sharing in decisions will continue to get the most out of their care, while those

less capable will continue to get less. So, we must find ways to support patients in becoming active partners in their care, making informed decisions based on what matters to them whatever their resources or ability.

Services will need to evolve not only to meet changes in clinical practice, but also changes in clinical need, as Mike Birtwistle sets out in his essay. Cancer patients are now older, but services are too often designed around the needs of younger people. This will need to change if service delivery is not to become increasingly out of step with the needs of the people who actually use them.

As Neil Goodwin argues, as cancer pathways become more complex, health services must act to join up their care and address unwarranted variations in quality. But meeting the challenge of cancer should not be left to health services alone - everyone must play their part.

In responding to these challenges, a common theme emerges: transfer power to the people who use services, enabling them to take greater control of their cancer team and their cancer journey. Mark Britnell, writing movingly about his own experience of cancer, argues that even the best care can miss the point if it fails to meet a person's most pressing needs. As Francesca Cignola argues, 'people power' not only enlists patients in their own care, but enables them to direct resources and focus to where they can deliver most benefit.

My hope is that these essays continue to shift the agenda of tackling cancer inequalities from the margins of public policy to centre stage.

There will be four million reasons why we need to get this right by 2030.

Precise and equitable: spreading the language of cancer care in 2030

Professor the Lord Darzi and Ryan Callahan

Lord Darzi holds the Paul Hamlyn Chair of Surgery at Imperial College London, Royal Marsden Hospital and Institute of Cancer Research. He was knighted for services in medicine and surgery in 2002 and in 2007 introduced to the House of Lords as Professor the Lord Darzi of Denham and appointed Parliamentary Under-Secretary of State (Department of Health). Upon stepping down in 2009 he sat as UK Global Ambassador for Health and Life Sciences until March 2013. Lord Darzi remains a member of Her Majesty's Most Honourable Privy Council. In September 2013 he was appointed to lead the clinically-led London Health Commission.

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Precise and equitable: spreading the language of cancer care in 2030

Professor the Lord Darzi and Ryan Callahan

Introduction

If we could hear a discussion about cancer care in 2030, it might sound like it was going on in a foreign language. If recent advances in diagnostic and therapeutic technology continue, we might strain to comprehend those future conversations, peppered with unfamiliar terms from the ever-evolving lexicon of precision medicine. For those clinicians and patients of 2030, today's neologisms – 'EGFR', 'triple-negative', 'KRAS wild-type', sometimes heard when selecting a precision therapy from among the handful available for each tumour type – may well have become linguistic relics, memories from our early ventures in precision medicine. The term 'precision cancer care' may no longer even exist, replaced simply again by 'cancer care' as we adapt specialised techniques into everyday practice.

But perhaps more worrying is the possibility that in some other future clinics, precision medicine would not have impacted conversations and changed the vocabulary of care to the same extent. In those rooms, for those patients, the options and the outcomes would remain mostly the same as they are today, without access to the latest targeted treatments or the advanced diagnostics that would inform them. Decades of object lessons in the inverse care law push us to grapple with this future as we now know that advances in medicine that require more intensive resources may not reach the patients who could benefit most from them. Cancer care is already an expensive, complex specialty. Moving further towards precision cancer care invites greater complexity in both diagnostic and therapeutic technologies and demands more resources in time, talent and treasure. The resource requirements for this kind of cancer care could

increase exponentially between now and 2030, and if inequality persists, gaps in resource availability could dramatically widen.

We believe that at the same time as medicine becomes more precise, it must also become more equitable. While we stand to benefit greatly as a society from precision medicine, we also risk exacerbating our existing inequalities in outcomes by making, as it were, only the best care today even better. Through all the technological improvements in healthcare, too many have been left behind as other groups benefited from progress. In this essay, we explain why this risk of greater inequality could be especially high in precision cancer care. We also discuss what we might do today to mitigate that risk through innovation, investment and policy change.

Where precision cancer care is headed

The commercialisation of diagnostics and therapeutics enabling clinicians to discriminate among tumours based on genetic information heralds the arrival of precision medicine in oncology. In fact, oncology is widely acknowledged to be the specialty furthest advanced in this field. For those who anticipate widespread adoption of precision medicine, the potential benefits are plenty, impacting each stage of the care pathway from prevention through survivorship (see Table 1). Precision medicine in cancer care promises not only to provide better, more targeted care, but also to reduce the overall burden of disease from cancer and to justify some of the increased expense for precision medicine technology by reducing costs in other areas. Today, the response rate for many (expensive) oncological treatments is poor, and we can improve care

and reduce costs by better understanding the mechanisms at work in the non-responding population.

In this future world, care planning for an individual patient would be better informed by the likelihood that a particular therapy would be successful given the genetic profile of the tumour and the patient. It is now accepted that this more sophisticated approach to treatment should be the standard of care in some situations,

for example in advanced colorectal cancer where biological therapies would be rendered ineffective against tumours with a KRAS gene mutation. Building on this experience, there is a strong drive to discover new biomarkers and their relationships with current and future therapies. The Lung Cancer Matrix trial currently underway in the UK is an example of the intense scientific focus and financial investment being made to push this frontier forwards.

Table 1 – Potential benefits from precision cancer care – adapted from Meric-Bernstam et al. (2013)²

Care pathway stage	Potential benefits to patients and society
Screening and Prevention	<ul style="list-style-type: none"> Lower incidence and earlier detection of cancer through risk assessment
Diagnosis	<ul style="list-style-type: none"> Care planning which anticipates tumour response based on oncological biomarkers
Treatment	<ul style="list-style-type: none"> Better survival from treatment with most effective therapeutic agents for patient characteristics and tumour biomarkers Improved patient experience and reduced cost from improved side-effect management Reduced monetary, physical and psychological cost for treatment from reduction in ineffective therapies
Survivorship	<ul style="list-style-type: none"> Lower recurrence of cancer through personalised survivorship

How precision cancer care could have an impact on inequality

While advances in precision medicine augur a new era in cancer care, we want to explore whether and how these technologies will reach and improve outcomes for patients on a large scale. This is no small ambition for precision medicine, and as its advocates aspire to revolutionise population-level cancer care, we believe that more attention is needed for the adoption and dissemination of these innovations at scale. It is on this level that we would hope to observe wide-ranging improvements in care and avoid uneven gains in which the benefits from technology are disproportionately concentrated in certain advantaged patient groups. In anticipation of the eventual population-level roll-out of precision medicine, we postulate three mechanisms by which precision medicine, with all respect to its potential to improve care, risks entrenching or worsening inequalities in cancer care today.

Failing to address core drivers of existing inequality in cancer care

We are mindful that inequality in cancer care exists not only in a hypothetical future world, but also today. There remains a statistically significant 'deprivation gap' between the lowest

and highest deprivation quintiles in survival, signalling the effects of many contributing factors, including tumour characteristics, patient characteristics and the effect of healthcare delivery. These factors are difficult to tease apart and weigh in importance relative to each other, but it is widely accepted that each has a role. While some inequalities in cancer care will reflect inequalities in healthcare generally, we believe there are specific aspects of cancer care delivery that are amenable to improvement, especially in a universal healthcare system.

From the point of view of a health system leader who wanted to reduce inequalities in cancer care, he or she would, following the evidence, focus principally on finding ways to improve stage of disease at diagnosis (that is, detect cancer earlier) and improve access to optimal treatments.^{3,4} In our view, these laudable priorities are not particularly well served by precision medicine. While optimal treatment in 2030 may look different and likely will be more effective, the issue of access will remain as important as ever. Although precision medicine may be helpful in detecting cancer earlier by providing individual patients with better risk assessment to inform prevention and screening, it remains to be seen if this could be a cost-effective strategy on a population level.⁵

Table 2 – Three risks of precision cancer care to entrench or worsen inequality

1.	Failing to address core drivers of existing inequality in cancer care
2.	Failing to mitigate the effects of the inverse equity law
3.	Failing to mitigate the effects of the inverse care law

We do not wish to saddle precision medicine with the difficult task of reducing inequality in cancer care when it has not claimed this as its own objective. We do, however, wish to reiterate to policymakers that the high and increasing enthusiasm about precision medicine and the application of finite resources of strategic priority, financial investment and public emphasis in this direction are not likely to result in a smaller deprivation gap in survival, simply because this is not the aim of these technologies. Furthermore, there exists a strong potential for this movement to have deleterious effects on inequality, which we discuss in the next section.

Failing to mitigate the effects of the inverse equity law

We have noted that inequality is a reality of cancer care today, but we must also be careful not to assume that this has not always been the case. Alongside the improvements in cancer survival in the last 50 years, there has been a concomitant trend of increasing inequality along the deprivation gradient – plainly said, the gap between cancer care for the rich and poor has mostly become worse. As Coleman et al. demonstrated in 2004 (and updated and confirmed in 2008 and 2010), gaps in survival between the most deprived and least deprived groups have, with only rare exceptions, widened and persisted since 1971.^{6,7,8} Given that these trends took place during an era of improving preventative, diagnostic and therapeutic technologies, we believe it is important to consider the potential role of technology adoption and any unintended consequences of improving the standard of care over time.

The ‘inverse equity law’ has been put forward as a model for understanding the impact of new technologies on inequalities in healthcare. It describes how more affluent segments of

society tend to be the early adopters, which has the effect of worsening any existing deprivation gap until the technology disseminates through the system, reaching the most deprived populations.⁹ When this framework is applied to cancer care, it proves difficult to isolate and track the specific impact of any single technological innovation given the complex and multidisciplinary nature of cancer care, but taken together over time, evolution and growing sophistication in the way cancer is treated seems to be linked to worsening inequality through the mechanism of technology adoption.¹⁰ Exactly why technology adoption takes place more slowly among less affluent segments of society is unclear, but it has been demonstrated that one important factor is whether patients have sufficient education to utilise, access or demand new technology. This is even more critical in diseases which have benefited from a great deal of innovation.¹¹ The proliferation of innovative therapies that is likely to result from precision medicine (and which is indeed essential to its success) will make cancer care even more susceptible to socio-economic gradients in adoption, if the inverse equity law is to be believed. In this way, the future ‘language’ of precision cancer care could become muddled to patients, carers and the public – in direct relationship to their levels of education and socio-economic status – assuming it is spoken at all in their healthcare setting, a point we will come on to shortly.

In the long term, the inverse equity law predicts that any such gaps will narrow, resulting from a combination of diminishing marginal improvements from new technology and sufficient lag time for all ‘old’ technologies to be disseminated throughout the system. However, for as long as technology continues to make significant strides in improving survival

(and precision medicine aims to do just this), we are likely to see continued, worsening inequalities unless steps are taken to diffuse new innovations more equitably, more quickly.

Failing to mitigate the effects of the inverse care law

According to the inverse care law, first described in 1971, the populations who are most in need of health care often have the least access and utilisation, and those who need it least have the most.¹² The challenge of providing care to needy populations is as important in precision medicine as it is across the healthcare system, and we believe there are two important implications of the inverse care law which apply uniquely to precision cancer care.

The first implication is closely linked with political considerations of resource apportionment and distribution of services. For precision medicine, which utilises advanced and expensive technology and encourages the fragmentation of cancer care expertise into ever-smaller specialties, these considerations have special import. Commissioners of cancer care will need to weigh the balance between centralising investment and expertise into cancer centres, and maintaining ease of access, especially for rural and remote populations. The experience of MD Anderson Cancer Center in the United States is instructive in this regard; even the best-equipped and best-funded cancer centres today could require ‘major investment in infrastructure’ to adopt precision medicine techniques.¹³ Even though a high degree of specialisation should be possible in theory in such a centre, MD Anderson leadership notes that dedicated decision-support resources are still needed for their clinicians, especially given the investigational nature of many therapies.

Even highly specialized oncologists at leading cancer centres typically cannot incorporate the vast amounts of genomic information into clinical decision making and selection of investigational therapy for individual patients.¹⁴

To us, it is clear that some mechanisms in the inverse care law which limit utilisation for needy patient groups – lack of access to specialised services and expertise – loom large as challenges in distributing the important, but very complex, investment and expertise in precision cancer care.

The second implication of the inverse care law has to do with the economics of precision cancer care. As the international Lancet Oncology Commission has noted, pharmacogenomics poses a challenge to the existing regulatory regime in many countries, including the UK. It is not clear that existing NICE protocols for evaluating cost-effectiveness and establishing an evidence base can or should be used in precision medicine.¹⁵ The uncertainty regarding cost-effectiveness and regulatory approval may further limit widespread implementation beyond high-profile cancer centres that are willing to take a role in shaping the regulatory regime.

What could be done to mitigate these risks

While we believe that a greater focus on precision cancer care may entrench or exacerbate inequalities, we reiterate that its potential value merits concerted action to mitigate these risks. We hope that precision cancer care will advance as rapidly and equitably as possible. To that end, we have made five policy recommendations which we believe would begin to address these problems.

Looking ahead

As we have discussed, there are at least three causes for concern that the promise of precision cancer care will not improve existing inequalities and may even contribute to their worsening. Amid the enthusiasm for a 'revolution' in the way we deliver cancer care, we believe a note of caution is necessary from the standpoint of equity, with greater consideration for the historical precedent in oncology and healthcare more broadly, in which innovation has, unfortunately, been applied unevenly and contributed to widening gaps in outcome. We hope that this discussion helps influence the way we speak about the future of precision cancer care, with success measured not just in the number of genomes we sequence or number of therapies we introduce, but also by the share of the population speaking a common language and reaping the benefits from precision cancer care.

Table 3 – Five recommendations for an equitable precision medicine policy agenda

1.	Prioritise those aspects of precision medicine that will address current inequalities – improve access to risk stratification for improved prevention
2.	Educate the public about new innovations in precision cancer care so that they will be prepared to look for and ask about them
3.	Automate processing and provide decision support where appropriate to enhance more clinicians' ability to participate in precision cancer care
4.	Make disproportionate investments in precision cancer care in deprived areas; for example, locate specialised diagnostic centres here, and monitor outcomes relative to investment levels
5.	Form knowledge affiliations between concentrated centres of precision cancer care expertise and secondary facilities to extend the benefits of precision cancer care more widely

The shape of cancer services in 2030

David Welbourn

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The shape of cancer services in 2030

David Welbourn

'I wouldn't start from here!' So runs the response when seeking particularly tricky travel directions.

Attempting to gaze forwards across a 16-year horizon to pinpoint the critical determinants of inequity in cancer treatments begs precisely such an answer, simultaneously pointing to the difficulty of providing helpful navigation through the twists and turns that will be involved, while implying a high risk of becoming lost again along the way.

As I mentally explore those elements that are likely to influence the way cancer and its treatment impact on our lives over the next 16 years, I am drawn to a list in which our growing understanding of the diversity of cancer plays a relatively minor part. Instinctively, I approach the question through a systems lens – beginning at a distance with coarse generalities and gradually converging onto the detail of the specific subject. On this basis, I begin by considering the global forces and effects that are confronting the planet, to explore how each of these will combine to create a range of scenarios that will exert significant influence to shape the context. Ultimately, it will be the features within these contextual themes that will determine the nature of cancer services and how these are organised and accessed to deliver a range of outcomes in which varying degrees of inequity become manifest.

Before proceeding in more detail, it is perhaps helpful to illustrate how the final outcomes are likely to be affected by apparently unconnected circumstances, each of which will be explored more systematically in what follows. We cannot ignore the reality that by 2030, the global population will have grown by nearly 20% to 8½ billion, with the majority of this growth

occurring in less-developed countries. Whereas the population of high-income, developed countries will be almost static, many of the least economically active areas will see their population grow by nearly 50% over the same period.

As we have seen from the Arab Spring onwards, the emergence of ever more sophisticated forms of social media technologies achieving unprecedented reach deep into previously disenfranchised communities is creating increasingly powerful new forces. These are of such strength to challenge the legitimacy and stability of traditional autocratic rule, beginning a process of building momentum where previous attempts to mobilise have failed. Over the coming years, demands for a more equitable distribution of wealth and fairer access to resources will inevitably grow in both intensity and impatience, making the current difficulties with global trade conversations seem trivial by comparison.

At the other extreme, in the more developed nations, the slowness of financial recovery from the global crisis, continuation of austerity measures, high levels of underemployment, concern about intrusive government surveillance, rising resentment of the privileged few (especially bankers) and expressions of mild xenophobia creating a backlash against migration all contribute to increasingly polarised political debate, disillusionment and mistrust of politicians.

On the global stage, deep-seated territorial divides threaten to spill over into crisis, reinforced by a seemingly increased prominence of extremism and intolerance in religious groups.

It is against this backdrop that attempts to explore the need for change within healthcare systems struggle. There is an increasingly urgent need for an honest and objective appraisal of the mix of successes and failures of both the national and global healthcare systems, but this objectivity is too frequently drowned out by the combination of strong emotional attachment to a vague notion of the status quo, underpinned by suspicion about real motives. The chaotic mix of deep-seated global inequity, growing tensions, conflicting demands for resource and increasingly polarised and frequently impotent political debate all conspire to diminish the quality of reasoned debate. More than anything, it is the volatility of this debate, rarely objective, usually emotionally charged, and invariably conducted in isolation from the global geopolitics that poses the biggest challenge to making the necessary progress in reforming and improving health care anywhere in the world. Throwing cancer with its mystery and fear into the mix of the debate is a sure way of increasing both the emotion and the polarisation.

But the urgency of this debate can no longer be denied using the favoured trick of pushing the issues into the long grass. Every developed nation is overwhelmed by the challenges created by the very successes of our healthcare systems. Where the historical imperative for healthcare was to make sick people well, we have now been so successful with medical intervention that more people survive serious illness and severe trauma than ever before, living to ever older ages, where frailty and the permanent consequences of conditions require more and more complex and ongoing care support. In the UK, we now spend 70% of the health and care budget helping people to live with the consequences of their conditions. Viewed by these individuals, arguably we spend such a high percentage of the budget because in too

many cases the health system fails to enable people to enjoy independent and fulfilling lives, living well with their conditions. Instead, it is often only after their conditions deteriorate to such an extent that they need emergency intervention that they receive the support and treatment that they need. Most of the advanced health systems are in a similar predicament – achieving fantastic progress to prolong and save lives in some areas, only to be overwhelmed by the ongoing levels of support required.

The success of medical advances means that the elderly are by far the fastest growing population group. The challenge for healthcare is that this is the very group that is the major user of care resources, and the group within which the interaction of multiple conditions makes both diagnosis and treatment hardest.

Against this backdrop, the path of progress in cancer treatment will be determined by the course through this maelstrom of several strands:

- the sense of personal and societal prosperity, determined by the way in which these tensions play out in global economic confidence, and its consequence on the local economy;
- the continuing battle between citizens and politicians for trust, meaningful engagement and democratic legitimacy, the outcome of which will define the evolving nature and boundaries of public services;
- the ability of the healthcare system to find a sustainable and affordable response to the challenges posed by demographics, new technology, the health impact of poor lifestyle choices and increased public expectation;

- the pace at which progress in genomics and proteomics will be able to convert the new scientific understanding into the heralded breakthrough treatments, whether they will deliver the anticipated step changes in outcomes, and whether they will be universally accessible and affordable.

Potentially the most significant of the global forces at work is the impact of continuing population growth which in itself is a driver of other global forces. The changing population demographic is one of the dominant national themes behind healthcare challenges in most developed countries, but the global effect has different and far wider consequences. At the current rate of growth in global population, numbers are increasing by one billion every 11 years. Most models suggest that the growth rate is close to its peak, though none of the scenarios suggests that the slowing of growth after the peak will have a marked effect within a 20- to 30-year span. By 2030, the figure is projected to be around $8\frac{1}{2}$ billion \pm $\frac{1}{4}$ billion, nearly 20% more than today. The distribution of this growth is potentially of greater interest and concern as one of the key geopolitical risk factors affecting the course of future events. In economically developed regions, predictions suggest a very modest growth of three per cent, mainly comprising a rising percentage of the very elderly. This figure rises to an average of 40% across the least developed nations, approaching 50% for Sub-Saharan Africa. Population growth is therefore concentrated in regions with the most vulnerable populations that are already facing significant challenges of deprivation, famine, drought and inadequate welfare. This disproportionate population change is bound to have an impact on wider elements of global politics because of the scale. For example, the population of Sub-Saharan Africa is currently

less than three-quarters of that in the developed nations, but is predicted to outnumber them by 2027.

Even at a more local level these population changes are not uniform. Although the most recent UN population studies predicted growth across all the major OECD nations of only 3% by 2030, this masks a reduction of 1% in Europe as a whole, but a predicted growth for the UK of 8.7%. The more recent figures produced by the ONS for the UK suggest an even greater growth rate, rising by 11% in the same period. This is underpinned by a range of factors, but dominated by the age demographics and the rapid improvement in life expectancy in recent years, resulting in disproportionate growth of the elderly age group, with a nearly 60% rise in numbers over 75. The demographics of city populations is markedly different from that of the wider population, generally with a much higher percentage of young people. Under-30s make up around 37% of the population across the UK as a whole, but in inner London they account for 44% of the population, whereas only 4% of this population is currently over 75. The combination of migration towards cities and the demographic shift means that the population of London is expected to grow by 18% by 2030, much faster than the national average. Although the rise in numbers in the elderly age group in London will outstrip the growth in other age groups, the rise in over-75s will see only about a third of the growth across the nation as a whole, reaching less than 6% of what is predicted to become a population of 10 million people in the London of 2030. As cancer is a disease of age, it could be argued that the high concentration of excellent specialist services and research favours the capital disproportionately with local need in other areas of the UK – a recurrent source of regional tension within the UK.

This changing population profile has a direct impact on the demands facing healthcare, but also has a wider impact through the way it changes society itself.

One of the important characteristics of any country lies in its political attitude towards social welfare and the extent to which this is perceived either as a responsibility or an inappropriate intervention by the state. The precise level at which this boundary is drawn has a significant influence on the nature of the health and care system operating in any country, especially by shaping the mechanism by which it is financed. Thus, the US healthcare system is dominated by the combination of large-scale inequity that excludes some 30 million people from routine access to care, and the extraordinarily high cost base that is nearly double that of any other nation, all fuelling the deep division over the federal intervention in the shape of the Affordable Care Act (2010). In contrast, the UK's health system seeks to eliminate similar inequity through its guarantee of universal access, free at the point of delivery. It struggles instead with unjustifiably high levels of variation in quality and outcomes, and in its attempts to distribute limited resources fairly, a number of new and expensive treatments are rejected or delayed. In the case of new cancer drugs that are invariably expensive, and which offer limited respite in some but not all cases, the debate is just as divisive but much more personal to those involved than the political divisions about the US care system. It is highly likely over this 16-year projection that debates over the legitimacy of policy will force unpredictable changes to the decision-making processes, as campaign groups increase their leverage through social media to weaken political resolve in this disputed space of personal versus societal value.

Perhaps less discussed is the reality that, whatever its scale, the social welfare system reflects a virtual trans-generational contract. This means that, irrespective of however progressive the taxation system, those in their economic prime of life contribute to society in order to support the young through their formative years and the elderly as they are likely to become increasingly dependent on others as they age. Unfortunately, this 'contract' is unwritten, rarely discussed, and is long term, spreading over 80 years or more, during which time key attitudes in society may change dramatically, changing the basis on which the contract is expected to be enforced. The elderly who are now drawing on this contract grew up in a culture where borrowing was frowned upon and it was essential to save towards anything not considered essential. This is in marked contrast to the expectations of the boomer generation and younger who are at ease with borrowing from tomorrow in order to enjoy the luxuries today. These two cultures clash head on in the expectations of social welfare (including health) when neither of the generation groups are keen to accept responsibility for budgeting for the level of demand on the social purse – the older ones argue they have already paid, and the younger ones argue that they are minority users of the services so should not foot the full bill.

The current hole in pension provision illustrates how this mismatch of expectation arises where the duration of contracts is much longer than the underlying development cycle. In the 1960s and 70s, UK life expectancy was around 71 for men, with the average pension provision covering six years. Since then, advances in healthcare have pushed life expectancy in retirement to upwards of 15 years prior to the enforced increase in retirement age. Good news for the success of healthcare, but a challenge

for the pension industry to meet the expectation arising from such a dramatic departure from the original premise.

But in the UK, the impact on healthcare is potentially even more stark, given that the taxation-based mechanism for funding the NHS buffers users of healthcare from the direct cost implications. Although the public perception of the NHS is often dominated by thoughts of acute hospital-based interventions, the reality has long been that the majority of the NHS workload is conducted in supporting people to live well with a range of permanent and debilitating conditions. Many of these conditions arise with age and become increasingly difficult to manage as they interact with each other. By the age of 75, the majority of people will have three or more of these long-term debilitating conditions and a quarter will have five or more. Despite making up only 8% of the population, the complexity of care for this group means that they each cost quadruple that of the average person, consuming a total of 25% of the NHS budget. The demographic changes described previously indicate a 60% growth in numbers in this population group by 2030, which in purely financial terms represents a further 10% growth in the required budget even without any of the other inflationary costs associated with health care.

Rather than celebrating the success that people's life expectancy has increased by an average of 10 years over the last 30 years or so, or recognising the valuable contribution that this generation has made to the current national prosperity, the reduced cohesion in our highly mobile and demanding society appears more comfortable to refer to the 'problem' or burden of age that this story implies. Recent discussion about the impact of capital on wealth and the

expectation that the millennial generation may be the first to be poorer than their predecessors combined with the inherent design that social welfare involves inter-generational transfer is likely to add a further blow to the chances of closing the gulf between political processes and citizens, with unpredictable consequences.

The term VUCA is growing in use to refer to the Volatility, Uncertainty, Complexity and Ambiguity that describes the combined effect of increased interconnectedness, growing activism and the speed with which behaviours can be adapted in light of new intelligence and insight. With VUCA comes chaos and paradox, themselves describing the failure of reasoned logical argument, the replacement of long-term strategy with an emphasis on the power of engagement through a compelling narrative, drawing people emotionally into the promise of how the future may be experienced.

The foregoing description of the global impact of population changes, large-scale economic inequity and the ability to mobilise dissent that is challenging the traditional forms of governmental legitimacy is part of the perfect storm of VUCA, where systems and processes that are centrally designed and controlled and evolve slowly will be replaced by those which are adaptive and agile to produce a dynamic response, and in which teams are driven towards a shared sense of purpose by their personal commitment and engagement and the wide-ranging permissions they have to make local decisions.

In the long-established health systems in the developed world, the organisational mechanisms for change, the political authority and even the healthcare professions themselves are designed for and work in a traditional,

non-VUCA world. The next 16 years will see a transformation in which the incumbent systems, processes and leaders will fight increasingly strong rearguard actions to defend the status quo, before ultimately collapsing in the face of new approaches that understand how to free-ride the waves of turbulence.

The challenge for cancer care is that it will be caught mid-transition. The world of science discovery on which the future depends is used to free-ride the waves. After all, the first full genome of any multi-cellular organism was published late in 1998, and only five years later the human genome sequence was completed – the net result of 13 years' effort and \$1bn. Just a decade on, the DNA can be sequenced within a day or so for less than \$5000. More significantly for cancer studies, the science of proteomics is able to sequence the entire set of proteins, offering the promise of pinpointing the specific protein involved in the cancer. Where the world of medical science may be suited to thrive in a VUCA world, the world of practical medicine is locked into systems of long-term testing and trials within a centrally dominated suite of processes and cultures that is healthcare. For the world of big data, proteomics and new science to impact successfully in personalised medicine, the whole structures of drug approval need to be redesigned and remodelled for the VUCA world, and the health system in which it is delivered needs to embrace new ways of working where co-design with service users focuses on longitudinal continuity of care and cutting through the organisational and professional boundaries that currently dominate.

The new inequities in the world of cancer treatment are going to be in those unpredictable and unexpected places which have the least propensity to adapt to the growing volatility and tensions of an increasingly turbulent world. They may well be the very places which have experienced the strongest fit to the way of working that we are struggling to leave behind – precisely the ones you would least expect to fail.

Buckle up for a challenging ride.

Cancer in 2030: the future is bright... if you're wealthy and well-informed

Pam Garside & Parker Moss

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Cancer in 2030: the future is bright... if you're wealthy and well-informed

Pam Garside & Parker Moss

The UK delivers world-leading pure and translational cancer research. Patients and clinicians are supported by NICE, an institution with global recognition for providing excellent guidance on the efficacy, quality and value for money of therapies and medical technology to ensure that effective treatments are made quickly available to the appropriate patients.

Cancer guidelines have gone a long way towards ensuring that patients throughout the country have access to high-quality specialist oncologists. The patient experience is modernising rapidly: most patients have access to their care plan and are regularly included in their clinical journey. The ideal of patient consent being 'no decision about me without me' is being ingrained and reinforced in cancer organisations throughout the country. Despite this progress, unacceptable variation exists in cancer outcomes.

Within this context, this paper focuses on the future risks to some UK patients with cancer. We propose that by 2030, the number of diagnostic and treatment options for people at risk and suffering from cancer will increase significantly due to the globalisation of clinical research and development and advances in personalised medicine. These very positive developments could, in the absence of greater international information sharing and trial collaboration, lead to a future where patients who have knowledge and financial resource will have much better access to these benefits. We recommend strategies to avoid these potential inequalities.

The scope of this paper

There are many complex drivers of cancer inequality, both today and in the future. This paper focuses on financial and information inequality. Two additional drivers that are particularly important but not addressed in this paper are:

- The high cost of some drug therapies, which puts them outside the range that NICE will invest in and what the majority of patients can afford to self-fund in the private sector. This is likely to worsen as the capital intensity of drug R&D increases and the target markets for these drugs decrease as personalised medicine targets smaller population segments. Clearly, financial solutions and new R&D models will be required in order to avoid long delays in novel treatments reaching UK citizens.
- Increased rationing in healthcare is leading some key opinion leaders to suggest that certain segments of society should be given greater access to expensive cancer treatments than others. The young are generally held up to be the most deserving because, it is argued, they have the potential to deliver a greater contribution to society than the elderly. We believe that if factors such as 'contribution to society' are considered along with statistics on the UK's ageing population (eg the ratio of non-working to working people in the UK is expected to increase from 1:8 in 1950 to 1:2 by 2050) then it becomes clear that cancer inequalities from age-based rationing policies would quickly become unacceptable. However, we recognise that a fair basis for rationing will become necessary as public funding for universal healthcare becomes further stretched

Both of the above risks to cancer equality require a deep analysis of pharmaceutical economics and utilitarian ethics respectively. We have therefore left these important topics out of the scope of this paper, but encourage this debate among observers of health economics and health ethics.

Drivers of inequality

The following meta-trends in cancer research (globalisation and personalised medicine) should be celebrated because they will accelerate innovation and benefit patients in the UK and around the world. Unfortunately, there are significant risks that these benefits will not be evenly distributed.

Globalisation of cancer research

- In the UK today, the majority of patients with cancer are treated with 'standard of care' protocols or within clinical trials that are delivered by NHS specialist cancer centres. More than 12% of cancer patients in the UK now take part in trials, a greater proportion than in any other European country or the USA¹⁶. However, there are growing numbers of expensive or pre-approval therapies that are only available privately or internationally. For example, proton therapy and various monoclonal antibody treatments are available in the USA and on the continent, but not yet in the UK. Some patients use private insurance or personal financial resources to purchase expensive novel drugs or treatment regimens, and an increasing number of UK cancer patients are travelling abroad for treatment.

- As with other innovative industries, we expect that within the next 15 years, cancer research will become much more globalised, with cancer research hubs in India, China and other regions making a larger contribution to the field. Taking China as an example, 21% of deaths in China today are due to cancer, yet cancer care represents 0.11% of gross national income per person. This compares with the UK, Japan and the USA, where it is 0.51, 0.6 and 1.02% respectively of gross national income per person. Perhaps more significantly, China accounts for only 1.5% of publications on clinical research and 1.7% of randomised trials, and only 3% of clinical trials sponsored by pharmaceutical companies are done in China¹⁷. This is already beginning to change, with pharmaceutical companies entering the Chinese market.
- We know that China is now investing significantly to close this gap in research and cancer care, and we expect that, by 2030, China and other emerging cancer research hubs will contribute significantly to cutting-edge personalised cancer treatments. While many of these treatments will diffuse to the UK, we expect that the international-only options for those seeking cancer treatment will increase significantly in the next 15 years.

Personalised medicine

- By 2030, advances in genomics will enable greater risk stratification for potential cancer patients. Vigilant at-risk patients will be empowered to screen for and detect cancer at an earlier stage. We expect that by

2030, the NHS will engage in much more proactive screening, but it is likely that many patients will also use the private sector and go abroad for this. The private company 23&Me¹⁸ provides an early indicator of consumer interest in this field, using SNP technology to sequence a portion of the genome to provide some health (and ancestral) insights (many not yet actionable). By March 2014,¹⁹ it had attracted 650,000 customers who were willing to pay \$99 for genotyping. We see this as a very early indicator that private sequencing centres will expand massively as molecular screening becomes less expensive and the results of these tests more actionable. The challenge will be in the interpretation of this increasing volume of omic data, though we do expect that decision support will start to empower clinical geneticists in a meaningful way in this field by 2030.

- Upon a diagnosis, an ever-expanding evidence base will reveal the influence that genomic variation, tumour gene expression, mutations and epigenetics can have on metastatic pathways and the spread of cancer. As we discover more about cancer sub-types, all cancers will in effect become rare. Breast cancer treatment is a good example of this happening today: until recently, it was considered to be a homogenous disease. Today, patient-oriented educational websites typically break breast cancer into 10 to 14 phenotypic sub-types. Research papers discuss the four common molecular sub-types of breast cancer (Luminal A, Luminal B, Triple negative/basal-like, HER2 type) and the many less common sub-types, but this molecular analysis is

often not included in pathology reports. And while this information may impact prognosis, it is only just beginning to impact treatment pathways. In the future, we expect breast cancer to be further segmented into more molecular-based sub-types, and each segment to be treated differently to maximise efficacy and minimise toxicity. This is the very essence of personalised medicine.

- Cancers will increasingly be treated by the genetic sub-type rather than the origin of the cancer. For example, there may be a clinic for Ras-mutation tumours rather than tumours of bladder or colonic origin. This will allow researchers to target cancers that have significant potential to cause harm earlier than before. As more drug targets and pathways are discovered, we will see an exponential growth of 'precision' clinical trials. Importantly, as these trials target smaller segments or rarer cancers, the number of patients eligible for enrolment in these trials or therapies will get smaller and smaller.
- People will live with cancer and multiple other long-term conditions at the same time because cancer itself has in many cases become a chronic disease. This complicates the issues surrounding treatment with new pharmaceutical and biological solutions, and is the major conundrum behind the need for 'mass customisation' of cancer therapies.

Consequences of globalisation and personalised medicine

The exponential growth in clinical trial opportunities in more global locations and addressing smaller and smaller population sub-groups of patients will create many more alternative treatment pathways. In sub-types where the standard of care still produces unfavourable prognoses, we believe that a patient's outcome will increasingly depend on their ability to enrol in the optimal clinical trial for their specific cancer. As the number of options expands exponentially, the NHS will not be able to offer all trials to all patients, and this will give patients a strong incentive to identify and access personalised treatments in either the private sector or abroad.

This growth in treatment options will also make it increasingly difficult for individual oncologists to stay abreast of the global opportunities for their patients beyond the NHS. Conversely, online patient forums will become increasingly effective at building global communities of highly engaged patients, discussing, sharing and comparing the international options for their cancer sub-type. This will further erode the gap between information available to patients and their doctors. It will inevitably lead to patient pressure on NHS oncologists to discuss and facilitate alternative treatment options. To benefit from the global market of trials, the onus may increasingly fall on patients to help identify and to fund access to these trials.

We have focused on the future of cancer 'treatment' in 2030, but the same principle applies to the whole patient journey, from screening and diagnosis through to end-of-life care. By 2030, will nanotechnology screening techniques, beyond what the NHS could afford

on a population-wide basis, mean that the wealthy could be monitored for signs of early or pre-cancerous conditions, leading to better outcomes? Will end-of-life technology offer much closer monitoring of pain and anxiety, allowing more precise titration of medication for those who can afford to pay for this med-tech sophistication?

We could be facing a future where patients in the UK who have a better understanding of their risk of disease, their diagnosis and their treatment options outside the NHS, and who can pay for this treatment, will be the greatest beneficiaries of advances in global cancer research.

Globalisation of cancer research and genotypic disease stratification will have a significant impact on the availability of clinical trials for NHS patients and the NHS's ability to recruit sufficient patient numbers for clinical trials. It is self-evident on affordability grounds that the trial options available from the NHS (and other health systems) will become a shrinking proportion of globally available trials. Furthermore, as clinical trials become increasingly personalised (i.e. exclusionary), oncologists and trial organisers will be forced to look to the international gene pool to recruit patients with rare cancer sub-types.

NICE will need to maintain its highly respected record for policy innovation as it faces increasing pressure to make treatments available for the growing number of 'rare cancers'. It will likely face pressure from patient advocates to fund international treatment for successful trials or proven therapies that are not offered in the UK. By 2030, NICE could be in the strained position

of having to validate the cost and efficacy of an exponentially growing number of cancer (and other disease) treatments. NICE may need to decline approval of therapies on the grounds of limited efficacy or cost, and private insurers may have to reduce cover to a more limited portfolio of drugs, demanding that substantial efficacy is proven over a long period of time. As this happens, the survival advantage for the wealthy and knowledgeable patient of cancer could become structural.

Solutions

Information technology and public policy should be put in place to ensure that, by 2030, life-saving treatments will be equally available. Improved access to information can help patients partner with oncologists to find appropriate trials and treatment options. Multicentre international cooperation through 'trial corridors' should establish large-scale international patient pools for rare cancer trials and enable free exchange of patients with their data.

Information technology solution

NHS cancer patients are poorly equipped to choose, plan or manage their health today. Despite endless policy pronouncements, patients are only beginning to have electronic access to their care plans or access to meaningful data on the treatment outcomes that are available from the NHS, let alone internationally. Patient communities provide emotional support and practical suggestions, but they are rife with misinformation and generally seen as no-go areas for oncologists. Long before 2030, patients will need to see development of 'decision-support tools'. Today, these are focused on clinical decisions but will need orienting towards supporting patient decision-making, as illustrated in the example below:

A parent of a child who has been in remission after first-line treatment for high-risk neuroblastoma discovers in a routine follow-up scan that the child has relapsed. The parent has access to the child's full medical record, including the phenotype and histology, the genotype and the treatment history. The parent is not satisfied with limiting treatment options to only those available in the UK, and needs to find out quickly what options are best for their child and which trials are recruiting.

This family would benefit greatly from access to a freely available online decision-support tool with which they could quickly submit the clinical data on their child and be shown a list of treatments and open trials available worldwide. Clinical outcome data for these treatments would be presented in a clear and meaningful format along with patient-centred experience and outcome measures, which might include data on expected pain levels, time in hospital, quality of life and late effects measures. The location, duration, estimated costs and administrator contact details would be shown, alongside educational material, in a format that meant the patient and parent could absorb this on their own as well as discuss it with their oncologist.

Unlike the 'doctor no-go' patient forums today, we expect patients and health professionals to converge around digital patient decision-support tools like the one imagined above. These tools would need oversight and moderation by clinical professionals, creating important roles for cancer charities and advocacy groups such as Macmillan. These groups could ensure that NHS and international treatment options are clearly explained to patients, and they could provide treatment consultants to help patients navigate decision-support tools, prepare the patients and perhaps join patients in discussions with their oncologists.

There are already fledgling examples of this kind of patient decision support (www.trialreach.com, for example) and we believe that services like this need to become more sophisticated and have a truly international reach in the future.

Policy solution

No amount of decision support will solve the economic problem that the NHS will face when more patients demand treatment abroad, or the challenge of recruiting patients with rare cancer sub-types for highly stratified clinical trials. A solution to these problems, which would be good for the NHS and for patients, would be to create international trial corridors in which patient data becomes the currency of exchange for patients. This would be particularly valuable for cancer sub-types with poor outcomes where accessing the optimal clinical trial is critical. We envisage a future of NHS partnerships with international multicentre cancer research hubs around the world, extending relationships beyond the academic collaboration and best practice sharing agreements that are already in place today.

Trial corridors would be organised by cancer sub-type. The principle of a trial corridor is that patients participating in trial hubs would have free access to trials and treatments wherever that hub has a reciprocal relationship. Meaningful reciprocity would need to be considered for each corridor, such that a true 'exchange' of patients could occur, and the opening of a patient floodgate avoided. These corridors would facilitate a reciprocal and cost-neutral exchange of patients, with the agreement that all trial data would be shared, enabling all participating hubs to audit detailed trial results and make agile decisions about which trials to participate in.

Patient consent for data sharing would be a necessary condition for participation in a corridor. Depending on the treatment protocol, patients could either travel to the trial location (eg necessary for proton therapy) or the treatment could travel to the patient (eg feasible for drug-based therapies), with suitable mechanisms for remote training of local staff on drug delivery, safety, care plans, etc. Not only could these trial corridors create an international marketplace for cancer patients, which would be inclusive of low-income patients, but they would also provide better data to participating health systems and bodies such as NICE. This would allow them to make rational and evidence-based decisions about which trials to import to their home country and which to access via international collaboration.

The pharmaceutical industry will increasingly be expected to provide value for money and efficacy studies for 'niche' and rare cancers. It will be required or requested by NICE and other regulators to provide the necessary evidence for reimbursement approval, increasingly shifting the burden of proof, as it

were, to the industry. Unlike national health systems, pharma companies are multinationals with global target markets. We expect the concept of multicentre trial corridors to therefore be welcomed by the industry, as this will help it to establish efficacy and to market its cancer solutions across national boundaries.

These corridors should also drive a greater collaboration and even integration of the international equivalents to NICE. This would benefit cancer patients around the world. Trial corridors would satisfy growing patient demand for treatment abroad and growing demands on UK cancer research to recruit rare cancer patients from an international patient pool. Clearly, enormous clinical and information governance as well as international regulatory and legal hurdles would need to be overcome to facilitate these trial corridors, and we do not think that these corridors would alleviate all potential financial inequalities.

However, we believe that for some cancers, the prize would be big and worth pursuing.

The hidden inequality: what can person-centred care tell us about present and future inequalities in cancer care?

Jo Bibby & Benjamin Gershlick

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The hidden inequality: what can person-centred care tell us about present and future inequalities in cancer care?

Jo Bibby & Benjamin Gershlick

Introduction

Better diagnosis and treatment means more people are being diagnosed with cancer and are living for longer afterwards, dealing with its impact every day. This places greater importance on people's ability to make an active contribution to their own health and health care – for care to be person-centred. A growing body of research shows that when decisions are shared – between clinicians and patients – and when people are enabled to self-manage – take control of their day-to-day health care – they may have better outcomes, better satisfaction and reduced inequalities. Of course, all decisions are shared to a greater or lesser degree, and likewise all people self-manage to a greater or lesser degree. However, this variation between the 'greater' and 'lesser' degree means variation in outcomes and satisfaction. This variation is not necessarily problematic if it is warranted: some people may have more severe cancer than others, or choose not to share in decisions or self-manage. But much of this variation in people's ability to take an active role in managing their health and care is not recognised and cannot be justified. It is a 'hidden inequality',²⁰ but one that can be identified by considering people's activation, capabilities and health literacy and can be addressed by adapting services to accommodate and address this variation.

What is the issue with inequality in cancer care?

Healthcare generally takes a conventional view of inequalities. Differences between countries,²¹ regions,²² hospitals,²³ wards,²⁴ socio-economic groups²⁵ and clinicians²⁶ are all well studied, and 'equal treatment for equal need' is central to our universal health coverage.²⁷ Often substantial sums of money are spent on reducing variation and 'levelling up' low and middling performers

to the level of the top performers. In fact, much of the way healthcare is designed and delivered attempts to reduce such variation – NICE sets standards, the resource allocation formula takes into account differences between regions, and hospitals use checklists.

But what about the inequalities that arise from the variation in an individual's ability to take an active role in their health and care? We rightly deplore the situation where someone receives worse care due to their *geography*. Yet we are less vocal about someone with low confidence receiving worse care than someone more assertive, just due to their *disposition*.²⁸ The most confident, activated and educated people have the most capacity, capability and will to make the most out of the health system. By contrast, many accept what they are given and find it difficult to manage their own health. This difference is a pervasive inequity, and as health care becomes more complex, multi-morbidities more common, and long-term conditions more commonplace, there is a risk that it will continue to increase.

Stephen Jay Gould, the influential evolutionary biologist, wrote compellingly about the impact that a sophisticated understanding of statistics had on his reaction to being diagnosed with cancer (abdominal mesothelioma).²⁹ He remarks that 'I have developed [statistical] knowledge – and I am convinced that it played a major role in saving my life'. Is it right, one might ask, that Dr Gould's life was significantly longer (he lived for another 20 years, far beyond the median survival of eight months) than those who happen not to be Harvard professors? Few would want to reduce Dr Gould's life,³⁰ but we assume most would wish to close the gap between him and those who suffer due to their circumstantial lack of knowledge, confidence and skills.³¹

What are self-management support and shared decision-making?

Self-management support (SMS) is:

the assistance caregivers give to patients with chronic disease in order to encourage daily decisions that improve health-related behaviours and clinical outcomes. [It] may be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership. The purpose of self-management support is to aid and inspire patients to become informed about their conditions and take an active role in their treatment.³²

Shared decision-making (SDM) is:

a process in which clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients' informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients' treatment preferences.³³

Both are part of person-centred care. One of the key differences is that decision-making largely takes place in the consultation room, aided by reflection and support outside it, while self-management largely happens outside the consultation room, with support from healthcare professionals or more informal interaction with friends, carers and the wider community.

Does person-centred care improve outcomes in cancer care?

There are some fairly intuitive, common sense examples of how person-centred care can improve outcomes in cancer care, beyond the Stephen Jay Gould example above. Physicians' preferences for their own end-of-life care differ significantly from their patients': 4% of physicians desire resuscitation if terminally ill and unable to make decisions compared to 44% of patients (with 83% of physicians specifically not wanting it, rather than answering 'don't know');³⁴ and in the Johns Hopkins Precursors study,³⁵ 64% of doctors had created an Advance Directive³⁶ (compared to 20% of the general public). Smoking rates among GPs are 4%,³⁷ compared to 27% among the public at that time.³⁸ A randomised trial in the USA showed that a decision aid with individualised risk information for women with breast cancer resulted in fewer women with tumours of low severity choosing additional treatment. It is hard to explain away all these differences beyond the fundamental fact that people who are better informed and enabled make different decisions and manage their health differently to those who are less well informed.

The current evidence base for SMS and SDM is equivocal but often positive, and the argument that they are the right thing to do is perhaps more compelling than the evidence base alone. In fact, it can be unhelpful to focus too much on instrumental benefits such as reduced costs and improved outcomes, partly because the evidence base is mixed, partly because it sends mixed messages on why more personalised care is beneficial and desirable, and partly as outcomes measured are often biomedical or system defined (such as survival rates) rather than those which matter most to patients (such as hope, fulfilment or a sense of agency).

The formal evidence base for the effectiveness of SDM and SMS in cancer is still underdeveloped and is hampered by variance in quality of programme design and evaluation. Here we present some of the more promising findings, although the Health Foundation has also published more thorough reviews of the evidence base for SDM and SMS.^{39,40} These also discuss the evidence suggesting that care and support that meets people's preferences may be more cost-effective than care that patients may not want (if they had the information, skills and confidence to make more informed decisions).

Table 1 – Selected indicative studies, SMS and SDM in cancer care

Setting and intervention	Outcomes	Citation
HOPE, a self-management support programme which was developed and tested as part of the National Cancer Survivorship Initiative	Improvements in hopefulness at six months. Positive patient outcomes – including quality of life, self-efficacy and ability to self-monitor – were maintained at 12 months	Batehup, L., Davies, N. & Lynall, A. (2011) <i>HOPE: supported self-management programme for post-treatment breast cancer survivors. Final Report on the development, evaluation, and outcomes of a sustainable model of supported self-management.</i> London.
MAGIC shared decision making programme	Gradual and persistent improvement in patients' understanding of the key features, risks and benefits of different treatment options	King, E., Taylor, J., Williams, R. & Vanson, T. (2013) <i>The MAGIC programme: evaluation.</i> London.
Usual care versus a 20-minute decision aid and a brochure prior to a planning consultation for women with newly diagnosed breast cancer	Better long-term body image outcomes and coping strategies	Vodermaier, A., Caspari, C., Wang, L., Koehm, J., Ditsch, N. & Untch, M. (2011) How and for whom are decision aids effective? Long-term psychological outcome of a randomized controlled trial in women with newly diagnosed breast cancer. <i>Health Psychol.</i> 30(1), 12–19.

Setting and intervention	Outcomes	Citation
Two assessment sessions followed by individualised treatment information for women at high risk of developing breast cancer	Sessions were associated with better general health and less depression	Van Roosmalen, M. S., Stalmeier, P. F. M., Verhoef, L. C. G., Hoekstra-Weebers, J. E. H. M., Oosterwijk, J. C., Hoogerbrugge, N., et al. (2004) Randomized trial of a shared decision-making intervention consisting of trade-offs and individualized treatment information for BRCA1/2 mutation carriers. <i>J Clin Oncol.</i> Aug 15 22(16), 3293–3301.
Systematic review of 23 randomised trials	More likely to participate in decision-making and achieve decisions more consistent with current scientific evidence and their informed values and preferences	Stacey, D., Samant, R. & Bennett, C. (2008) Decision making in oncology: a review of patient decision aids to support patient participation. <i>CA Cancer J Clin.</i> 58(5), 293–304.
Randomised trial in the USA of CD-ROM decision aid for women at high risk of breast cancer	Increased likelihood of reaching a management decision, decreased decisional uncertainty and increased satisfaction	Schwartz, M. D., Valdimarsdottir, H. B., DeMarco, T. A., Peshkin, B. N., Lawrence, W., Rispoli, J., et al. (2009) Randomized trial of a decision aid for BRCA1/BRCA2 mutation carriers: impact on measures of decision making and satisfaction. <i>Health Psychol.</i> Jan 28(1), 11–9.
Group self-management rehabilitation	Improved cancer survivors' quality of life	Korstjens, I., May, A. M., van Weert, E., Mesters, I., Tan, F., Ros, W. J. G., et al. (2008) Quality of life after self-management cancer rehabilitation: a randomized controlled trial comparing physical and cognitive-behavioral training versus physical training. <i>Psychosom Med.</i> May 70(4), 422–429.

At some point in their lives, 47% of people will sit in front of a clinician and be told that they have cancer. More still will face a cancer scare. That so many people will be faced with such a diagnosis is unquestionably tragic. Nonetheless, it presents a unique and underutilised opportunity for engagement with such a large section of the public, and may be an opportunity to support them to take a more active role in their health and healthcare.

How do you measure inequalities in, and the impediments to, the person-centredness of cancer care?

It may be important to ‘meet people where they are’ in order to increase the capability of people to self-manage and share in decision-making. This is for (at least) two reasons: (1) interventions are likely to be more effective if they are tailored to people’s current capability, and (2) if people are engaged in a way only appropriate for the more activated, then improvements are unlikely in those not yet at that level. The question, then, is ‘how do we know how enabled people are?’ or, more appropriately, ‘what impedes people’s ability to fully engage with their decisions and care?’ We will look at three ways of answering this question:

- The patient activation measure (which measures patients’ knowledge, skill and confidence)
- The capabilities approach (which looks at how free people are to do and be what matters most)
- Health literacy (which examines people’s ability to understand and use health information)

However, none of these alone will be sufficient to answer the question, and a number of measures will be needed to get a sense of where people and services ‘are at’.⁴¹

Patient activation measure

Patient activation is ‘an individual’s knowledge, skill, and confidence for managing their health and health care’.⁴² One way of measuring it is using the Patient Activation Measure (PAM), which is a patient-reported measure based on 13 questions. It produces a score between one and 100 (the higher, the more activated), often subdivided into four ‘levels’. By this measure, 40% of the population (and 66% of those with poor health) have low levels of activation.⁴³ For every 10 points higher in patient activation, the likelihood of having a breast cancer screen was one percentage point higher.⁴⁴ The PAM is not perfect, but it is undoubtedly a useful tool for assessing people’s levels of engagement with their own health. Due to its well-known status and validation, there is a fairly large evidence base for the link between PAM score and positive behaviours such as eating healthily and exercising, clinical outcomes such as BMI and cholesterol levels, and health outcomes such as quality of life and satisfaction.⁴⁵

Table 2 – Level of activation, US adults with chronic conditions, 2007

Activation level	Level 1 (least)	Level 2	Level 3	Level 4 (most)	Overall activation score (adjusted)
All people with chronic conditions	8.6	17.3	33.9	40.1	64.2
Cancer	7.8	12.2*	34.5	45.5*	65.8
Diabetes	7.9	18.9	35.3	37.9	65.3*
Asthma	8.1	16.8	32.5	42.7	64.8
Heart disease	11.6	18.9	34.0	35.5*	64.0
Hypertension	9.6	18.5	34.2	37.7*	63.5*
Arthritis	11.2*	19.1	32.2	37.5*	63.2*
Depression	12.6*	21.1*	29.4*	36.8*	62.1*
Three or more conditions	11.7**	19.8	32.6	35.9	66.0
Fair or poor perceived health status	15.4	22.7	31.6	30.2	61.0

* Statistically significant difference to person who does not have condition at $p < 0.05$ level.

** Statistically significant difference to those with one condition at $p < 0.05$ level.

Source: HSC Household Tracking Survey data in Hibbard & Cunningham (2008).⁴⁶

The capabilities approach

Another way to think about these issues is to think about capabilities. Capabilities are people's real opportunities to achieve functionings.⁴⁷ While sounding somewhat abstract, it taps into a very tangible idea: what makes for a good life is being free (and able) to be (and do) what matters most to the individual concerned. So a functioning might be going for a walk (a 'doing') or being well nourished (a 'being'). This capabilities approach was pioneered largely by economist Amartya Sen and developed by philosopher Martha Nussbaum. It has had particular traction and effectiveness in studying poverty and inequality.

It is an important way of conceptualising what a person has or does not have in a way that is dependent on things that people value. It is a broader, deeper measure than a lot of the other ways of understanding poverty and inequality. Rather than trying to quantify very narrow aspects of people's wellbeing (such as their income or blood pressure), it considers broader aspects (their freedom and ability to do and be what matters most to them). Of course, this approach has its downsides: it is significantly harder to measure and monitor, to know when interventions successfully improve people's capabilities, to engage policymakers on, to allocate resources, and to determine access to different interventions or treatment.

Inequality here arises when people's capabilities are differentially deprived. It helps to frame why improvements in certain measures might be desirable: why is it that improved blood pressure, mobility, sleep and length of life are good things? Because, the capabilities approach suggests, they improve our ability to do the important things in life.⁴⁸

Health literacy

SDM and SMS are at least in part about helping people to understand and incorporate information in order to make decisions that are right for them and to help them become knowledgeable, confident problem-solvers.⁴⁹

Health literacy is linked to literacy and entails the motivation, knowledge and competencies to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life throughout the course of life.⁵⁰

People's ability to understand and incorporate health information is known as health literacy. Sørensen et al. give a useful definition:

When assessed across eight EU member states, 12% of people have inadequate health literacy while 16% have excellent health literacy.⁵¹ These measures are often designed so that they will tend to have a somewhat normal distribution (some will be in the lowest group, some in the highest group, and most will be in between). Nonetheless, this is genuine variation in people's ability to use health information and results in worrying inequalities in outcomes. To some

extent, the health service needs to play the cards it is dealt: many of people's literacy, monetary and time issues are due to social determinants. The percentage of people with limited (inadequate or problematic) health literacy who have a very low social status is 74%, who have a low level of education is 68%, who are in a low-income household is 66%, who are 76 years or older is 61%.⁵² Of course, very few would suggest that health interventions should make people richer or younger or better schooled in order to achieve better outcomes.⁵³ But, nonetheless, it is important to recognise this variation in health literacy and use it to tailor interventions to help those that need it most and make sure the interventions are as effective as possible. In bowel cancer screening, 'participants varied in how they understood and integrated quantitative risk information about the benefits and harms of screening into their decision making; some read it carefully and used it to justify their screening decision, whereas others dismissed it because they were sceptical of it or lacked confidence in their own numeracy ability'.⁵⁴

How can we reduce the inequalities in the person-centredness of cancer care?

In the UK there have been a number of large-scale attempts to support people to self-manage and share decision-making over the past decade. The Health Foundation will be publishing a report bringing together the evidence from these programmes later this year.⁵⁵

While initiatives to improve people's ability to self-manage and share decision-making can be effective at improving these skills in the least capable, often that group of people are not involved in the initiatives. Reaching out to the

entire population is a common problem for medical researchers, pollsters and public health interventions. If an intervention advertises for participants by putting flyers up in the local GP surgery, then you will get participants who are better off, more literate, more confident, and suffering from less severe illnesses.

It is not obvious what the solution is, but it is worth mentioning some promising ways of engaging those least likely to engage. The first is by engaging and enabling communities. Work has been done on this through NESTA's Neighbourhood Challenge, and Coulter⁵⁶ scopes out this role of communities in health improvement. The second is related to the support group that people have around them, namely understanding inequalities in people's end-of-life care. The third is through using new, innovative, social media to reach a demographic which is typically not reached through more traditional, formal channels.

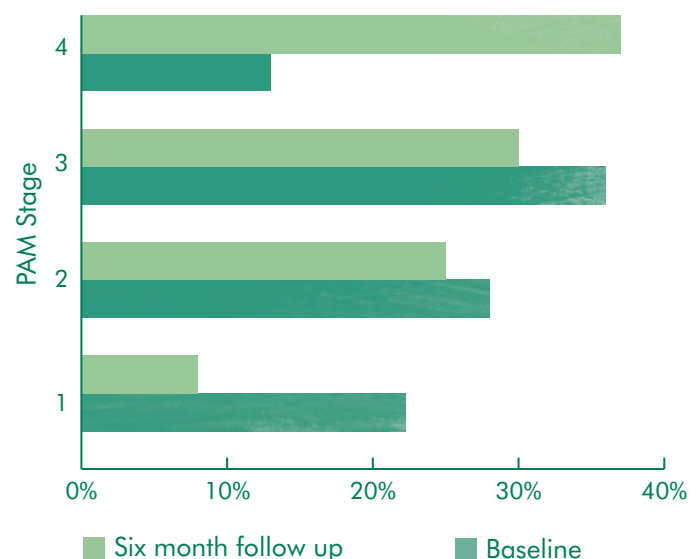
Co-Creating Health (CCH)

This Health Foundation self-management support programme (SMP) focused on supporting people with long-term conditions to build the knowledge, skills and confidence to self-manage; helping clinicians to develop the skills, knowledge and attitude to support and motivate people with long-term conditions; and changing health systems so that they encourage and facilitate self-management.

The independent evaluation⁵⁷ found significant reported improvements for people with depression (anxiety, health status and quality of life); musculoskeletal pain (pain symptoms, confidence to manage their pain, health status and anxiety and depression); people with COPD (mastery over their condition); and people with diabetes (diabetes-specific quality of life).

Figure 1 – The 'levelling up' of diabetes patients in CCH. The percentage of people in the lowest stage was cut by two-thirds and tripled in the highest stage.

PAM stages (higher = more activated) at baseline and six month follow up, patients with diabetes.



We should be cautious generalising to other treatments outside of the programme, but all participants, irrespective of condition, were significantly better at some aspects of self-managing their condition at the end of the programme. Crucially, the evaluation found that the sites were relatively more successful than other comparable SMPs in recruiting patients who do not traditionally attend SMPs (eg men, black and minority ethnic patients and patients of lower socio-economic status). In fact, patients who were younger, more anxious, less activated and had poorer quality of life made the best gains in terms of activation. 34.5% of participants were at the lowest activation level at baseline, more than any other stage.

The Health Foundation is funding four of the CCH health economies to find out more about how to effectively sustain and spread self-management support and to share their learning with others. This work has also partly been adopted by Macmillan's Survivorship programme.

Conclusion

Currently, some people get more out of the health system than others. Those diagnosed with cancer who are more confident, more assertive and better supported are likely to experience better clinical outcomes, better satisfaction with their care and a higher health-related quality of life. Every year more people are living with cancer, health care becomes more complicated, and more people have more long-term conditions. Those most capable of self-managing and sharing in decisions will continue to get the most out of their care, while those less capable (in this sense) will continue to get less. It is vital that sustained effort and investment is put into reducing this unwarranted variation, this hidden inequality. If person-centred care is 'the right way' to treat people, it should be the only way we treat people.

Designed for a different age?

The challenge of delivering cancer care to older people

Mike Birtwistle

Mike Birtwistle is a founding partner of Incisive Health, a specialist health policy and communications consultancy. He has helped advise the Department of Health on the development of the last two cancer strategies. He sits on a range of NHS England advisory groups and was a founder member of the National Cancer Equality Initiative. He writes regularly for the Health Service Journal and has been named as one of the health service 'twitterati'. You can follow him @MBirty.

Designed for a different age?

The challenge of delivering cancer care to older people

Mike Birtwistle

Abstract

Modern cancer services were designed in the 1990s, a time when the average age of cancer patients was significantly younger. Yet cancer is a condition usually associated with older age; as the population gets older, so do cancer patients. The challenge is for services to adapt the way they work to meet the needs of older people. Outcomes for older people appear to be worse in England than they are in other countries and older people appear less likely to receive active treatment, irrespective of their fitness to do so. The causes of this are complex; outdated perceptions of cancer, attitudes towards older people, gaps in evidence and problems in support services are all likely to play a part. Yet the potential prize for getting this right is significant – better outcomes, more effective and efficient services, and an approach to cancer care which reflects the realities of the population who will need it the most.

Introduction

Amid all the heat and fury in the debate about the future of the NHS, there is a consensus that services should be designed around the needs of those who actually use them. Yet this is easier said than done; needs are changing, as indeed are the people who use the services. The challenge is for the design and delivery of care to keep pace. As with many areas of health, cancer is a good reference point for the challenges we face in this respect.

Cancer embodies many of the opportunities and challenges that modern health systems face. We know more about cancer than ever before. Our understanding of how to prevent, diagnose and treat it has been transformed in recent decades. Patients are feeling the benefit.

Survival and quality of life are increasing; what was once a death sentence is now, in many cases, a condition that can be well managed. However, there are significant challenges. New treatments are expensive and, although they may be more effective, targeted and kinder, they are still associated with significant and debilitating side effects. Moreover, too many people who receive a cancer diagnosis will not experience long-term survival or a good quality of life. Outcomes are still poorer than in other countries. There may have been progress, but there is much more to do.

Yet, if we were seeking to address a static set of needs then the task would be straightforward, if tough. The reality is more challenging. A demographic shift is occurring in cancer. Although incidence rates for all cancers combined have increased since the 1970s, by far the largest increase has been in the 75+ age group, for whom European age-standardised rates increased by 44% between 1975/77 and 2009/11.⁵⁸ Patients are getting older; in 2012, over 102,000 people over the age of 75 were diagnosed with cancer. Nearly 32,000 of them were over the age of 85.⁵⁹

This is reflected in the usage of cancer services. More than a quarter of all admitted episodes for cancer in England occur in the over-75s.⁶⁰ In the past decade, the increase in admissions in this group has far outstripped the increase observed for cancer patients of all ages.

The needs of the new generation of cancer patients are therefore more complex than those who went before. Many people affected by cancer will have multiple medical conditions. Others may simply be older and frailer. This is hardly a unique phenomenon in cancer. As the

population gets older, it will be the case for many conditions. Yet the impact on cancer outcomes is stark. One estimate suggests that, if the UK matched US levels of survival for over-75s, then 14,000 lives could be saved.⁶¹ The question is whether the attitudes of the professionals who care for patients, or the design of the services who support them, can keep pace (or catch up) with this change?

Designed for a different age?

In many ways, the concept of modern cancer services was born in the 1990s. The Calman-Hine Report sent out a clarion call for specialisation, offering patients a consistent standard of care wherever they lived and wherever they were treated. The concept was translated into reality in the 2000s. As a result of the Improving Outcomes Guidance, services were by and large (and sometimes painfully) reorganised to enable multidisciplinary team working and to ensure services treated a sufficient volume of patients to be considered to be sufficiently specialist.

Change was powered by the investment and planning that underpinned cancer services in that decade, heralded by the NHS Cancer Plan, one of the architects of whom is now Chief Executive of NHS England. More professionals treated more patients with better equipment. Waiting times were reduced and kept low. National guidance began to iron out the significant wrinkles in quality that had occurred. Cancer services as we knew it took shape.

Understandably, the specific needs of older people with cancer were not the focus at this time. When cancer outcomes were poor and too many patients were being let down by a service that treated them too slowly, with old equipment

and treatments and insufficient levels of multidisciplinary expertise, the major challenge was elsewhere.

Although there is no room for complacency on any of these issues, services have undeniably been improved. However, an improved service can still be one that fails to meet the needs of its users, particularly when those needs have changed. As the population of cancer patients ages, this is the risk we face.

Obstacles throughout the pathway

Tailoring cancer services to meet the needs of older people will require action throughout the cancer pathway. A person's risk of developing most forms of cancer increases with age, yet the public stereotypes associated do not reflect this. It is perhaps unsurprising that older people's perceptions of their risk do not match the reality. Two-thirds of women aged 70 and over wrongly think women of all ages are equally likely to get breast cancer, when in fact a woman's risk of breast cancer increases with age; around 13,500 women aged 70 and over are diagnosed with breast cancer in England each year.⁶² Poor awareness translates into late diagnosis and poor outcomes. For breast, bowel, lung and prostate cancer, significantly more people over the age of 70 are diagnosed with cancer only after an emergency presentation.⁶³

When it comes to treatment, we see significant reductions with age in the proportion of patients who receive surgery and drugs for their cancer.^{64,65} Some reduction would be expected – older people may be less able to withstand intensive or invasive treatment and in any case may be more likely to choose not to receive treatment – but the scale of decline and the age

at which it occurs is stunning. For breast cancer, for example, 85% of symptomatic patients under the age of 70 had surgery whereas only 54% of patients over the age of 70 did.⁶⁶ For cancer drugs, the figures are even more stark. A bowel cancer patient in the 75–79 age group has less than half the chance of receiving chemotherapy as someone in the 55–59 group.⁶⁷

The reasons for this decline are complex and require further exploration. The NHS is not 'blocking' use of these treatments (indeed the Department of Health has long made clear that age alone should not be used as a determinant of access to treatment and the law now prohibits it^{68,69}), but there is evidence to suggest that clinical decision-making is a factor.⁷⁰ Even though doctors may understand that chronological age should not be a determinant, evidence suggests that it often is. This is not just an NHS problem. Clinicians around the world appear to have remarkably similar attitudes.⁷¹

Doctors are part of society, and if society has a tendency to write off older people, then it shouldn't be a surprise that they can as well. Of course there are very valid reasons why clinicians may be concerned about cancer treatment in older people. The principle of 'do no harm' is an important one. But the secondary imperative should be to 'do some good'.

Treatment is often invasive or toxic and, too often, older people have not been included in sufficient numbers in the research to test new treatments.⁷² Yet recent literature reviews show that, with appropriate management, treatment can be highly effective and side effects limited.⁷³ For surgery, there is no good reason why older people should not receive treatment. Biological rather than chronological age should be the determining factor.

In relation to side effects, there is worrying evidence that we are in a vicious circle. Services are rightly concerned about the impact of side effects on older patients, yet analyses of the National Cancer Patient Experience Survey have shown that older patients appear to be less likely to be informed of side effects. Precisely the people who need the information the most are the least likely to recall receiving it.⁷⁴

In any treatment decision, clinical choice is only one part of the equation. Patient preference should be the final determinant. Yet, again, patient perceptions may not match reality. Work by the Department of Health, Age UK and Macmillan Cancer Support suggests that many older people underestimate their own life expectancy and often overestimate the side effects of treatment. Staff reported concerns that some older people were declining treatment without being given the relevant information to make an informed choice.⁷⁵ Any decision must balance the benefits of a treatment against its drawbacks. Older people appear to be understating the benefits and overstating the risks.

That they do this may well be because services are not able to fully assess and meet the support requirements of older people. Half of all people aged 75 and over live alone, and one in 10 people have less than monthly contact with friends, family and neighbours. Isolation can be particularly difficult when a person is receiving ongoing treatment.⁷⁶ Furthermore, one in five people aged 75 and over state they find it very difficult to get to their local hospital.⁷⁷ Caring responsibilities can also get in the way of people accepting treatment; over half a million people aged 65 and over have caring responsibilities that take up at least 20 hours per week.⁷⁸

The size of the prize

Cancer services are not delivering the best service for the group that is increasingly their largest user. Addressing this failing will be a defining challenge for the NHS in the coming decade. The size of the prize is significant: extended survival and reduced cancer mortality, improved quality of life, faster recovery from treatment, enhanced experience and safer care for a group of particularly vulnerable patients.

It is too easy to dismiss this as a cultural issue that requires society to change before it can be addressed. To do so would be to fail patients. Achieving the change will be complex, but is achievable (after all, cancer services have delivered significant change in the past and they can do so again).

Change will require different groups of specialists to work together in teams. Geriatricians will need to be every much as part of the cancer team as oncologists. Clinicians will need to critically appraise their practice, reflecting and acting upon how they might do things better for older patients. Commissioners and providers will need to invest in tailoring care to the needs of older people. This will be difficult in the current financial environment, but we will pay for the cost of cancer in older people either way. It is better to invest in getting services right, rather than simply paying for the costs of getting it wrong through increased emergency admissions and rescue care. In return, we should expect to see evidence of better outcomes. Delivering change will also require researchers to ensure that trials better reflect the populations who require treatment. Finally, we need to work to change the expectations of older people themselves.

This is a daunting cost but there are grounds for optimism. NHS England is alive to the issue and the National Clinical Director for Cancer has made improving services for older people a personal priority. Charities are increasingly focusing on what is one of the most endemic inequalities in cancer. The evidence about the nature and scale of the issue is growing all the time. There is an increasingly vibrant research community developing solutions.

We need to be clear that this is a problem born out of success. People are living longer and they are living longer with cancer. Cancer services in general are more effective. It is now all of our tasks to ensure that this effectiveness is translated for older people. Cancer is not unique but it is an exemplar of the challenges facing modern health services. If we get it right for older cancer patients, we can get it right for older people with any condition.

Addressing inequalities in cancer care

Dr Neil Goodwin CBE

Dr Neil Goodwin CBE is chair of the London Cancer Alliance, a membership organisation of 16 London cancer centres and units with the aim of improving cancer services for five million people across south and west London. He also chairs the Aintree University Hospital NHS Foundation Trust in Merseyside. Neil is a leadership academic and has been visiting professor of leadership studies at Manchester Business School for ten years. He is a former university hospital and strategic health authority CEO in the English NHS.

Addressing inequalities in cancer care

Dr Neil Goodwin CBE

Introduction

The incidence of cancer has increased by over 30% since the 1970s and currently there are two million patients living with cancer in the UK. In England, cancer accounts for 29% of all deaths and today more than one in three people will develop cancer during their lifetime.

The challenge for the UK is that survival across a number of cancers is lower than the best-performing countries in the world. It is estimated that 5,000 to 10,000 of cancer deaths in the UK would be avoidable within five years of diagnosis if the survival rates were the same as the best survival rates in Europe. Key interventions to reduce these avoidable deaths include improving early diagnosis, and provision and access to effective treatment. However, inequalities also play a significant part in explaining the UK's position relative to other developed countries.

Cancer survival has risen steadily across most cancers over the past 25 years in England. However, there are persistent inequalities in survival between patients living in areas of high and low socio-economic deprivation. Most telling of all is that these inequalities in survival represented more than 2,500 deaths per year. These would have been reduced if all cancer patients had had the same chance of surviving up to five years after diagnosis as patients in the most affluent group.

This essay explores inequalities in cancer care in light of the prediction that the number of people living with cancer is predicted to be four million by 2030. It will be argued that although healthcare services can do much to address inequalities of cancer care provision and treatment, there is an equally pressing

need for concomitant action to address social inequalities, including behavioural risk factors that directly contribute to the incidence and mortality of cancer.

Technological advances in treatment such as developments in screening technologies, molecular diagnostics, radiotherapy and surgery will be major drivers to improve cancer outcomes. However, of equal importance is urgent action to address social and health inequalities to ensure that technological advances are built upon an effective and cost-efficient model of cancer care in the UK appropriate for the future needs of the population.

Social context

Cancer incidence and mortality show a positive socio-economic gradient. Recent data continues to paint a graphic picture demonstrating the higher incidence and mortality of cancer with increasing socio-economic deprivation across most cancer types. Importantly, the variation with socio-economic deprivation of lung cancer incidence and mortality rates dominates that of almost all other cancers.

Behavioural determinants of health and access to health care are important contributory factors but should not be viewed in isolation. It is essential to recognise that health inequalities result from social inequalities. Health inequalities have widened in the UK and effective action to reduce the gap requires intervention across all the social and economic determinants of health including income, employment, educational attainment and environmental determinants such as housing, air pollution and access to green spaces.

The relationship between behavioural or lifestyle risk factors and cancer is well known; for example, each year:

- 60,000 UK cancer cases are attributable to smoking
- 17,000 cancer cases are attributable to overweight and obesity
- 12,500 cancer cases are directly associated with alcohol consumption
- Overexposure to ultraviolet radiation from the sun and sunbeds causes most skin cancers

Higher rates of smoking, obesity and physical activity are all associated with socio-economic deprivation. Smoking prevalence has fallen but the strong socio-economic gradient remains with smoking rates highest among those living in the most deprived areas. Smoking is the most important cause of preventable ill health and premature mortality in the UK and is a major risk factor for many cancers, specifically for lung cancer.

England has a high prevalence of obesity compared to most other countries in the OECD; of 33 countries, only Scotland, New Zealand, Hungary, Mexico and the United States have a higher prevalence than England. Adult obesity rates have almost quadrupled in the last 25 years, with nearly a quarter of British people now being obese; this is predicted to increase to one-third by 2020. For children, most recent data showed that those aged 10 to 11 years who have excess weight varied from 38% in the most deprived areas to 26% in the least deprived areas. Unless this inequality is addressed, these children are increasingly likely to present with significant healthcare problems, including cancer, later in life.

There are clearly links between obesity and physical activity but research on the relationship between physical activity and environmental factors in young people is still evolving. Having said that, it does appear that variables clustered around the concepts of access, opportunities and availability to be active are associated with higher levels of physical activity. There is evidence from observational studies that clearly show the link with wider social policy; for example, there is a positive association between levels of activity and access to facilities and outside space.

In common with the rest of the inequalities agenda, the research on physical activity has implications for national and local government policy. It demonstrates, among other things, the need to take a longer-term approach to investing in appropriate educational and environmental facilities to provide greater opportunities for physical activity.

International context

The summary results of Eurocare-5, the study of comparative cancer survival in Europe, were published at the end of 2013. The findings demonstrate that while five-year survival rates have increased steadily over time for all regions, there was a persistent gap in survival for most cancers between the UK and the best-performing regions.

Commenting on these findings, *The Lancet* suggested that factors that contribute to differences in survival between countries include differences in stage at diagnosis and accessibility to high-quality care, different diagnostic and screening approaches, and differences in cancer biology. Interestingly, although the variation in survival partly

represents differences in resources allocated to healthcare, the data from countries with similar expenditure suggests that health spending is not the only factor affecting cancer outcomes. Variations in socio-economic, lifestyle and general health factors between populations are likely to lead to differences in healthcare-seeking behaviours, patient management decisions and treatment effectiveness. In light of their findings, it is no surprise that Eurocare-5 asked member states to consider further research spanning a wide agenda from health inequalities, organisation of healthcare delivery and adoption of evidence-based clinical guidelines to survivorship and quality of life.

Additional evidence has illustrated that healthcare systems with a gatekeeping role, such as the UK, were found to have significantly lower one-year relative cancer survival compared to healthcare systems without a gatekeeping role. The implication is that effective initiatives to improve survival must address access to cancer services. Other important initiatives to ensure that all patients receive high-quality cancer care include strengthening the governance of cancer care and monitoring and robust use of data to benchmark performance.

Inequalities in care and treatment

The social and international contexts underscore the idea that addressing the UK's poorer outcomes compared to other countries requires earlier diagnosis and improved treatment. To improve early diagnosis of cancer, a wide range of interventions are required across the cancer pathway including raising public awareness of signs and symptoms of cancer, primary care practitioner education, primary care direct access to diagnostic testing, higher uptake of screening and more timely diagnosis and access to treatment.

Promoting dissemination and implementation of evidence based on new and innovative practice is an important driver to deliver improvements in cancer treatments. There is variation in access to newer surgical techniques as well as to radiotherapy and chemotherapy, and advances in technology will require investment in radiotherapy and appropriate access to cancer drugs.

Successful implementation of these initiatives will undoubtedly improve cancer care. However, unless unwarranted variations in treatment are also addressed, they will be limited in their impact as increasing numbers of patients will be referred into health systems that fail to deliver wholly effective and efficient cancer care to meet the needs of all population groups.

To address unwarranted variation, the work of the London Cancer Alliance is examined. The Alliance is an integrated cancer system covering five million plus people, mainly across south and west London. Core membership comprises five cancer centres and 11 cancer units, coupled with strong links to academic health science networks and the third sector.

Cancer currently accounts for over a quarter of all deaths across the Alliance with 20,000 new cases of cancer diagnosed every year. The Alliance has three priorities: improving cancer outcomes, improving patient experience and reducing unwarranted variation. The following examples summarise the Alliance's working context:

- Variation in the incidence of all cancers: ranges across London boroughs from 283 per 100,000 people in Kensington & Chelsea to 450 per 100,000 in Islington.

- Variation in mortality: the socio-economic mortality gradient for cancer has an almost twofold variation across London with 84 deaths per 100,000 people in Harrow to 136 per 100,000 in Barking & Dagenham.
- Variation in survival: the 5-year survival rate of colorectal cancer ranges from 47% to 54% across London.
- Variation in access: the provision of minimally invasive surgery varies between 10 and 80% for endometrial cancer surgery and between 11 and 54% for colorectal surgery across the Alliance.

The London Cancer Alliance's approach is built on developing strong clinical engagement with over 2,500 clinical staff drawn from its member organisations and primary care, along with the active involvement of the third sector. They all work collaboratively to reduce unwarranted variation by ensuring the following:

- Standardisation of processes and clinical practices across all cancer pathways by agreeing revised clinical guidelines and protocols that apply across all of LCA's hospitals and pathways.
- Development of timely, integrated cancer pathways to meet the needs of all population groups from diagnosis to survivorship or end-of-life care.
- Use of comparative data to benchmark the quality and overall performance of cancer services provided by LCA's cancer centres and units, which allows early identification of performance issues and enables the sharing of best practice.
- Pursuing transformational change on a health system-wide basis not only for treatment and early detection but also

research and development, training and education, and workforce planning and development.

The Alliance operates on the principle that developing greater integration in cancer care and working collaboratively across the whole health system will improve the quality of care for patients and lead to cost efficiencies, particularly at a time of unprecedented citizen and economic pressures on healthcare services both in the UK and internationally. The Alliance's approach also reflects recent UK think-tank reports highlighting the need to increase investment in primary and community care services to create robust platforms for integrated care both within and outside hospital settings. Establishing better integrated care is particularly important because many patients have unmet emotional, psychological and practical needs that require a more holistic approach.

Collaborative work of all the organisations involved in cancer care is essential to develop integrated cancer pathways to improve quality of cancer services. In addition to hospitals, primary care, public health and the charitable or third sector all hold key roles in the process, particularly in early diagnosis and post-treatment care. In particular, variation in the quality of primary care has an impact on the early part of the cancer pathway, which is crucial to ensure prompt patient referrals. For example, in London the number of primary care urgent referrals of patients with suspected cancer ranges between 814 and 2,280 per 100,000 people compared to the England average of 1,980. It is interesting to note that cancer patients significantly increase their visits to primary care following a diagnosis of cancer. In the last 10 years, the number of visits has risen by over 30% and will continue to increase.

The importance of commissioning

While system-based provider models like the London Cancer Alliance, with their collaborative approach spanning multiple organisations and sectors, are to be supported and encouraged, the commissioning of cancer care requires an equally radical change of approach.

The aim of any healthcare system must be to improve outcomes for patients as cost-effectively as possible. Furthermore, the delivery of effective and efficient cancer care underscores the need for organisations responsible for commissioning healthcare to take an approach that is system wide rather than organisationally focused. For many people with cancer, navigating care and treatment pathways can be challenging and adds to their emotional stress, which is exacerbated by many of the current commissioning arrangements.

To achieve a system-wide approach requires commissioners and providers to work more closely together to create an integrated care and delivery system. While delivery systems need to be built around one or more centres of excellence, they also need to span several organisations and facilities to ensure care, treatment and support can be accessed locally. Finally, to maintain high-quality services, all facilities need to operate according to common protocols and guidelines for treatment and care.

There are, however, other considerations because moving to a system approach requires appropriate transactional arrangements and incentives to support transformation in cancer care. For example, costing and activity data will need to be devised as the basis of developing a new tariff to allow reimbursement of costs through bundles of care and not individual treatments. Furthermore, the development of

financial incentives is equally essential because the incentives would act as a powerful lever to advance the development of integrated care. Moving to cost-based pathways with bundled prices for care cycles based on actual costs has huge potential for commissioning to deliver value and thereby improve outcomes for patients.

Finally, there is the need for commissioners of cancer care to reflect both health and healthcare in their work. Given the links between social deprivation, lifestyle and the incidence of cancer, commissioners should conjoin with local government to commission transformational change across both health and healthcare in order to transform both service provision and lifestyle behavioural change. Currently, few commissioners are undertaking innovation along these lines and a concerted national effort is required.

Conclusion

The gap created by socio-economic deprivation and health inequalities continues to widen. For a geographically small country like the United Kingdom to have such a wide range of social and health inequalities is lamentable, and highlights the need for a much more radical approach to the development and implementation of social policy.

Unless there is a change of approach to tackling inequalities then it is debatable how much can be achieved solely by the healthcare sector, innovations in clinical practice and scientific developments in reducing the incidence of cancer. To go further, given the persistence of social inequalities and their obvious link to the incidence of cancer, coupled with the lack of radical social policy, it is unlikely there will be any significant reduction in the incidence of

cancer during the next decade and beyond as a direct result of social policy interventions. This is clearly unacceptable.

The key message for social policymakers therefore is 'must do better'. The need to tackle policy across a number of fronts from education through food and drink legislation to physical activity raises questions about national government leadership structures for tackling not only cancer but also other disease groups in which prevalence is driven significantly by lifestyle behaviours.

There is clearly the need for more effective joined-up government with clear leadership identified for ensuring that relevant policy is developed across the whole of government to reduce the incidence of cancer. Furthermore, although there have been repeated analyses of lifestyle factors and related challenges, more work is required to understand how to support behaviour change to complement the necessary changes required across environmental, education and consumer policy.

Looking more optimistically, it is most likely that greater success in the immediate future will come from eliminating unwarranted variation in the provision and treatment of cancer through more integrated service provision. These changes then need to be developed by vertically integrating the horizontal integration of cancer care providers with primary care to create a fully integrated model of cancer care. Furthermore, these emerging models of provision will require new commissioning arrangements to support them, with a focus on developing pathways of care underpinned with revised transactional arrangements to incentivise transformational change.

In conclusion, the UK's healthcare system cannot assume the full burden for meeting the country's challenges from the increasing incidence of cancer. Everyone must play their part.

Acknowledgement

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Patients should be partners in care

Mark Britnell

Mark Britnell is Chairman & Partner of KPMG's Global Health Practice. Over the past five years, Mark has worked in over 60 countries with hundreds of organizations. He was one of the youngest ever NHS Chief Executives, leading the University Hospital Birmingham NHS FT to be amongst the highest performing in the UK. He was later CEO for the region from Oxford to Isle of Wight, helped to develop the NHS Plan and went on to become Director-General at the Department of Health. Since joining KPMG in 2009, Mark has driven the growth and development of their health practices around the world, giving KPMG a truly global insight into what works in health. He was recently appointed as a member of the World Economic Forum Council on the Future of the Health Sector.

Patients should be partners in care

Mark Britnell

As Global Chairman for Health for KPMG, I've had the privilege of working in 60 countries over the past five years. When I look at the global picture on cancer care delivery now and how that's likely to change over the next decade, I see a number of trends emerging in response to pressures on health systems, advances in care and new evidence of what works.

We recently conducted a study involving detailed interviews with patient groups, representing millions of patients – including cancer networks – in six different countries in Europe, Asia and the Americas. The problems our analysis uncovered were clear: wide gaps exist between what patients say they want and what healthcare providers offer.

In particular, people across continents said they were treated as an intervention site, rather than like a human being. They said they were often told what was going to happen, rather than being meaningfully involved in decisions. They also said that while the focus was on informing them, it was just as valuable to be equipped with skills and supported emotionally.

One of the most common failings appears to be that while people want to be looked after throughout the journey of diagnosis, treatment and recovery, in reality health providers are good at points, but then leave people at important stages, particularly at the point of discharge.

As a sector, healthcare often appears peculiarly resistant to consumer-driven change. While other industries have transformed themselves in recent decades to respond to customer insight and shifts in demand, the model for health service delivery has changed very little. In banking and telecoms, we now expect seamless

integration of different services with a single point of contact – how many providers can honestly say this has been achieved for their cancer patients?

We've known that partnership and patient experience are essential components of quality for decades now, so why has healthcare been slow to change? Maybe it's because partnership takes time and clinicians have very little of that spare. Or because ultimately as human beings we don't actually want to be 'empowered patients' – because really we don't want to get ill in the first place.

Certainly, when I found out that I had prostate cancer at the age of 42 the last thing I thought about was partnership. I wanted the cancer removed. Within three weeks – from being fit and able – I'd had a radical prostatectomy and was incontinent, infertile and impotent. Fortunately, two of these three problems were reversed over time but the physical discomfort was nothing compared to the psychological distress. It is not uncommon for cancer patients to feel low or depressed and I certainly felt alone with no one to talk to.

I had world-class care in the NHS and the surgery was brilliant. The NHS saved my life and I shall always be grateful to the dedicated staff. I left hospital the same day as the operation and felt the primary concern of the surgical team was to cut the cancer out, but there was little ongoing care. Poor post-discharge communication with the community team and GP left me as the care coordinator, a task I took on as an enthusiastic amateur.

On reflection, I think if people had talked and trained me to be a partner in care then I would have been better prepared for the side effects

and made a quicker recovery. As it was, I didn't know who to turn to. I remember seeing a cancer help desk in the hospital but it was open from 10am–2pm, hardly convenient for my work.

I wanted to make this better for others and took the opportunity to join the Board of Prostate Cancer UK. We have a great support service and help desk run by specialist nurses. I've seen first-hand how this makes a difference to prostate cancer patients, their loved ones and carers. It's especially important for black men (who are four times more likely to get the disease) and working-class men (who present later). Spreading awareness is such an important job in the fight against cancer.

These are important improvements, but incremental ones. What we're now seeing with healthcare organisations across the world is an appreciation that the transformation to person-centred care needs to happen much more rapidly than it has before. At a recent global healthcare conference we ran, 82% of healthcare leaders from 30 countries – across six continents – said that they expected health system reforms creating more patient-centred, integrated care to be a major feature of the next five years.

Each country will do this differently, but many are moving in similar directions. First, we can expect the patient perspective to be much more integrated into payment and incentive systems. 93% of the leaders at our conference expected their organisations to be paid much more around value (including patient experience) than activity in the future. At the individual level, a global crowdsourcing exercise we conducted with healthcare leaders revealed that only

around half currently include patient experience measures in clinicians' or managers' appraisals. This will surely become more common.

Figure 2 – 'Measurements of patient experience impact on how my organisation delivers care'

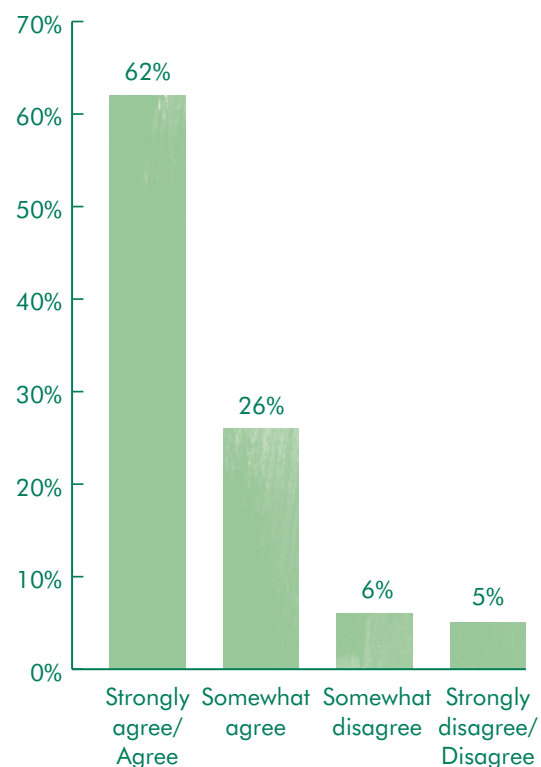
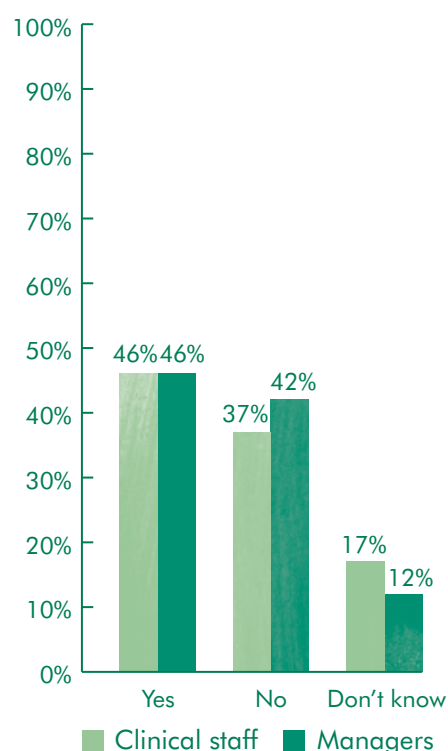


Figure 3 – Are patient experience measures used in the performance appraisal of clinical staff and managers within your organisation?



Source: KPMG What Works Healthcare Insights global crowd sourcing community

Secondly, we are already seeing an increasing interest and sophistication being brought to patient segmentation. Not only is this a critical approach to resolving health inequalities across populations, but it's essential for value too: targeting resources where they improve outcomes and reducing waste. As commercial organisations have demonstrated for years, segmenting groups of people consistently shows how one-size-fits-all approaches don't work – and often particularly fail those who have most to benefit.

Thirdly, we will be hearing more and more about 'patient activation': the extent to which patients are actively engaged in monitoring, managing and improving their health. Robust measures for this now exist that will help to shift the focus away from passively giving people a good experience to involving them and tapping into patient power and community resources. Research suggests that activated patients cost between eight and 21% less, as well as achieving better health outcomes.

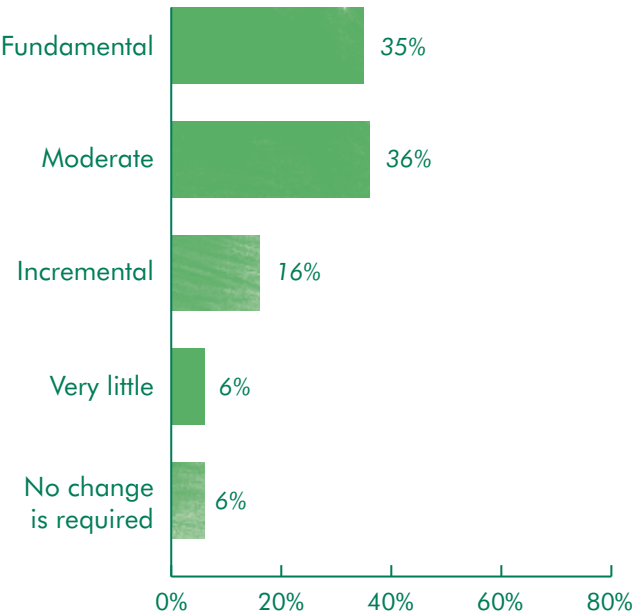
Finally, we will see the spread of programmes to make shared decision-making the easy and default approach for health professionals. Shared decision-making is so important because it leads to better quality care while eliminating non-value-adding processes and procedures. Professional cultures are hard to change, especially when so many clinicians are time-poor. With technology and training, we are seeing that these barriers can be overcome, however. Cancer care is already a pioneer in this area but it can, and will, go further.

One of the major barriers these improvements face is organisations thinking that it's the system, not them, that needs to change. Our research with leaders showed that while there is widespread acceptance of the need for transformation, many think their organisation is different. Among our crowdsourcing community, 73% see a need for fundamental change in their health system, but only 35% in their own organisation. This may inhibit the pace of progress.

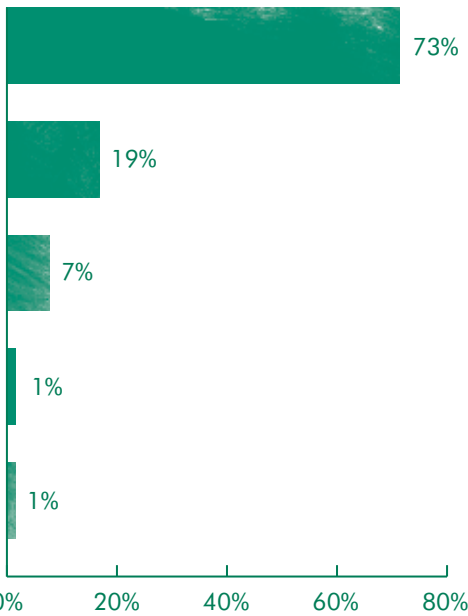
In the relatively short period of treatment for my cancer, I was able to see the vital importance of partnership with patients – both for me and the NHS. As more and more people live with cancer as a long-term condition, partnership needs to be a key focus for service redesign in the coming years. My hope is that this will lead to radical changes to service delivery perhaps even to rival the advances we hope to see in cancer medicine.

Figure 4

What is the scale of change required in your organisation?



What is the scale of change required in the healthcare sector in your country?



Source: KPMG What Works Healthcare Insights global crowd sourcing community

Coping with cancer in 2030: Innovation through people

Francesca Cignola

Francesca Cignola leads Innovation Unit's portfolio of work around health and social care. Over the last ten years she has been supporting socio-economic development initiatives in the UK and internationally, from supporting women groups' income generating activities in northern Ghana to developing new models of care for health services with patient and clinicians. She is passionate about facilitating services that tap into the – often overlooked – strengths of people and communities to foster resilience and enable everyone to achieve their goals.

Coping with cancer in 2030: Innovation through people

Francesca Cignola

The cancer lottery

What are people in Britain most afraid of?

- Knife crime
- Eastern European immigrants
- Flooding
- The financial crisis
- Nuclear and biological conflict

Answer: **Cancer.**

According to a survey commissioned by Cancer Research in 2011, cancer is the number one fear for the British public, feared ahead of debt, knife crime, Alzheimer's disease and losing a job. Strikingly, over 30% of those interviewed thought the disease was down to fate.⁷⁹

The fact is that 910 people are diagnosed every day in the UK.⁸⁰ Though it may feel a bit like a lottery – who gets it and who doesn't – there is more than just fate at play.

At Innovation Unit we would argue that anyone diagnosed with cancer will want to feel as much in control of this 'lottery' as they can. They will want to have access to effective treatment and to people who they can trust and who trust them; to have access to people who respect their own experience and priorities as patients; to be supported by a range of people who can help them live as well as possible for however long they have – at least 10 years for a good half of those diagnosed.⁸¹

Our approach to innovation in health services calls on all those involved – commissioners, clinicians and patients – to understand and respond to this argument. Innovation in cancer services has to be more than medical or technical; it must involve patients in their own care if they are to become more confident and better able to manage their condition. Importantly, it must recognise that day-to-day management of conditions such as cancer has to happen outside traditional health settings – in homes, workplaces and wider communities.

We know that these People Powered Health systems have the potential to save costs as well as create better outcomes for those using them.⁸² In cancer services, this approach can include changing the nature of consultations – with models like social prescribing where communities support patients – to 'more than medicine' approaches to commissioning where services are co-designed around patients' needs and can be delivered by collaboratives, partnerships and alliances. Commissioning is itself collaborative, focused on outcomes and involves a range of people in commissioning, design and delivery of services.

Innovation in cancer care – putting people at the centre

Over the last 30 years, the incidence of cancer in the UK has grown by a third due to a combination of growing numbers of people living to an older age and our increasingly unhealthy lifestyles. However, over the same period long-term survival has doubled thanks to better diagnosis, nationwide screening programmes and better treatment.⁸³ So, as well as being something people *die from*, cancer is increasingly becoming something people *live with*.

Though it is fair to say that over the years we have won some battles with cancer, taking a glance 15 years forward from now, when four million people in the UK are projected⁸⁴ to be living with cancer, it will be the case that in this war we still need to be deploying our best strategies and all the weapons we've got.

We are firmly behind the power of research to discover new treatments and improve existing ones. We also think that there are other 'technologies' that we need to deploy more consistently in this war, not only to save lives *from* cancer but also to enhance the quality of life *with* cancer.

Studies⁸⁵ have observed large increases over the last few decades in the incidence of cancers that are strongly linked to lifestyle, with more than 40% of all cancers in the UK being linked to factors like tobacco, alcohol, diet, being overweight, inactivity, infection, radiation or occupation. Moreover, analysis of survival rates suggests that there are noticeable inequalities between people living in richer and poorer areas due to delays in diagnosis, unequal access to treatment and worse general health.⁸⁶

What these statistics say is that while it is right to look with hopeful expectation to research for life-saving solutions, more power than we realise lies in our own hands to prevent and spot cancer, as well as to mitigate the impact it has on our day-to-day lives when we survive it.

This calls for deploying, at the individual and wider societal level, the 'technologies' of behaviour change and culture change. We see this happening in three ways:

1) at the individual level, helping people to feel more in control of their health;

2) harnessing the power of peers to model behaviours and provide networks of support; and

3) in the relationship with health professionals, promoting more equal and genuinely helpful interactions that support people to achieve what matters most to them.

At Innovation Unit we believe that the greatest untapped potential in our public services lies in its users, their knowledge of and aspirations for their lives and those of their children.⁸⁷ We think that all services, and especially health services, would achieve much more if they truly put users at their heart, taking what really matters to each individual as the starting point of all interactions and helping people to look after themselves and one another. We recognise that this is not the answer to all health needs, but we argue that there is scope for bringing more 'people power' to almost all services anyone can think of. More 'people power' equals greater respect, more sense of control, higher satisfaction and wider opportunities.

Before sharing some examples of the kind of 'people-powered technologies' we have in mind to revolutionise the future of our war against cancer, we should take a look at what the world might be like in the near-future of 2030.

The world in 2030

It does not take a crystal ball to forecast that in 2030 technology will continue to influence people's lives. Ever more powerful, more mobile and ever smaller computing devices will be a feature of everyday life, from wearable devices to implanted microchips that contain our medical histories or regulate our bodies. And technologies like 3D printing will enable us to create goods ourselves.⁸⁸

New regional and global powers will emerge, populations will continue to be more mobile and cultures will come into closer contact. Our cities will be ever more diverse and densely populated, yet many people will become more lonely and isolated, not less. Depression is predicted to become the leading global disease burden.⁸⁹

The job market will also see significant changes. Many of today's biggest companies are likely to be split up or swallowed up to achieve efficiency.⁹⁰ Many jobs will disappear only to reappear in a different guise. The rewards for people who are highly connected, adaptable and mobile will grow exponentially, creating greater inequality.

The UK population will be older, with more people living with multiple long-term conditions. There will be 2.8 people of working age for each person of pensionable age (compared to 3.2 in 2008).⁹¹ This will mean greater pressure on public finances and possibly new models of individual contribution to the cost of health and care services.

In short, change will be deep and it will be getting faster. The 'human and social technologies' referred to below will still be important. Indeed, socially focused solutions to cancer and other long-term conditions are likely to see their impact enhanced by advances in the traditional biomedical technology found in health care.

People-powered technologies

People-powered public services start from the premise that it is people – patients, carers, professionals, communities – that make services, not budgets, institutions or KPIs. People-powered services recognise that people are unique and strongly believe that everybody, even the frailest, sickest person, has strengths, attitudes, skills and knowledge that can be useful to themselves and to others. In line with this is the fact that, if they are to truly work and not just to perpetuate dependencies, services need to start from what people want and can do and then help them achieve that. The three dimensions of people-powered technology I set out above – self, peer and relationships with professionals – are the three legs of a stool, which, combined, make people-powered services a reality.

1. **Self** – For people to play an active and informed role in the management of their health they need to have confidence, information and motivation. While self-management is increasingly on the health policy agenda, there is still untapped potential in driving behaviour change around prevention by making use of new technology and data and in exploring innovative ways of supporting self-management through peer interaction, cognitive-based interventions and, possibly, incentives.

At a national scale, information campaigns, like the successful 'Act FAST' stroke campaign and the 'Clear on Cancer' campaign, can play an important role in making people more aware of and responsive to symptoms that need to be checked out. *Behavioural insights* can also be used to develop initiatives that encourage healthier choices.⁹³

Smartphone technology has introduced endless potential in supporting people to be informed and active in the management of their health, from apps that promote symptom awareness, like *Cancer Signs and Symptoms*⁹⁴ from Cancer Research, to apps that track and record healthy behaviours, like the *Nike+ Running app*⁹⁵ or the *NHS Stop smoking app*⁹⁶, to portable health records, like *My Health Locker*⁹⁷ and *MyMedRec*⁹⁸. There are even apps, like *Ginger.io*⁹⁹, which use data from people's phones to analyse and predict patterns and dips in their health. And at the lower end of the tech scale, texting services like *text4baby*,¹⁰⁰ offering free texts with useful information and reminders for mums on their babies' health, show high levels of take-up in groups of lower socio-economic status.

Training programmes can be used to enhance people's confidence in self-management by teaching useful information and techniques, as well as connecting patients with peers who are going through similar experiences. The Health Foundation's *Co-creating Health*¹⁰¹ developed and tested a training programme around self-management for patients, alongside training in co-delivery for clinicians, to drive wider culture change. It found that self-management support for patients improved the activation and quality of life of people with long-term conditions, but also pointed out that adopting self-management approaches requires long-term behaviour change and therefore long-term support interventions.¹⁰²

The positive impact of *mindfulness-based interventions* has been demonstrated for a number of conditions, including cancer. Patients showed improved mood, reduced anxiety, fatigue and sleep problems. To increase access, online delivery of mindfulness-based cancer recovery is being tested.¹⁰³

And to drive extrinsic motivation for better health management and prevention, some insurance providers run incentive schemes, like *Vitality*,¹⁰⁴ which offer discounts and financial rewards to their members for adopting healthy lifestyles.

2. **Peers** – Humans are intrinsically social beings. The design of many health services misses important opportunities by neglecting this. People are more likely to follow the advice of their peers than that of doctors. Being in contact with people who are experiencing or have experienced similar health issues and having opportunities to connect with one's community and be active can make all the difference between coping and not coping, between deterioration and recovery.

The concept of using peers to model healthy behaviours and to act as ambassadors for their communities is not new. The *Community Health Champions* programme¹⁰⁵ and Turning Point's *Connected Care* model¹⁰⁶ are both examples of this. *Maslaha's* project in Tower Hamlets¹⁰⁷ provided medical and Islamic advice for people with diabetes on looking after their health. It was an interesting initiative aimed to address some of the inequalities of access faced by Muslim communities.

Peer support groups are a well-established people-powered technology, which tends to deliver high value for their members as well as demonstrable health benefits.¹⁰⁸ The prostate cancer ‘One-to-one support’¹⁰⁹ programme and the email support for breast cancer ‘Someone like me’¹¹⁰ are just two of many examples. *Patientslikeme*¹¹¹ and *Healthtalkonline.org*¹¹² are hubs that enable the sharing of lived experience between patients and with the professional community. They are a great asset for patients, professionals and researchers alike.

Sharing information and comparing experiences of illness are extremely important to help people cope and recover, but connecting or reconnecting with normal life is as important and often not as well supported. The *Aquaterra cancer survivorship programme*,¹¹³ run in partnership with Macmillan, is a free 12-week supervised exercise programme aimed at managing the side effects of treatment and then gradually assisting long-term recovery. The *Health and Wellbeing Clinics*¹¹⁴ piloted by the National Cancer Survivorship Initiative (NCSI) were designed as one-off events to educate patients about clinical and holistic aspects of the management of their disease and to connect them with local facilities, supportive care and opportunities that are available to them and their families. *Maggie’s centres*¹¹⁵ offer a comprehensive range of free practical, emotional and social support to people with cancer and their families and friends, from group activities to help managing stress, talking about cancer to loved ones, starting treatment and returning to work. Finally, the *Vocational Rehabilitation Project*¹¹⁶ run by NCSI in

partnership with Macmillan, DH and NHS England surfaced important learning on the elements required of a service that effectively supports cancer survivors to get back to work.

3. **Relationships with professionals** – Out of the three areas, this is the one where there is the greatest need and greatest scope for change and innovation to happen. Relationships between users and professionals in health services, more than any other public service, are often shaped by a perceived ‘monopoly of wisdom and information’ on the part of professionals and the belief – shared by both sides – that ‘professionals know best’.

The approach of people-powered services challenges this assumption in many ways. Firstly, it suggests that when it comes to finding the best solutions for coping with a life-changing condition, medical and scientific knowledge is as important as the knowledge of a person’s own life, strengths, patterns and preferences, and who is more of an expert in that than the patient themselves? Secondly, it stresses that if you want to find solutions that improve people’s health, you must take into account their life as a whole and the factors that have an impact on it beyond their health condition. Finally, it suggests that holistic care requires a range of skills at different levels and that it takes a mixed team of professionals and non-professionals to deliver it.

NCSI’s *recovery package*¹¹⁷ models some of these principles, defining a framework for patient-professional interactions that includes a holistic needs assessment, care planning and open access to information on the patient’s condition and on useful services. The framework is a step in the

right direction, but it relies on the right types of relationships being in place for its impact to be meaningful. The *Chen Med*¹¹⁸ medical centres in Florida offer a good example of promoting a culture of strong doctor-patient relationships, with a nominated doctor and longer consultations, alongside training for clinicians.

Macmillan's *One-to-One Support*¹¹⁹ model pulls together a multidisciplinary team that supports the patient across the whole cancer pathway. It also creates new roles to enable the provision of seamless care. We would argue that, along with clinical nurse specialists and associated health professionals, support workers, district and practice nurses, there are opportunities for non-clinical figures to be part of this team and play a role in supporting people through their journey with cancer. For example, figures like the Navigators, who offer patients at the *Earl's Court Health and Wellbeing Centre*¹²⁰ a listening ear and signposting to relevant health or social care services available, or the *Linkworkers in Newcastle's social prescribing scheme*.¹²¹

It will take time and effort at all levels to manage the culture shift that will transform relationships between patients and clinicians making them more equal and genuinely helpful and supportive of the delivery of truly holistic care. Findings from the *Co-creating Health Advanced Development Programme*¹²² for clinicians highlighted that the skills for co-delivery should be embedded in undergraduate and postgraduate education and in continuing professional development. Tools like the *Macmillan top tips guide on patient experience*¹²³ demonstrate how a culture shift requires effort at all levels: by clinicians, patients and commissioners.

Conclusion

We know that technical developments will make it easier to prevent and cope with life-changing health conditions like cancer. Who knows what is in store for us over the next 15 years? Whatever new technologies we will have access to, we know from the work we have done at Innovation Unit that health services must become better at putting people at their heart, drawing on the empathy and creativity of patients, professionals and communities and playing a part in helping people to achieve their aspirations, however big or small they may be.

Successful health systems are those that adapt to address the range of needs of all those they support, address the underlying causes of ill health and use all the resources they have available in the commissioning, design and delivery of services. The People Powered Health approach draws on the expertise and commitment of the people it serves, and supports them to change behaviours and create social networks that improve health outcomes. This approach is critical to supporting the increasing numbers of people living with cancer, wherever they are.

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