DELIVERING AFFORDABLE CANCER CARE
A VALUE CHALLENGE TO HEALTH SYSTEMS

Report of the WISH Delivering Affordable Cancer Care Forum 2015

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Professor the Lord Darzi of Denham

Professor Robert JS Thomas
FOREWORD

We must confront a stark reality: cancer care is not affordable for most patients, many payers, and nearly all governments. This is a real and immediate issue across the world. In resource constrained countries the costs for best-practice cancer care are not affordable at all. In high-income counties different challenges related to affordability and sustainability of cancer care have emerged. The expectation is that these challenges will only intensify.

Issues of affordability are not unique to cancer. Cancer, however, often strikes unpredictably and with devastating consequences, and treatment and testing, where available, is expensive and can be required over many years. In many countries, it is one of the highest areas of health spending, and for many people, a diagnosis of cancer leads to personal bankruptcy.

Addressing this problem means navigating through great complexity across a variety of health settings. Affordability is inextricably linked to value, but also tied to issues of quality, efficiency, equity and accessibility. We asked – can we present evidence about affordability from a patient perspective, as well as a systems perspective? How can we address the incidence of cancer, demanding an inquiry into expenditure on prevention? How far can we go beyond health and into the international regulatory issue of drugs pricing? We asked ourselves, can we develop a report that is applicable to all health economies, each facing its own unique challenges?

In the face of this complexity we have investigated international best practice for evidence of innovative programs that are improving value in cancer care. In writing this paper we were not interested in single-minded cost-reduction measures, such as cutting back on support staff in hospitals or attacking procurement prices. We have instead focused on the development of solutions that can be driven forward by policymakers without reduction in quality of care.

Looking ahead we know that, to address affordability challenges, clinical engagement will be critical. The success stories presented in this paper consistently reflect this. We conclude by presenting a prioritized action plan, based on patient pathways, which can be used across a variety of cancer care settings. Our plan harnesses clinical responsibility to drive value in cancer care: achieving better outcomes and patient experience with less money.

It has been a privilege to work with the World Innovation Summit for Health (WISH) forum members to present the recommendations in this paper. Our hope is that, through sharing our collective knowledge, we can enhance the global dialogue and practical implementation of value in cancer care.

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EXECUTIVE SUMMARY

Outstanding progress has been made in cancer research, leading to advances in the way we screen, diagnose, treat and provide follow-up care for cancer patients. We are better, too, at organizing our health systems around the needs of patients via a standardized pathway approach.

The resources that countries have deployed to control cancer, particularly through the adoption of innovation and technology in acute care settings, are significant. Cancer care is responsible for 5–7 percent of healthcare costs in high-income countries, reaching approximately $290 billion per year in 2010. For many countries, cancer is one of the top three areas of healthcare spending.

The expectation in many health economies is that these costs will rise dramatically, driven by increasing incidence as well as better survivorship and the associated longer periods of treatment and follow-up care. This is compounded by treatment costs themselves growing rapidly. While we accept that high cancer spending may be justified, we are also aware that there is significant variation in per-case costs across and within health economies, with outcomes failing to correlate to expenditure. Within this context, we test the hypothesis that spending in cancer care may be excessive and ask what might be done to better align systems to focus on value: sustaining progress in improved outcomes while restraining cost growth.

In this paper we explore the root causes of excess spending in order to further define and recommend how value in cancer care may be achieved. We propose an action plan with four priority areas, supported by case studies, to guide the delivery of better value in cancer care for patients and the community (see Figure 1).

For those health systems and practitioners who take up our challenge, we propose how to harness proven reforms and emerging innovations, build on the breakthroughs in cancer care and control, and refocus cancer care delivery on a new, crucial objective: affordability.
Figure 1: Root causes of excess spending and proposed action plan

Addressing the root causes of excess spending...

- Over-treatment and unnecessary interventions.
- Disconnect between value and technology adoption.
- Inefficient cancer service delivery.

... through policies that promote value in cancer care delivery

- Ensure patient engagement in personalized care.
- Inform decision-making in the clinical setting.
- Reduce delivery costs while upholding standards of care.
- Reward patient-centred outcomes and clinician responsibility.

Taking this agenda forward will be complex and will require change and priority-setting across the health system. Being a clinically focused agenda, it remains crucial that those who would take up this work thoroughly and consistently connect with the inherent instinct of clinicians to improve care for their patients. Harnessing the power of clinical engagement through professional bodies, medical education, academic medicine, and clinical leadership, will be the single most important enabler for driving value. As you will see in the case studies where health systems have been successful in implementing projects in the four action areas, clinical leadership is crucial.
The economic challenges facing health systems around the world are well known. The long-term upward trend in spending as a proportion of gross domestic product (GDP) has left many countries’ health systems in an unsustainable position. Increasingly, health systems are struggling to address the so-called ‘iron triangle’ of controlling costs, expanding access, and improving outcomes. Strained public finances have sharpened focus on delivering value in healthcare.

Meanwhile, economic development and aging populations worldwide have led to a surge in non-communicable diseases, posing a shared, grave threat to health system sustainability. Cancer is the second largest contributor to the non-communicable disease burden and its impact continues to rise. An analysis by the Harvard School of Public Health and the World Economic Forum estimated that there were 13.3 million new cases of cancer in 2010, with the number projected to rise to 21.5 million in 2030.1

As the number of cases rise, so does the pressure on finances. This pressure is compounded because, for a variety of reasons, cancer is becoming more expensive to treat each year. Its financial cost has escalated largely unchallenged in most developed countries and it is demanding an increased share of health system budgets, as are other conditions with growing prevalence, such as diabetes and dementia.

This challenge is not just one facing high-income countries. As progress is made in low-income countries to address communicable diseases, gains in life expectancy are made, meaning more people will develop non-communicable diseases, including cancer, and will need treatment. As these economies develop, new, strategically resourced service delivery models will be required to provide comprehensive care.

Fortunately, technological and therapeutic breakthroughs, and even stronger service systems, mean more accurate and timely diagnosis and better treatment options are increasingly available. Our review of National Cancer Institute statistics indicates that since 1975, five-year relative survival for all cancers in the United States (US) has increased from 48.9 percent to 68.3 percent. More and more people are living normal lives after undergoing treatment for cancer. Even when the disease is not curable, it can be stabilized and patients may survive with cancer for many years. All of this progress, however, has come at an economic cost, and it is now important to re-focus the debate on affordable care within a value-based framework.

A useful starting point for work on cost control is the patient pathway, which considers the patient journey as an integrated one throughout the healthcare system (see Figure 2). System leaders using this approach have been able to drive quality, raise standards of care and improve outcomes. Thus far, the comprehensive pathway approach remains largely a missed opportunity to test affordability across different models and systems of cancer care. The pathway can be used to understand costs at each stage of a patient’s journey, and to model the measurement and comparison of costs (variation) between providers and systems.
Figure 2: Cancer care across the end-to-end pathway

To put forward a plan for how to deliver cancer care more affordably, this report first examines current and future costs and expenditure in cancer care, and the root causes of these costs across cancer care pathways.
THE COSTS OF CANCER CARE TODAY AND WHERE THEY ARE HEADING

Cancer care is now responsible for 5–7 percent of healthcare costs in high-income countries, reaching approximately $290 billion per year in 2010. Worldwide spending on cancer is equivalent to the GDP of Hong Kong, the 35th largest economy in the world. For many health economies, cancer is one of the three largest areas of medical spending.

As striking as those figures may be, many people would argue that high cancer spending is nonetheless justified. Cancer is a major cause of premature morbidity and mortality. That said, there are concerning facts about cancer care spending that deserve consideration.

1. Overall cancer expenditure will inevitably increase as cancer incidence accelerates.
2. There has been very high growth in treatment costs, the largest item of per-case spending.
3. There is already significant variation in per-case costs across and within health economies, with outcomes not correlating to expenditure.

Today there is an expectation in many health economies that the costs of cancer will rise dramatically. Available projections from the US, United Kingdom (UK) and Australia suggest that cancer costs in these countries could increase by 42–66 percent above current levels by 2025 (see Figure 3).

Figure 3: Cancer cost projections 2015–2025 by compound annual growth rate (CAGR)

- **United States**: 5.2% CAGR, 66%
- **United Kingdom**: 4.5% CAGR, 55%
- **Australia**: 3.6% CAGR, 42%

At the same time, many health systems foresee their funding being constrained over the next 10 years and are looking for ways to cut spending. The National Health Service (NHS) in the UK, for example, faces a so-called “decade of austerity” according to the Nuffield Trust, in which funding is likely to increase only with GDP growth at 2.4 percent each year, while outpaced by spending (including cancer, projected at 4.5 percent growth per year). The arguments for efficiencies and cost reductions in many other developed world health systems are just as urgent and important to our discussion of cancer cost growth.
Although population growth and our improved ability to detect cancer play a part, much of the recent growth in incidence has been caused by a change in the risk profile of the population. More people require access to cancer care than ever before and their number will continue to grow, particularly because of aging. As shown in Figure 4, developed health economies worldwide are expecting increases of 16–32 percent in new diagnoses over the next 10 years.9, 10, 11, 12, 13, 14, 15, 16, 17

Figure 4: Cancer incidence projections 2015–2025
Prevention, screening and public health

Much of the success in slowing the number of predicted cancer deaths in the developed world has resulted from prevention and screening efforts over the last 30 years. Smoking cessation and tobacco control, breast cancer screening, and colorectal cancer screening have all saved lives. In the US, it is estimated that over one million cancer deaths were averted, through a combination of prevention (thought to be entirely responsible for the decline in lung cancer death rates), early detection, and improvements in treatment, as deaths increased less quickly in the 1990s.\(^{18}\)

Further development of these programs remains crucial to limiting the burden of disease, and therefore overall cancer costs. Research suggests that poor lifestyle and environmental factors may still be a contributing factor in 40 percent of cancer cases.\(^{19}\) For these cancers, the ultimate trajectory of incidence will be driven by public health success in reducing risk in diet, physical activity, and environmental health. It is worth bearing in mind that, while anti-smoking efforts have succeeded – for example, in reducing smoking prevalence in men from 41.2 percent to 31.1 percent from 1980 to 2012 – there is still a great deal of good work to be done. There are still 6.25 trillion cigarettes smoked worldwide each year.\(^{20}\)

In this paper, we focus primarily on the costs of those cancers which will unfortunately continue to occur. For many types of cancer there is still no viable preventative or screening intervention, and even the most successful public health programs fail to reach some people. Nonetheless, many preventative and screening measures consistently rate as cost-effective in the health economic literature and deserve continued investment. Those directed at higher risk groups – vaccinations for HPV and Hepatitis B for example – are particularly likely to have a significant impact in the future. We would expect, over time, to see the burden of disease reduced through success in public health, but we do not rely on it to contain costs in the near term.
The burden of cancer is rising even faster in low- and middle-income countries. Experts estimate that, from 2008 to 2030, cancer incidence will rise by 65 percent in high-income countries, 80 percent in middle-income countries, and 100 percent in the world’s poorest countries. The successes and failures of the approach to cancer care delivery taken by high-income countries may be applied in some middle- and low-income countries as health systems evolve to confront the rising challenge.

Incidence is not the only driver of quantity, as those who survive the disease remain in the pool of those receiving ongoing surveillance, often for the rest of their lives. As a positive result of better treatment, this population of ‘survivors’ is growing around the world. In the US, it is estimated that 14.5 million cancer survivors were alive in 2014 and this figure is expected to increase to 19 million by 2024.

The projected increase in the patient population alone could lead to much higher cancer costs, assuming no change in the mix of cancer types or per-case cost of cancer. As we will now discuss, per-case costs are compounding the cost problem further.

**Growing costs for treatment**

Understanding the relative contribution of different components of cancer spending requires aggregating financial data across sites of care to encompass the full patient journey; regrettably, this has not often been done in a way that enables comparisons over time or across countries. There are only select examples which can help us frame the major areas of cost in general terms.

- One study of cancer costs in Europe (see Figure 5) shows that the main costs of cancer care accrue in the inpatient setting, representing, on average, 56 percent of cancer costs in the European Union (EU). Drugs are also a significant contributor but represent no more than 43 percent of the total cost in any single country, with the EU average being 27 percent.
- An international collaboration of health systems in Australia, England and Singapore organized by McKinsey & Company showed that treatment costs accounted for 41–53 percent of total costs in colorectal cancer care, and were universally the largest category (see Figure 6).
Treatment costs have grown rapidly over the last several decades. For example, between 1991 and 2002, the average spending on initial breast cancer treatment in the US rose from $4,000 to over $20,000. Peter Bach and colleagues in the US have shown that the monthly prices of new cancer drugs have increased from $2,000 to over $5,000 from 2000 to 2010. And a group of oncologists involved in treating a particularly expensive form of cancer, chronic myelogenous leukemia, have documented that drug treatment has grown from $5,000 per month 10 years ago to more than $10,000 per month today. Overall, the global oncology drug market has more than doubled since 2003, a 160 percent increase from $35 billion to $91 billion. A 2014 Institute of Medicine workshop attributed the rise in oncology drug costs to pricing practices and the high cost of developing new drugs; shortages of generic drugs; reduced competition in healthcare; and reimbursement incentives that foster the use of high cost drugs and the shift of site of care from the community to hospital settings. Importantly, the rise in cost of oncology drugs has outpaced the total global drug market which increased by 91 percent over the same period reflecting a combination of drivers including higher prices, higher utilization, and a larger patient population.
While drug costs form only a portion of the total cost of cancer care, the growth in this area has been rapid, well-documented, and deserving of further consideration. We explore this area in more detail in the ‘A vision for affordability’ section. We believe any discussion of affordability of cancer care must also include a critical assessment of the way treatment is delivered, especially in the inpatient setting.

Variation in per-case spending

Per-case cancer spending varies considerably between countries, but the outcomes of cancer care do not necessarily correlate with expenditure. For example, one health economic evaluation shows that, to achieve approximately the same five-year survival outcomes in colorectal cancer, health systems invest very different amounts, varying as much as six-fold (see Figure 7).31

Figure 7: Comparison of colorectal cancer spending and outcomes

Similar variation in cost per case can be observed within health systems. Various studies identify large differences in treatments used or outcomes in a country and even in the same city, which account for differences in the cost of cancer care within a health system. For example, in Stockholm, Sweden, the treatment offered to men with prostate cancer has been seen to differ widely from hospital to hospital.32 Across England, The NHS Atlas of Variation in Healthcare shows substantial variation in five aspects of cancer care delivery. For example, average emergency bed days per new cancer registration range from 7.1 days to 18.2 days.33

It is crucial to identify not just where costs are large, or quickly growing, but where they may be excessive or fail to correlate with outcomes.34 We will now examine some of the root causes of excessive spending in cancer care, including those that are emerging and likely to accelerate the upward trend.
ROOT CAUSES OF EXCESS SPENDING AND FUTURE SPENDING GROWTH: THE CANCER VALUE CHALLENGE

We have identified three root causes of excess spending which we believe form the cancer value challenge to health systems worldwide. Tackling these issues will help bring cancer costs under control without sacrificing outcomes or patient experience.

1. Over-treatment and unnecessary interventions, especially at the end of life.
2. Disconnect between value and technology adoption.
3. Inefficient cancer service delivery.

Over-treatment and unnecessary interventions especially at the end of life

There is growing professional recognition that there are more tests, procedures, treatments and drugs being given than necessary according to the available evidence. This is exemplified by the Choosing Wisely campaign in the US, an initiative that encourages dialogue between physicians and patients about the overuse or misuse of medical tests and procedures that offer little benefit.\(^{35}\) The American Society of Clinical Oncology (ASCO), for example, each year publishes a Top Five list as part of this campaign, which names commonly used interventions that should be discontinued.\(^ {36}\) There are comparable examples in radiology,\(^ {37}\) hematology,\(^ {38}\) and many other disciplines, and partner organizations like the European Society for Medical Oncology are helping to scale these efforts across the world. These are the most straightforward examples of how cancer costs are higher than they should be, since they run contrary to professional guidelines and accumulated knowledge on how to best treat cancer.

2013 ASCO Top Five list

1. Do not give patients starting on a chemotherapy regimen that has a low or moderate risk of causing nausea and vomiting antiemetic drugs intended for use with a regimen that has a high risk of causing nausea and vomiting.
2. Do not use combination chemotherapy (multiple drugs) instead of chemotherapy with one drug when treating an individual for metastatic breast cancer unless the patient needs a rapid response to relieve tumor-related symptoms.
Over-screening and diagnosis of potentially insignificant cancers

As seen in recommendation 4 in the ASCO list, the intense focus on finding and curing cancer may have led to more screening activity than has an overall population health benefit. For example, a study looking at breast cancer in the US found that the increase in screening led to a larger number of diagnosed cases but only marginally reduced the rate at which women presented with advanced cancer. The study estimated that in 2008, breast cancer was over-diagnosed (excessively detecting early-stage cancers unlikely to cause harm) in more than 70,000 women, which accounted for 31 percent of all breast cancers diagnosed.

Further analysis for prostate cancer found that a large number of men in the US, once diagnosed with the disease, received unnecessary and aggressive treatment and, in some cases, treatments known to be ineffective or even harmful. One study in particular showed a large degree of variation in how clinicians treated patients who had a good prognosis, with a substantial number of patients receiving unnecessarily aggressive therapies that cause harm.

End-of-life care

In 2012, the first ASCO Top Five list recommendation was “Don’t use cancer-directed therapy for solid tumor patients with the following characteristics: low performance status (3 or 4), no benefit from prior evidence-based interventions, not eligible for a clinical trial, and no strong evidence supporting the clinical value of further anti-cancer treatment” which speaks directly to a central issue in over-treatment: deciding to discontinue further treatment near the end of life.

As cancer is still often a fatal disease, end-of-life care is an important issue and one which has not received nearly the same attention or investment as curative therapies. Aggressive treatment near the end of life is still common (and is a growing area of focus in the popular press), driven by a combination of the optimistic nature and training of some cancer clinicians, defensive medicine practices, hope of patients

(Continued)
and families,\textsuperscript{45} and failure to engage palliative care. However, these aggressive treatments are of questionable value. A 2010 study demonstrated that patients with metastatic lung cancer who received early palliative care benefited from better quality of life and even longer overall survival, despite having less-aggressive treatment.\textsuperscript{46} We know that when patients are near the end of life, they prefer to die at home, yet few do. The unnecessary and unwanted cost associated with hospital stays (and continued treatments which can make them necessary) near the end of life should be considered in any framework developed to control cancer expenditure.\textsuperscript{47}

**Disconnect between value and technology adoption**

That cancer treatments and outcomes are improving is largely the consequence of sustained technological progress, and we acknowledge that high prices for valuable drugs and technology are not necessarily unjustified. However, there is cause for concern that it is difficult on many levels to determine whether a given therapy represents good value for money and thus there is a danger that low-value therapies are being used too frequently. In economic terms, not having the right information means that resources cannot be allocated efficiently.

In the clinical setting, the available evidence does not always give clinicians the right information to make a value-based decision to pursue one course of treatment or another. The measure of increase in overall survival (how long a patient lives) is critical. There is a growing recognition that the clinical trial data used for regulatory approval is of limited use in the real-world clinical setting.\textsuperscript{48} In response, ASCO has formed a working group to identify ‘meaningful clinical outcomes’ to guide the development of clinical trials with more impact, especially those that evaluate improvements in overall survival.\textsuperscript{49} A recent analysis showed that, of the 71 solid tumor therapies approved by the Food and Drug Administration (FDA) between 2002 and 2014, only 30 (42 percent) met the ASCO standards.\textsuperscript{50}

Regulators face additional challenges in evaluating new cancer therapies. One study demonstrated that the combination of very high prices for cancer therapies and political pressure for better cancer care is leading to increasing “cancer exceptionalism” in economic evaluation.\textsuperscript{51} In these cases, regulators bend the traditional rules of determining the suitability of a given therapy for widespread use in a health economy. One prominent example of this exceptionalism is the NHS England Cancer Drugs Fund, which makes £200 million available for cancer treatments which do not qualify under the normal National Institute for Health and Care Excellence (NICE) regulatory scheme. This fund is a stopgap measure developed in response to unfavorable public reactions to NICE decisions on a number of cancer drugs that were not deemed to be cost-effective.\textsuperscript{52} At the same time, however, research shows that, when specifically asked to consider the trade-off with other diseases, the public may not support this preferential treatment for cancer.\textsuperscript{53}
Precision (personalized or stratified) medicine

Genetic testing is having a significant impact on cancer care. Clinicians can increasingly predict which individuals will develop cancer and which treatments will work for specific patients with cancer. An example of this progress is the Qatar Genome project, which matches patients with known biomarkers, generates risk profiles, and finds target gene mutations for new therapies. The share of oncology spending going to these targeted therapies more than quadrupled over the last 10 years (see Figure 8). The pace of development is continuing to accelerate as new biomarkers are discovered, and gene sequencing becomes less costly and more regularly used in clinical practice.

**Figure 8: Oncology drug spending 2003–2013**

![Oncology drug spending 2003–2013](image)

**Figure 9: Biomarkers used in clinical stratification**

![Biomarkers used in clinical stratification](image)

Currently, across the world, the significant costs of precision or targeted therapies are not generally factored into current or future spending projections and are in addition to existing rising costs in cancer care.

However, precision medicine does have the potential to reduce costs in cancer care. Gene sequencing for known biomarkers can identify heritable tendencies for cancer, allowing therapeutic intervention prior to a cancer developing, or to earlier...
Inefficient cancer service delivery

In many cases, cancer care is provided in higher-cost settings than necessary. One study in the US showed that inpatient care (excluding chemotherapy) was responsible for 67 percent of variation in advanced cancer spending across regions, suggesting that higher-cost centers were spending excessively. The authors note that “although little emphasis has yet been placed on reducing acute hospital care in cancer patients, this concept appears to be feasible.”58 Another project, in Manchester in the UK, found significant variation and a 10 percent cost improvement potential if cancer services were better managed to reduce unnecessary hospitalizations and streamline care for breast and lung cancer.59

Even when inpatient procedures and admissions are necessary, cancer care delivery can still be made more efficient. For example, innovations in oncology workforce strategy have not been taken up widely, and there are remaining opportunities to engage nurses and physicians’ assistants in more cancer-related procedures40,41 and care co-ordination.42

Genomic testing can also provide information on tumor characteristics, which can guide treatment planning. Most women with localized breast cancer currently receive aggressive therapy with surgery, radiation, chemotherapy and hormonal therapy. However, if these patients can be shown to have a very non-aggressive tumor by genomic analysis then much less treatment is needed with less cost and better patient experience. We look forward to the time when there will be better matching of therapies to tumor and patient characteristics.
POTENTIAL CONSEQUENCES OF FAILING TO MEET THE CANCER VALUE CHALLENGE

As we have seen, many health systems will struggle to fund cancer care if the dynamics we have described continue to put more demand on a system which is already strained. It is important to note that these consequences may not be as clear as a negative number on an income statement. Failing to address cancer costs could lead to a variety of undesirable system-level outcomes, such as:

- Overall budget increases caused by cancer care resulting in a greater cost to society in the form of rising premiums and/or taxes to cover outlays.
- Cost-shifting to patients in the form of out-of-pocket payments with potentially harmful financial consequences such as bankruptcy.\(^\text{(63)}\)
- Cancer care taking up a greater proportion of healthcare spending, taking away from other disciplines, to the potential detriment of outcomes in those areas.
- Where no more funding is available, restrictions on access to care may lead to worse patient outcomes.
- Uneven availability of care because limited resources are given preferentially to some segments of society.

The way each health system considers affordability and how it responds will differ. We believe, however, that the consequences listed above are already beginning to take hold in many places and are likely to continue without robust policy responses to the challenges we have presented.
A VISION FOR AFFORDABILITY

Cancer care services and systems should consistently evolve to drive better value for patients and the community.

As we have already discussed, prevention and effective screening programs can reduce the incidence, and therefore the costs of cancer care. This paper provides a complementary vision to drive value for money in clinical (particularly acute) settings by addressing the immediate root causes of excess and future growth in spending.

Meeting the cancer value challenge will allow health systems to face the costs inherent in the growth of cancer incidence. It will allow for the provision of treatment with confidence and enable health systems to preserve financial sustainability. However, doing this will require a relentless focus on value, including quality, throughout the system and a new policy environment that enables patients, clinicians and payers to co-create affordable cancer care.

We see four priority areas for action that provide a framework for policymakers to bring about value-based cancer care:

1. Ensure patient engagement in personalized care.
2. Inform decision-making in the clinical setting.
3. Reduce delivery costs while upholding standards of care.
4. Reward patient-centered outcomes and clinician responsibility.

We have selected case studies and developed recommendations to describe how affordability can be achieved for each of these action areas.

1. Ensure patient engagement in personalized care

Patients need to be engaged in delivering affordable cancer care because of the financial implications involved, but also because the often costly treatments offered may have little benefit to them individually. Patients should be informed about the benefits and risks of different courses of treatment, including curative and palliative care options.

It is not clear, however, whether patients are put in the position to make informed choices that include questions of affordability during care planning. Oncologists can be reticent to bring up the subject of cost or can be under-informed about its importance. Even when the conversation does occur, it can be very challenging for patients, especially the elderly. Patients, carers and families should be given the information, opportunity and professional support to make the trade-offs about the cost of a therapy, its likelihood of success, and its impact on quality of life.
Would patients always make expensive choices? Perhaps not, if given all the information. Studies conducted in the UK, Norway, and Brazil have all found that healthcare professionals are less likely to choose aggressive courses of treatment than patients. Indeed when the healthcare professionals themselves have cancer they are less likely to pursue the ‘futile care’ they have observed over the course of their career. In one study in the Netherlands, patients’ assessments of their own capabilities to weigh the evidence discouraged them from participating in decision-making. It is likely that patients’ instinctive survival reaction, to pursue ongoing lines of therapy, wins out in the absence of true participation, professional support and provision of accessible, actionable information.

**RECOMMENDATION 1A. Develop decision-making tools and systems that engage patients in treatment options and associated costs.**

Health systems can provide tools which mediate the decision-making process and incorporate patients into a more holistic discussion of the impact of choosing to pursue a course of treatment or not. For example, Wrightington, Wigan and Leigh NHS Foundation Trust in England developed a simple user interface to inform a shared decision-making process. The tool encourages patient input to treatment planning by suggesting words patients and carers can easily identify. Many tools to aid patient–clinician communication have been developed for specific cancer types, but few of these have included cost. The financial impact of treatment should be prioritized in patient–clinician discussions. The wider use of a validated patient-reported outcome measure which evaluates the financial distress associated with a course of treatment, could provide a starting point for further conversation.

**RECOMMENDATION 1B. Empower professionally led cancer consumer groups to drive knowledge around affordability.**

Communities of cancer patients and survivors can be of great value to cancer patients who are struggling to make difficult trade-offs and are seeking tailored, impartial guidance. Online portals such as PatientsLikeMe provide a unique relationship-based environment for patients to learn about their condition and treatment options based on others’ experiences. PatientsLikeMe and drug manufacturer Genentech recently agreed to collaborate on research projects that will focus on patients’ experience with oncology therapies. These communities should be similarly empowered by health systems as they represent a resource for knowledge dissemination, public engagement and collaboration around the issue of affordability. Alongside clinical advisory groups, these associations can help identify specific issues in cancer care provision that can be addressed by regulatory and health system leaders. They can also play a key practical role to empower patients at critical times in their journey, such as in multidisciplinary meetings.

**RECOMMENDATION 1C. Take action to ensure cancer patients’ preferences are met in end-of-life planning.**

Health systems should make sure that mechanisms are in place that allow cancer patients to choose how they would like to plan for the end of life and make these
agreements known to all healthcare professionals, as is done with the Coordinate My Care program in the UK. This program demonstrated that there is a substantial population of people who die in hospital when they would rather not, and showed that advance planning can avoid this. System leadership can drive change toward respecting patient preferences in end-of-life planning by tracking these preferences in registries and using adherence as a marker of quality of cancer care services. Enabling people to die at home and in home-like environments will require investment in community-based palliative care, but as research in Australia has revealed, these costs can be offset by a reduction in institutional care costs.

Case study: Kaiser Permanente’s in-home palliative care

Kaiser Permanente has introduced an in-home palliative care program which supports patients with their follow-up care. Patients are referred to the specialist program by their primary care physician, and a multidisciplinary team, including outbound carers, co-ordinates the care that is required. Not only has the program reported higher levels of patient satisfaction (93 percent compared with 80 percent among usual care patients) but the company has reported savings of 33 percent in total costs of medical care against the usual, hospital-based care. Reduction in hospitalization costs and in unnecessary tests and treatments that tend to be offered in the hospital setting are the main reasons for this saving.

2. Inform decision-making in the clinical setting

Costs and affordability are also becoming increasingly important considerations in everyday clinical practice and for the tools that support it, including clinical pathways, guidelines, and decision-support systems.

New ways of integrating clinical and cost data across patient pathways and providers enable informed discussion between clinicians and patients on treatment options, and support the reframing of affordability in cancer care. This can occur, for example, through a comparison of the financial impact of different treatment plans and patient journeys, which may in turn inform the creation of efficient, standardized value-based pathways of care. A better understanding of the current standard and the desired step-change standard of care can send smarter demand signals to innovators in industry and spur the development of breakthrough technologies.

RECOMMENDATION 2A. Use the principle of clinically meaningful outcomes in regulatory processes for new technologies.

The expensive process of drug development and testing can be made more efficient by aligning the goals of clinical trials with modest but significant goals for outcome improvement. In this way, trials can be run with fewer participants and innovation
that has a real impact can be rewarded. The ASCO Clinically Meaningful Outcomes project is a helpful template for how health economies can engage with clinical advisory groups to determine what constitutes a meaningful improvement in outcomes and what information is needed for therapies to be adopted more widely and appropriately. This should be a critical consideration for any therapy approval, and should extend beyond drugs to include a range of therapies, including palliative surgery and radiotherapy.

RECOMMENDATION 2B. Use integrated clinical datasets to directly compare real world effectiveness of cancer treatment options.

In addition to the data which is made available as part of the approval process for new therapies, ongoing monitoring of the effectiveness of therapies in the ‘real world’ will be, in all likelihood, even more helpful to clinicians in determining an appropriate course of treatment. So-called ‘phase 4 trials’ would continue the evaluation process after a new therapy is introduced. If this approach reaches its potential, health systems will spend less on ineffective treatments and clinicians will be able to pursue the best treatment approach on the first try.

To collect, organize, and distribute this information, health systems and cancer care services in particular should adopt the principles behind a ‘continuous learning healthcare system’ which establishes standards and expectations for data collection, ensures a secure legal framework for data sharing, and incentivizes innovation from all sectors to make the data usable and meaningful. Health systems should incorporate data collection and dissemination as an essential component of their cancer strategy, as Qatar has done within its National Cancer Program. Private companies and the technology sector are contributing to this effort. For example, Flatiron Health in New York has developed a cancer-focused data analytics platform which aggregates relevant data from electronic medical record systems, standardizes it and organizes it to deliver insights about which treatments work best in treating cancers.

RECOMMENDATION 2C. Integrate cost data into decision support tools to create efficient, standardized value-based pathways of care.

While many jurisdictions have introduced evidence-based pathways, guidelines and frameworks to drive quality improvements in cancer care, most of these do not include evidence around affordability or value.

Integrated clinical and cost data provides the knowledge base which value-based decision support tools can draw on. If these tools are implemented with the benefit of this integrated data, clinicians are empowered to prioritize and drive value through a powerful combination of evidence-based medicine and information on costs and cost-effectiveness. In some places, existing resources can be leveraged to greater effect. In the UK, for example, NICE produces clinical guidelines for practitioners based on both clinical and economic evidence, and with the aim to drive value for money, but these are for guidance only and therefore are not always integrated into everyday practice.
Sharing data between clinical providers at a system level also creates opportunities for greater transparency about the cost of care, making it possible to close the gaps evident between clinicians and providers. The objective remains to encourage take-up of best practice pathways which achieve at least the same outcomes at lower costs. The Independent Clinical Oncology Network (ICON) in South Africa (see case study box) is integrating provider and payer data from its members, which will enable it to identify waste and inefficiencies in the way care is delivered by providers and drive constant improvement.

Case study: Independent Clinical Oncology Network (ICON)

ICON is a network of oncology specialists in South Africa who are working together to address challenges in cost, variation, and access to cancer care. ICON contracts with chemotherapy and radiation therapy facilities across South Africa. More than 80 percent of South Africa’s oncologists are part of the network.

ICON drives improvements using a range of innovations, including an electronic platform that enables clinical decision-making according to diagnosis, staging and intent of treatment – curative or palliative. Cost of treatment options are automatically calculated, providing clinicians with an understanding of the possible financial impact of a treatment plan.

One of the core enablers of improvement is the capability to aggregate provider and payer data for the entire network, which allows a granular understanding of care delivery for patient journeys covering a large proportion of cancer care in South Africa. This integration of data enables ICON to propose enhancements to providers of cancer care. Broadly, five improvements have been introduced:

- Use of data to improve screening by understanding risk factors and improving the way patients are targeted, which requires collaboration at a national level.
- Elimination of waste by identifying duplication, and co-ordinating its removal from the system.
- Better understanding of clinical pathways to improve medical education.
- Mapping the overall patient journey to identify different options for patients and inform decision-making.
- Comparative analysis of similar patient journeys, helping to understand the differences in spending and outcomes to improve resource deployment.

ICON is able to show that the average cost of treating patients under their model is significantly lower than other treatment options – on average 43 percent for breast cancer patients, 22 percent for colorectal cancer, and 19 percent for prostate cancer. Table 1 shows their protocol-based approach along with specific cost savings for breast cancer.\textsuperscript{94}
Table 1: Average cost savings for breast cancer

<table>
<thead>
<tr>
<th>Intent</th>
<th>Cases</th>
<th>Cost with ICON standard protocols</th>
<th>Cases</th>
<th>Cost with no ICON protocols</th>
<th>Cost savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curative – adjuvant</td>
<td>1,937</td>
<td>R 26,525</td>
<td>2,086</td>
<td>R 47,891</td>
<td>45%</td>
</tr>
<tr>
<td>Curative – definitive</td>
<td>5</td>
<td>R 14,358</td>
<td>118</td>
<td>R 54,869</td>
<td>74%</td>
</tr>
<tr>
<td>Curative – neo-adjuvant</td>
<td>108</td>
<td>R 52,340</td>
<td>146</td>
<td>R 85,480</td>
<td>39%</td>
</tr>
<tr>
<td>Non-curative – improved survival</td>
<td>412</td>
<td>R 37,816</td>
<td>603</td>
<td>R 58,993</td>
<td>36%</td>
</tr>
<tr>
<td>Palliative – symptom control</td>
<td>205</td>
<td>R 23,924</td>
<td>254</td>
<td>R 41,567</td>
<td>42%</td>
</tr>
</tbody>
</table>

Breast cancer total 2,667 R 29,092 3,207 R 51,433 43%

3. Reduce delivery costs while upholding standards of care

Finding innovative ways to reduce costs within health service settings, including through the adoption of new funding and workforce models, has long occupied policymakers and health administrators. With the compounding high-cost therapies and increasing incidence of cancer, oncology is the obvious medical specialty to receive such attention. Yet, we are aware that across (and within) health settings, there are varying levels of efficiency and ability to address the root causes of excess spending in cancer. There are also significant variations in practice patterns among medical oncologists.

One approach to delivering greater value in cancer care is to address practice variances along with the rising cost of cancer therapies. Strategies can involve developing new, efficient models of cancer care, particularly in community settings, supported by effective workforce models. Across service settings, however, we can apply standardized and value-driven cancer pathways that are informed by both cost and quality data (as seen in Recommendation 2c). Upholding clinical standards of care will necessarily involve physician input, but we are also aware that value-driven cancer pathways will only succeed if designed and implemented with the support of clinical advisory groups.

85 RECOMMENDATION 3A. Develop centralized specialist centers of care supported by innovative workforce models.

It has been demonstrated that outcomes for major surgery, such as a pancreatectomy, are affected by the volume of surgeries a unit undertakes. More recently, a similar relationship in breast surgery has been seen.86 In these high-volume facilities, better outcomes (fewer complications and fewer deaths) also reduce costs associated with avoidable and unnecessary care. Centers of excellence are known for delivering high-quality outcomes but, because of centralization of clinical talent,
breakthrough technology and medical innovations, they often contribute to the burgeoning costs that health systems face. To get the most benefit from centralization while minimizing cost, health systems should promote approaches like the ones used by Narayana Health in India to drive efficiency in hospitals, up-skill nurses and other staff, and maximize value from clinicians. System managers should ensure that models are developed with clinicians that maintain quality of care, and develop the necessary enablers (for example, checklists, decision support tools) to expand the scope of what can be done by staff. It is critical to engage the workforce in the adoption of these models so that they become the norm, not the exception.

**Case study: Mazumdar-Shaw Cancer Center**

In India, Narayana Health has introduced specialist cancer hospitals which fundamentally change the economics of cancer care. Founded by Dr Devi Shetty, Narayana Health is known for disruptive innovation in heart surgery, where efficiency savings of more than 80–95 percent have been achieved for equivalent outcomes and survival rates compared with the US. Success has been achieved through a focused approach to treatments, eliminating waste and extras, training the workforce appropriately, and improving clinical and non-clinical standardized protocols and guidelines. Narayana Health has now used this approach to redesign cancer care through the Mazumdar-Shaw Cancer Center, which is a 1,400-bed facility aiming to realize the same vision for cancer care that their main hospital achieved for cardiac care.

**RECOMMENDATION 3B. Support community- and home-based cancer care co-ordination models.**

While co-ordinated cancer care has long been considered critical to quality improvement and patient experience, there has been movement towards community- and home-based care co-ordination models. The fundamental premise of these models is to treat and care for patients as close to home as possible, while ensuring hospitals are able to focus on acute care services. Where possible, community models should be one-stop shops to both enhance patient experience and benefit from economies of scale.

**Case study: US oncology patient-centered medical homes**

In the US, oncology medical homes operate as one-stop shops for oncology and provide a co-ordinated approach to cancer care for patients. Typically, oncology medical homes offer more comprehensive and better focused services, diagnostics, education and medications management. They also provide support in co-ordinating care services, including referrals to specialists in acute settings and other providers. An assessment of one pilot project in Pennsylvania showed potential to reduce health system costs, with a 65 percent reduction in
RECOMMENDATION 3C. Authorize clinical advisory groups to effectively introduce cost-effective optimal cancer pathways, and reward clinician compliance with these pathways.

Each case of cancer will have characteristics that differentiate it from a hypothetical average case. Nevertheless, the path the majority of cancer patients take through the system can be logical, co-ordinated and efficient. Payers, together with clinicians, have a significant opportunity to improve value using standardized pathways and encouraging professionals to manage patients effectively without being overly prescriptive. With these pathways as a standard, it becomes possible to drive best practice through integrating proven innovations in the pathways as well as better knowledge on therapy and service delivery cost-effectiveness.

A simple reward for compliance will incentivize clinicians and providers to implement standardized pathways. As the case studies demonstrate, this reward serves as an investment in behavior change which pays off in terms of lower overall costs on the recommended pathways. Looking ahead, it can be a subtle first change in the model of paying for cancer care, and an essential part of a broader journey toward accountable care models, as we describe in more detail below.

Case study: Standardized pathways for cancer at US private payers

Two large, private payers in the US, WellPoint and CareFirst BlueCross BlueShield, are pursuing standardized pathways as a means of reducing costs. At CareFirst, 46 sites covering 4,713 patients saved $10 million, or $2,000 per patient, through standardized pathways compared with projected cost increases by rewarding compliance with pathways.

The WellPoint Cancer Care Quality Program plans to introduce standardized pathways in exchange for financial bonuses in a similar model. Providers who follow a pathway for breast, lung, or colorectal cancer will be reimbursed an additional $350 per month per patient. As in the CareFirst case, providers will be free to continue with alternative or ‘off-pathway’ care on a personalized basis and this will be reimbursed as before, but the inducement to behavior change comes from the potential reward rather than a penalty. The program’s goal is to save 3–4 percent of the total cost of care after accounting for the increased spending per patient.
4. Reward patient-centered outcomes and clinician responsibility

Accountable models of healthcare are increasingly being heralded for their focus on payments for measurable improvements in health outcomes rather than ‘outputs of episodic care’ (or ‘fee for service’ approaches). Accountable care models aim to drive quality improvements while reducing costs through effective resource allocation.

In cancer control settings, models of accountable care are yet to be comprehensively tested, yet the advent of expensive precision medicine makes the evolution to more accountable systems more urgent. A number of new models to address the rising complexity in cancer care have been proposed – for example, payers pursuing global payments for precision-based treatment that include the cost of sequencing. More accountable reimbursement models in cancer have also been explored through novel ‘bundled’ payment schemes for oncologists that apply standard treatment regimens for specific cancers. There are also drug reimbursement models where payment is tied to measurable impact of a given therapy.

**RECOMMENDATION 4A. Move cancer care services towards pathway-based payment systems and outcome-based reimbursement models.**

Any effort to move cancer care services toward pathway or treatment-based systems that focus on reimbursement for outcomes needs to be underpinned by access to better data and information to improve transparency and enhance decision-making. Policymakers need to better understand the true cost of achieving the outcomes that patients expect, and ensure that providers are reimbursed accordingly instead of driving unnecessary waste, duplication, or over-treatment in cancer care.

The significant savings of the UnitedHealth Group pilot (see case study), which provided upfront bundled payments for standard treatment regimens, could be scaled up to other high-income countries and, even if the benefit is not as large, the approach could transform cancer care by making service delivery more accountable.

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**Case study: UnitedHealth Group bundled payments**

For UnitedHealth Group, a major insurer in the US, cancer therapy accounts for 11 percent of spending. Their reimbursement model for providers has been operating in a fee-for-service structure, which is not set up to incentivize providers to focus on improving outcomes and controlling costs, but simply pays providers a fee for activity, including drug prescriptions.

UnitedHealth Group undertook a three-year study with five medical oncology groups focused on reducing costs in breast, colon, and lung cancer by changing the payment...
RECOMMENDATION 4B. Pursue novel performance-linked reimbursement schemes for cancer therapies.

Health systems should make greater use of innovations which tie the performance of a therapy in real-world settings with reimbursement. These schemes are distinct from more common economic ‘risk-sharing’ with industry because they assess clinical endpoints for patients who receive the drug to understand whether it is having an impact.

Some of these efforts are already in place in oncology. In the UK, cancer drugs bortezomib and cetuximab have been subject to refunds for non-responders, as is the case for nilotinib in Italy. Elsewhere, payment innovations which have been instituted in other therapeutic areas could have a similar benefit if applied to cancer care. In the case of Diovan, a medication for hypertension, the drug company will refund patients’ out-of-pocket expense if their blood pressure does not reach the target zone. If more injections of the macular degeneration drug Lucentis are required than expected, the additional doses are provided free of charge in the UK and Australia.

Aside from these early efforts, any move away from straightforward payment per unit of therapy remains largely theoretical. The promise of better outcomes for targeted therapies, and the expectation of higher reimbursement for those therapies,
must be tempered by a robust mechanism for accountability. In many cases, the measurable progression of cancer, as seen in imaging or detected by diagnostics, provides a viable place to begin these sorts of innovative payment schemes. When data systems can be put in place to track outcomes with greater accuracy over time, outcome measures such as survival could be introduced to reimbursement schemes. Partnering to create the requisite trust and mutually agreeable data quality, as has been done between WellPoint and AstraZeneca (a global biopharmaceutical company), will ultimately enable these sorts of risk-sharing reimbursement schemes and create value for the health economy as a whole. The partnership has generated more than 25 research projects and an assessment of resource use patterns among patients with thyroid cancer.

Focus on low- and middle-income countries

A common misconception exists that cancer has an impact on only high-income countries. The cancer burden in low- and middle-income countries is increasing due to population growth and aging. The rising incidence of cancer in these countries is driven by multiple causes, with smoking a key factor. While smoking rates are generally declining in high-income countries (for example, in Australia and Brazil, smoking rates for men are as low as 22 percent), smoking rates in middle-income countries are estimated to be in the range of 37–39 percent. In low-income countries, the rate is lower at 30 percent, but we are witness to a steep rise in these rates in recent years. In the World Health Organization (WHO) region of the Western Pacific, including China, smoking rates are estimated at 51 percent. These levels of smoking will significantly add to the burden of cancer treatment, above the trend line associated with increased and aging populations.

Cancer fatality rates differ across income groups and cancer classifications. The World Bank groups countries into four categories: low-income (less than $1,045 per capita Gross National Income); lower-middle income ($1,045–$4,125); upper-middle income ($4,125–$12,746); high-income (greater than $12,476). Cervical cancer, for example, is disproportionately represented in low- and middle-income countries as seen in Figure 10, where screening programs are usually non-existent and early-stage disease is rarely seen. Breast, cervical and colorectal cancer have the greatest disparity in fatality rates, indicating the impact of screening in high-income countries.
Figure 10: Cancer case fatality rates by World Bank income group

The estimated percentage increase in cancer incidence by 2030 (compared with 2008) will be greater in low- and lower-middle-income countries (82 percent and 70 percent respectively) compared with the upper-middle- and high-income countries (58 percent and 40 percent). Without any changes in underlying risk factors (that is, based only on anticipated demographic changes), between 10 and 11 million cancers will be diagnosed annually in 2030 in the low- and lower-middle-income countries.

Often the lack and maldistribution of medical infrastructure in lower- and middle-income countries is such that this cancer burden cannot be managed. Primary care is often inadequate, biopsy facilities, surgical and pathology services absent, and continuity of care difficult. Radiotherapy is rarely available. Any plan to deal with the high and increasing cancer load in low- and middle-income countries has to be aware of this situation. While future service planning will be critical, the application of a high-resource solution to a low- or middle-income country’s problems may not be logical in every case.

However, the lack of legacy systems, entrenched workforce models and payment mechanisms may, in some cases, present opportunities for the application of solutions articulated in the four action areas outlined above. For example, the value of high-volume, quality models of care (Mazumdar-Shaw Cancer Center) may be realized in any income setting. It is clear, however, that while informed service planning will need to occur and learning applied from other settings, the most significant and immediate effect will undoubtedly happen at the start of the patient pathway – in the area of prevention and screening. Programs for smoking control, cervical cancer screening, vaccination for HPV and Hepatitis virus, are all fundamental changes which could be introduced at a low cost and without extensive service system development. For example, low-cost cervical cancer screening programs based on visual inspection of the cervix with acetic acid have shown to be effective when integrated into existing reproductive health programs.
DELIVERING AFFORDABLE CANCER CARE: A ROADMAP FOR ACTION

This paper provides a summary of some of the diverse work being done to deliver affordable cancer care in a variety of service settings. From our knowledge of the challenges, as well as the case studies, we derived a series of priority action areas and recommendations. To start to address these priorities and recommendations, policymakers and stakeholders can use the following roadmap for action in affordable cancer care.

Affordable cancer care: a roadmap for action

1. Facilitating patient involvement in clinical decision-making that is informed by costs along the patient pathway and end-of-life options.

2. Developing consistent and uniform transit for cancer patients through adherence to cost-informed clinical pathways, complemented by incentives for participating clinicians and patients.

3. Eliminating waste in cancer care service systems by rewarding control and minimization of duplicative and excessive spending along the clinical pathway.

4. Developing new costing models for drugs based on a ‘pay for results’ principle.

5. Incrementally introducing accountable care reward systems on a jurisdictional and disease basis.

6. Developing plans to address the introduction of potentially disruptive technologies associated with genomic medicine.

While all of these actions will influence value in cancer care, it is acknowledged that the challenges and opportunities will differ across countries and service settings, influencing prioritization and implementation. Looking ahead, it is therefore necessary to identify the major levers or tools immediately available to policymakers keen to pursue this opportunity.

Engaging with clinicians

When we consider the best practice examples in this paper and the roadmap for action, it is clear that a prerequisite for success in delivering affordable cancer care in service settings is robust clinician engagement. Cancer clinicians must be involved and responsible for improving outcomes and value within their systems, along defined clinical pathways. Jurisdictions adopt different models of clinician engagement, but its defining feature is a contract between clinicians and payers [whether governments or private providers] for the provision of advice on policy, planning, service delivery and implementation matters. As demonstrated in Figure 11, one key way that clinician engagement could be used to promote affordable cancer care is through identifying evidence-based clinical pathways, defining and measuring variation from these pathways, and planning interventions to eliminate those variants responsible for driving inappropriate costs.
Figure 11: Engaging with clinician advisory groups

Using data to reach a greater understanding of clinical pathways and variants will invigorate clinician advisory groups. They can also consider process inefficiencies within healthcare settings, which in turn can be used in service redesign projects. Mapping process inefficiencies can lead to deeper considerations of the appropriate use of the workforce and the shifting of care to lower-cost settings where appropriate.

Clinician advisory groups provide a clear starting point for exploring value in the delivery of cancer care. They can be used in a variety of healthcare settings across low-, middle- and high-income countries. Policymakers, however, will be required to create the environment for engagement, and support and reward the consistent implementation of service delivery reforms.
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Any errors or omissions remain the responsibility of the authors.

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