Towards sustainable cancer care:

Reducing inefficiencies, improving outcomes

A policy report from the All.Can initiative.

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All.Can Changing cancer care together

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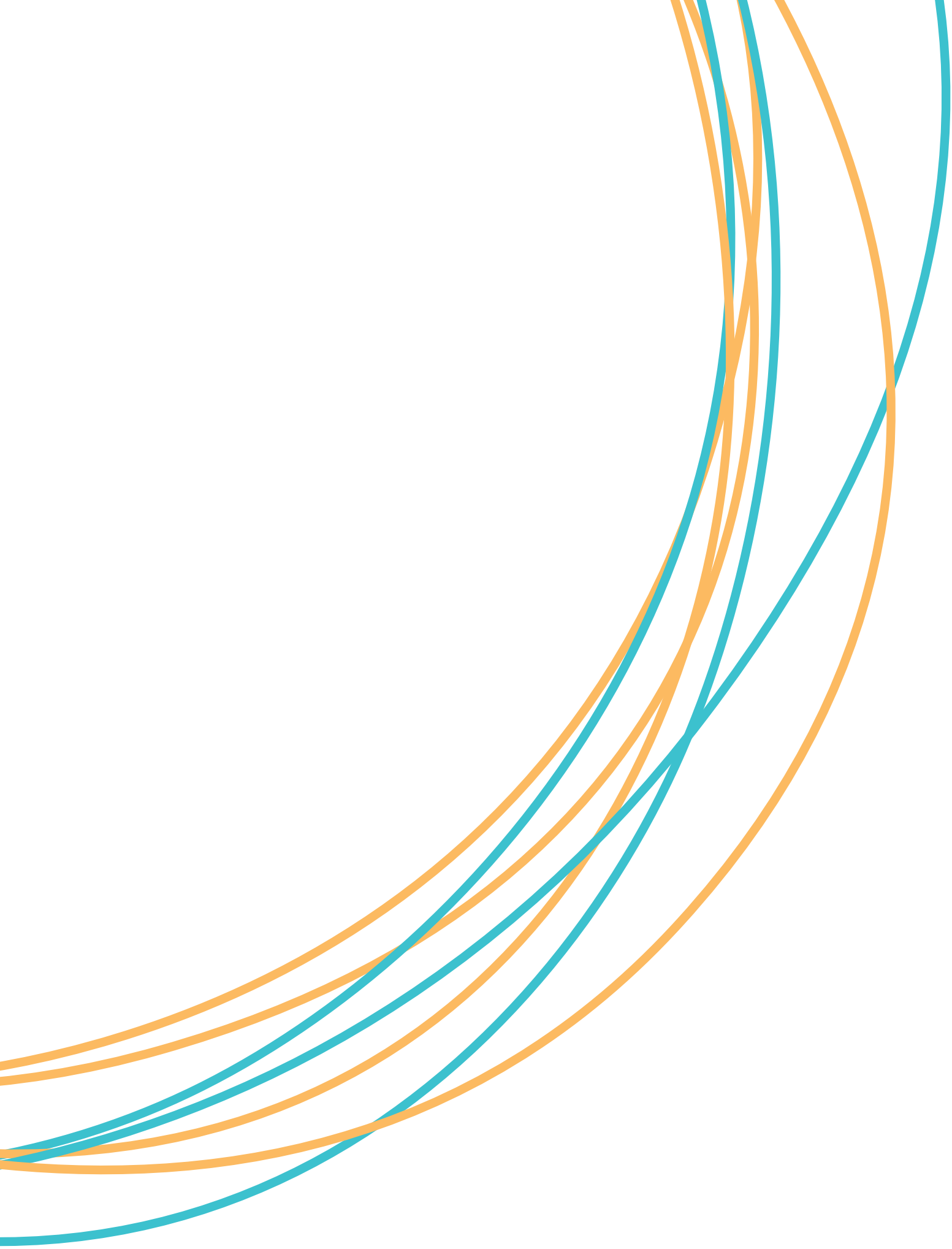

About the All.Can initiative

The All.Can group aims to help define better solutions for sustainable cancer care and improve patient outcomes in the future. It was established to create political and public engagement on the need to improve the efficiency of cancer care. To do this, it focuses on what matters most to patients, and makes sure resources are targeted towards achieving these outcomes.

The All.Can group comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry. The group aims to identify ways we can optimise the use of our resources in cancer care. This involves examining what system inefficiencies exist, finding examples of how we can improve efficiency in cancer care and implementing concrete policy actions based on these findings.

The All.Can initiative is made possible with financial support from Bristol-Myers Squibb (main sponsor), Amgen, MSD and Johnson & Johnson (sponsors).

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Executive summary

The past few decades have seen considerable advances in the way we diagnose and treat cancer. Yet with the growing prevalence of cancer and ongoing pressures on limited healthcare budgets, equal access to the latest scientific advances and their affordability has become a challenge.

Past and current approaches to cancer care may not be sufficient for tomorrow. We face limited resources and a demand for cancer that will only increase in quantity and complexity in years to come. As a result, we need to find new ways to make the most of the resources we have.

Improving the efficiency of cancer care must start with a clear understanding of what outcomes we are trying to achieve for patients. This means both eliminating what brings little or no benefit to patients and prioritising interventions that offer the greatest benefit to patients and value to the system overall. Without this, we risk not being able to offer future generations the benefits of advances in cancer care, as governments will not be able, or willing, to pay for them.

This report looks at improving efficiency in cancer care as a means of securing better health outcomes for patients and making better use of available resources as a result. It examines where system inefficiencies exist, collects examples of good practice and derives lessons from them to help trigger policy action.

Improving efficiency across the entire cancer care pathway is a complex and pressing challenge that will require close, and sometimes new, forms of collaboration between all stakeholders. We will need to move away from budget siloes and fragmentation in our current healthcare systems; measure the impact of what we do by investing in the right data; and use these data to drive a culture of continuous improvement, with clear accountability mechanisms in place.

However, increasing efficiency cannot become a goal in itself; it is rather a means to deliver what matters most to patients and achieve the greatest improvements in their care for both their benefit and that of society overall.

To achieve this, everyone has their part to play – but making real, lasting changes needs to start with policymakers and those who decide on how resources and funding in healthcare is allocated today.

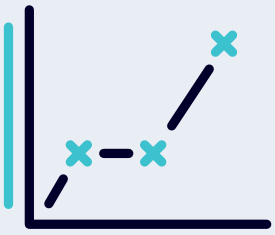
To reduce inefficiencies and ultimately protect the financial sustainability of high-quality cancer care for all European citizens, we need to:

01

Focus political will — to drive efficiency measures and strategic reinvestment across the entire cancer care pathway.

02

Place patient-relevant outcomes at the heart of everything we do — by including patients and their representatives in all aspects of cancer care planning, delivery, and evaluation. Across all aspects of cancer care, we must ensure that we are focusing on what matters most to patients.



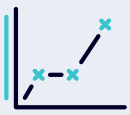
03

Invest in data — in the form of real-world data collection to capture variations in use of care and patient-relevant outcomes. We also need better linkages between health information systems and big data analytics to guide a continuous cycle of improvement, help target care more effectively and support technological and service innovation.

04

Create greater accountability — through measurement and public reporting of outcomes, outcomes-based reimbursement and built-in mechanisms to systematically identify and remove inefficiencies in cancer care.

What can policymakers do to help achieve more efficient cancer care?

	At the European level
 **Focus political will**	As a follow-up to the Cancer Control Joint Action, as well as the Economic and Financial Affairs Council's commitment to ensuring fiscal sustainability and access to good quality healthcare services for all,[1] collect good practices and explore models for creating greater efficiency in cancer care.
 **Place patient-relevant outcomes at the heart of everything we do**	Ensure that all health policies (i.e. in health promotion, prevention, and care) take account of the experience and perspectives of patients and citizens in healthcare. Empower patient organisations to help drive greater efficiency throughout the system, possibly in the form of a Choosing Wisely campaign driven by patients.
 **Invest in data**	Invest in public-private partnerships that aim to collect and merge real-world datasets across different countries. Map country-level variation in relevant cancer outcomes across countries, building for example on the EuroHOPE study, to compare variations of cancer care and outcomes, and drive improvement over time.[2]
 **Create greater accountability**	Within the European Semester, include credible measures of efficiency against which healthcare systems may be held accountable, and monitor progress against these measures over time, taking cancer care as an example.

At the national level

Make efficiency in cancer care a priority in national health policy and invest in a national consultation to identify existing inefficiencies.

Develop clear objectives to remedy these inefficiencies, with dedicated resources to ensure successful implementation.

Always involve patients or their representatives in all prioritisation decisions in national-level planning, purchasing and evaluation bodies (such as health technology assessment (HTA) agencies or their equivalents).

Ensure that care pathways are built around a clear understanding of patients' perspectives and experience.

Map regional variations in the use of care and patient-relevant outcomes across different cancers, and report these data back to individual practices or hospitals to promote adaptive improvements over time.

Explore the implementation of outcomes-based reimbursement schemes to encourage the development of new technologies that provide the greatest outcomes to patients.

Section 01
Introduction

Across European healthcare systems, 20% of spending is currently estimated to be wasted on ineffective interventions.[3]

Apart from its impact on our healthcare systems, waste and inefficiency also represent a considerable and unnecessary cost for patients and their families – in terms of lost time, anxiety and fear, impact on quality of life and financial burden. Ineffective interventions may also increase risk of harm, and ultimately lead to poorer outcomes for patients.

The rationale for achieving greater efficiency is thus clear for patients: it should free up resources that can be used to provide treatment and care that deliver the most benefit (see **Box 1**).

Reducing waste and inefficiency in the organisation and delivery of care will become increasingly necessary to help relieve budgetary pressures stemming from rising demands on healthcare systems. Ultimately, improved efficiency will contribute to more equal access to, and affordability of, healthcare.

Box 1. Quantifying inefficiencies within healthcare systems

Data on inefficiencies is not always easy to find. That which does exist points to high costs:

- Inefficient practices due to unwanted variations in hospital processes cost **£5 billion** per year, or **9%** of hospital spending, in England alone.[4]
- Poor adherence to medicines costs **€125 billion** per year in Europe.[5]
- Poor communication between doctors and patients costs over **€1.1 billion** per year in England.[6]

The potential for savings and better outcomes for patients – key data:

- The World Health Organisation (WHO) estimated that removing wasteful and ineffective interventions can deliver a **20-40%** efficiency saving in health spending across Europe.[3]
- The Organisation for Economic Co-operation and Development (OECD) countries could gain approximately two years life expectancy by reducing inefficiencies across healthcare systems.[7]
- Over **€7.2 billion** could be saved in Germany every year through better coordination of care leading to reduced hospital admissions.[8]
- According to a recent analysis, appropriate use of generics and biosimilars between 2015 and 2020 could bring an estimated saving of **€7.1 billion** for Belgium, Denmark, France, Germany, Italy, the Netherlands Poland, Sweden and the UK.[9]
- Eliminating avoidable adverse drug reactions would result in an annual saving of **£466 million** in the UK.[10]

A focus on cancer

Although it may be argued that greater efficiency is needed across all disease areas, in cancer this need is especially urgent (see **Box 2**). Advances in the way we diagnose and treat many forms of cancer promise to transform outcomes for many patients in years to come. However, a number of expert commissions and professional groups[11-14] have suggested that we must find ways to allocate resources more efficiently in cancer care, and reorganise our priorities in terms of long-term investments rather than short-term policy fixes. Without such innovation, we risk not being able to offer future generations the benefits of these advances, as governments will not be able or willing to pay for them. The fact that one in five countries in Europe already has insufficient funds to implement their National Cancer Control Plans (NCCPs) as drafted, confirms the urgency of this situation.[9]

'Cancer patients in Europe live a paradox: the personalised medicine revolution has produced several extremely effective new treatments for cancer patients, but not all patients who would benefit from them have access to innovation. Innovation is meaningless if not available to everyone who needs it in a timely fashion.'

Professor Francesco De Lorenzo, President, European Cancer Patient Coalition

'We are... at a crossroads where our choices, or refusal to make choices, have clear implications for our ability to provide care in the future.'

Richard Sullivan, the Lancet Commission for Sustainable Cancer Care Commission in High-Income Countries, 2011[11]

Box 2. Why focus on cancer?

Growing prevalence and societal burden:

Cancer is the second largest cause of death in Europe after cardiovascular disease[15] and its prevalence is increasing with the ageing of the population.[16] Up to 2.5 million Europeans are diagnosed with cancer every year, leading to 1.2 million deaths.[17]

Considerable societal burden:

The cost of cancer will undoubtedly grow with rising prevalence – and at least half of that burden falls on patients and their families.[18] Cancer represents 17% of the total burden of disease in Europe (EU27).[9] Approximately 6% of all health expenditure is spent on cancer, and this figure has remained stable over the last few years.[16]

High unmet needs:

Despite considerable increases in survival rates over the past few years, half of people diagnosed with cancer will not survive beyond five years.[17] Progress in survival has been uneven across cancer types, with survival rates varying from 13% in lung cancer to over 80% for skin or breast cancer. Survival rates for some rare cancers, and variations in survival for these cancers, are even worse,[19,20] with very few treatments available in many cases.[13]

Significant variations in outcomes of care:

For example, there is a fourfold variation in survival from lung cancer at five years across OECD countries. Re-operation rates for breast cancer vary sevenfold within countries, and rates of complications from radical surgery for prostate cancer vary ninefold.[21] Yet such variations in outcomes between countries do not necessarily reflect differences in spending,[12,22,23] suggesting that there is considerable room for improvement. People within lower socioeconomic groups are at a particular risk of poorer outcomes from cancer.[24-28]

Growing inequalities in access to care:

Budgetary pressures have led to growing inequalities in access to cancer care both between and within European countries. For example, radiotherapy is only used at 70% of its optimal usage as defined by clinical guidelines.[29] Worldwide, scaling up radiotherapy capacity during 2015–2035 could bring a health benefit of 10.7 million life-years.[30] There are also known inequalities in access to surgical procedures across Europe.[31] Gaps in access to anti-cancer medicines are significant as well. Although disparities are greatest for the newer, more expensive medicines, gaps also exist for many long-standing, low-cost medicines as well as medicines included in the WHO Model List of Essential Medicines.[32]

Financial toxicity for patients and their families:

As a result of limited public funding for some cancer treatments, out-of-pocket costs are rising among cancer patients, particularly in poorer countries,[18,32] often creating considerable financial pressure for families.[33,34] This may lead to 'financial toxicity'; patients may forego treatment on costs grounds, have lower adherence to treatment and even higher mortality as a result of the financial pressures caused by their care.[35]

Significant cost to society:

Lost productivity due to cancer costs society €52 billion across the EU, and 60% of the costs of cancer are non-healthcare related.[18] Improving the efficiency of cancer care may therefore have a broad impact on our society, well beyond its impact on health.

Reducing inefficiency is a precondition for fostering innovation in cancer care

'As a patient, it is extremely frustrating and desperately worrying to be told that there is not enough money to fund the innovative cancer treatments you need when there is so much obvious waste within the healthcare system.'

Kathy Oliver,
The International Brain Tumour Alliance

With current concerns over rising inequalities in access to the newer cancer medicines and other technologies, some people may equate 'improving efficiency' with cost-cutting, and therefore see efforts to improve efficiency as being an impediment to innovation in cancer care.

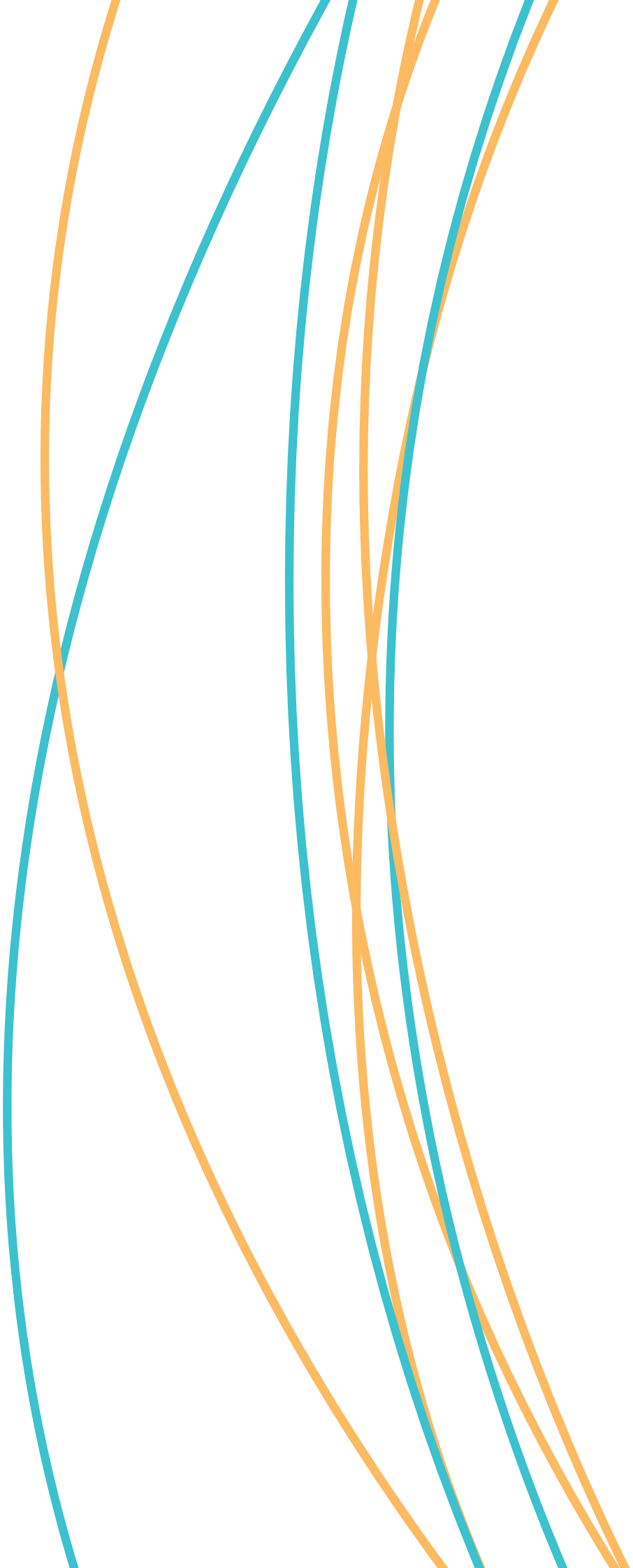
This report, therefore, takes a different view. Our underlying premise is that improving efficiency and investing in innovation should be considered in tandem, with the common thread being a focus on improving outcomes for patients. With the rising demands and increasing complexity of cancer care, disinvestment from inefficient practices may help free up resources for innovative care approaches.[14,36] Addressing inefficiencies today is thus a vital measure to safeguard the quality of cancer care and allow it to continuously evolve and improve for the benefit of the entire healthcare system and society as a whole.

Achieving greater efficiency calls for a whole-system view of cancer care, focused on delivering optimal outcomes for patients across the entire care pathway. It also requires less emphasis on the upfront cost of a given intervention or policy (i.e. year by year), and greater value placed on the long-term impact of care choices, investments and on outcomes and costs – including social costs. Sometimes seemingly 'expensive' technologies or practices may offer long-term value for patients, society and health systems alike, and their introduction may require changing practices or ways of delivering care. These so-called 'disruptive innovations', may help achieve optimal outcomes for patients and present 'possible new ways of developing sustainable European health systems.'[37] With such prizes at stake, our healthcare systems need to be ready to integrate them, and find sustainable ways of doing so over time.

About this report

This report was drafted by members of the All.Can initiative – a group of patient and family representatives, health professionals, health economists, politicians and industry representatives, who are united in their belief that we can do better with the resources available in cancer care – for the benefit of cancer patients today and tomorrow.

This report is intended as a starting point for the All.Can initiative, which aims to create political and public engagement to implement mechanisms, policies and actions that will improve efficiency and outcomes for cancer patients in years to come.



Section 02
Defining efficiency in cancer care

'Efficiency is concerned with the relation between resource inputs (costs, in the form of labour, capital, or equipment) and... final health outcomes (lives saved, life years gained and quality-adjusted life years).

Adopting the criterion of economic efficiency implies that society makes choices which maximise the health outcomes gained from the resources allocated to healthcare. Inefficiency exists when resources could be reallocated in a way which would increase the health outcomes produced.'[38]

The term 'efficiency' is often mistakenly taken to be synonymous with 'cost-containment.' However, improving efficiency is not a simple cost-cutting exercise.

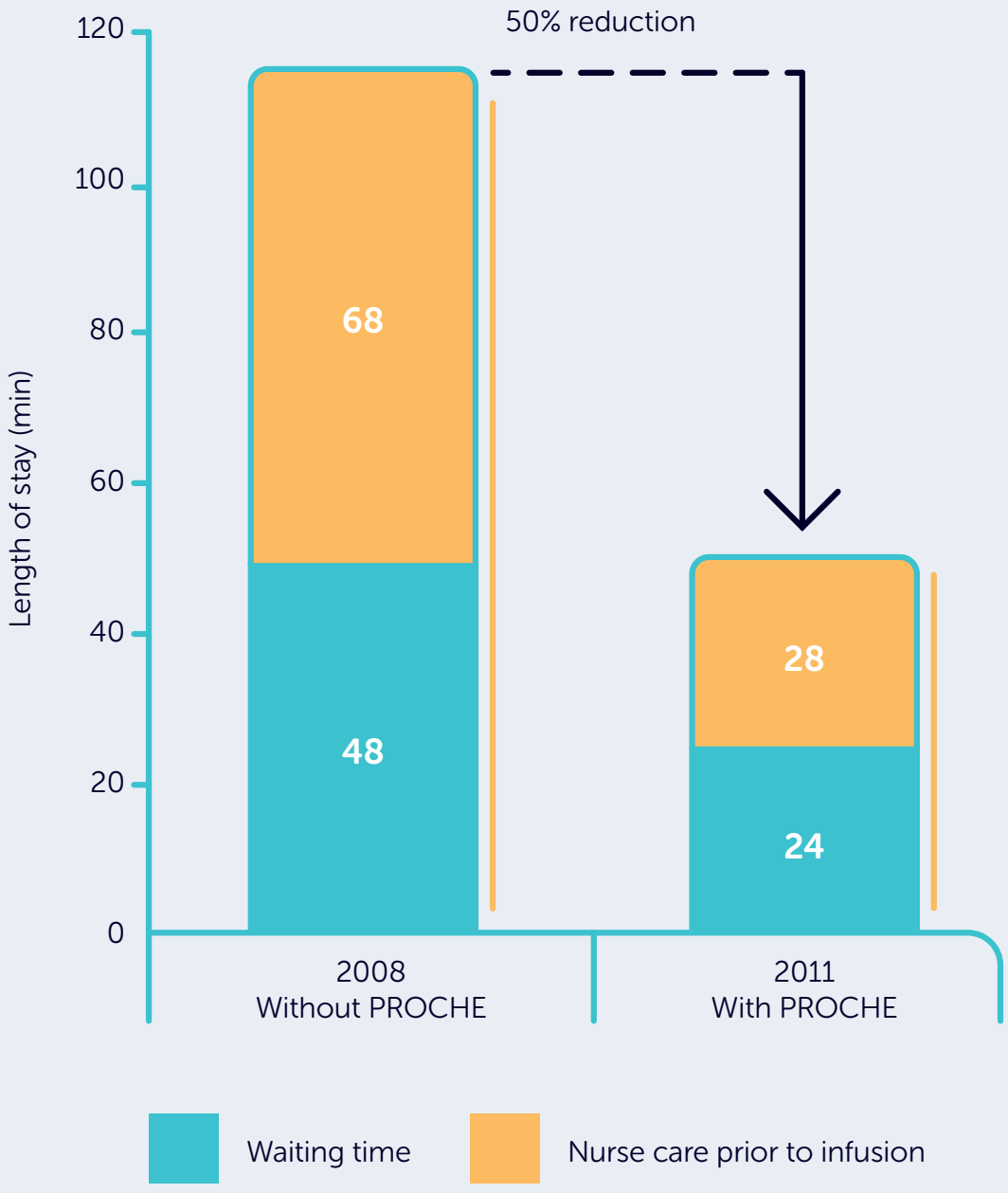
In fact, experts have suggested that cost-containment efforts to date that have not looked at the impact of policies on patient outcomes have failed to reduce healthcare spending until now.[39-41]

At the George Pompidou Hospital in Paris, a simple programme has been set up to improve the efficiency of chemotherapy delivery for cancer patients. Previously, each time patients went to hospital to receive their scheduled chemotherapy, considerable time was spent gathering information about any adverse events they might have experienced since the last session. Often, treatments needed to be modified, postponed or cancelled based on this information – resulting in drug wastage, lost time for patients, their caregivers and hospital staff, and potentially lower treatment benefits.

The PROCHE programme was set up to address this inefficiency. Through this system, hospital nurses call patients two days before each programmed chemotherapy session, collect data on previous adverse events and then transmit this information to the lab so that it can be integrated into the planning of each chemotherapy session.

As a result, the waiting time for patients and work time for nurses has been halved, fewer chemotherapy drugs have been wasted, fewer appointments have been cancelled and the overall capacity of the unit has improved. Furthermore, patients have reported a lower incidence of pain and severity of fatigue (see **Figure 1**).[42]

Figure 1. Impact of using patient data to improve the efficiency of service delivery: the PROCHE programme at the European Hospital George Pompidou[42]



Adapted from Scotté et al., 2013[42]

This simple intervention demonstrates two important points:

01

Improving efficiency must start with a clear understanding of what outcomes we are trying to achieve for patients. It should strive to improve outcomes, not just reduce costs.

02

Underpinning all efforts to improve efficiency is the collection and transparent reporting of patient-relevant outcomes data. These data should then be used to identify areas for adaptive changes and improve practices.

A focus on outcomes, not just costs

We need comprehensive data on outcomes as well as costs across the entire care pathway to underpin any efficiency effort and guide decisions. Without these data, it is impossible to identify what works and what does not, or to track any deficiencies in care to their root causes.

Low availability of reliable outcomes data, however, poses a particular challenge. Patient-relevant outcomes data, focused for example on a patient's return to normal functioning or freedom from complications, are usually not systematically recorded in clinical practice. Instead, more readily available process or transactional measures, such as the number of procedures performed, latest results or waiting times, are used to assess performance.[41]

'Unfortunately, the patient perspective is rarely central to the way we deliver, plan or evaluate cancer care.'

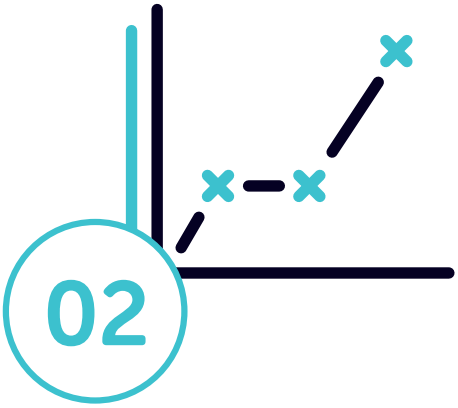
Bettina Ryll,
Melanoma Patient Network Europe

Poor availability of these data is partly linked to the fact that our healthcare information systems were not designed to collect comprehensive cost and outcomes data across the entire care pathway. Isolated budgets, fragmented information systems and lack of uniform electronic patient records, among other hindering factors, often make comprehensive collection of these data difficult (see **Section 5**).[41]

'We talk about focusing resources on delivering what matters most to patients. But too often, we don't have the data available to really scrutinise the impact of given interventions or practices on patients across the entire cancer care pathway, and our efforts collapse into short-term cost-containment as a result.'

Vivek Muthu,
Marivek Health Consulting

However, without meaningful patient-relevant outcomes data, we end up making decisions based on what limited and blunt measures are available, not necessarily what is important to patients.[41] What's more, if collected measures do not reflect what matters most to patients, improvement efforts targeting these measures are likely to have little impact on improving patient outcomes. In fact, ill-targeted efforts may have unintended adverse consequences on patients.



Data creating a cycle of continuous improvement

Systematic and holistic reporting of data is vital to create a cycle of continuous improvement and drive accountability across the entire care pathway.

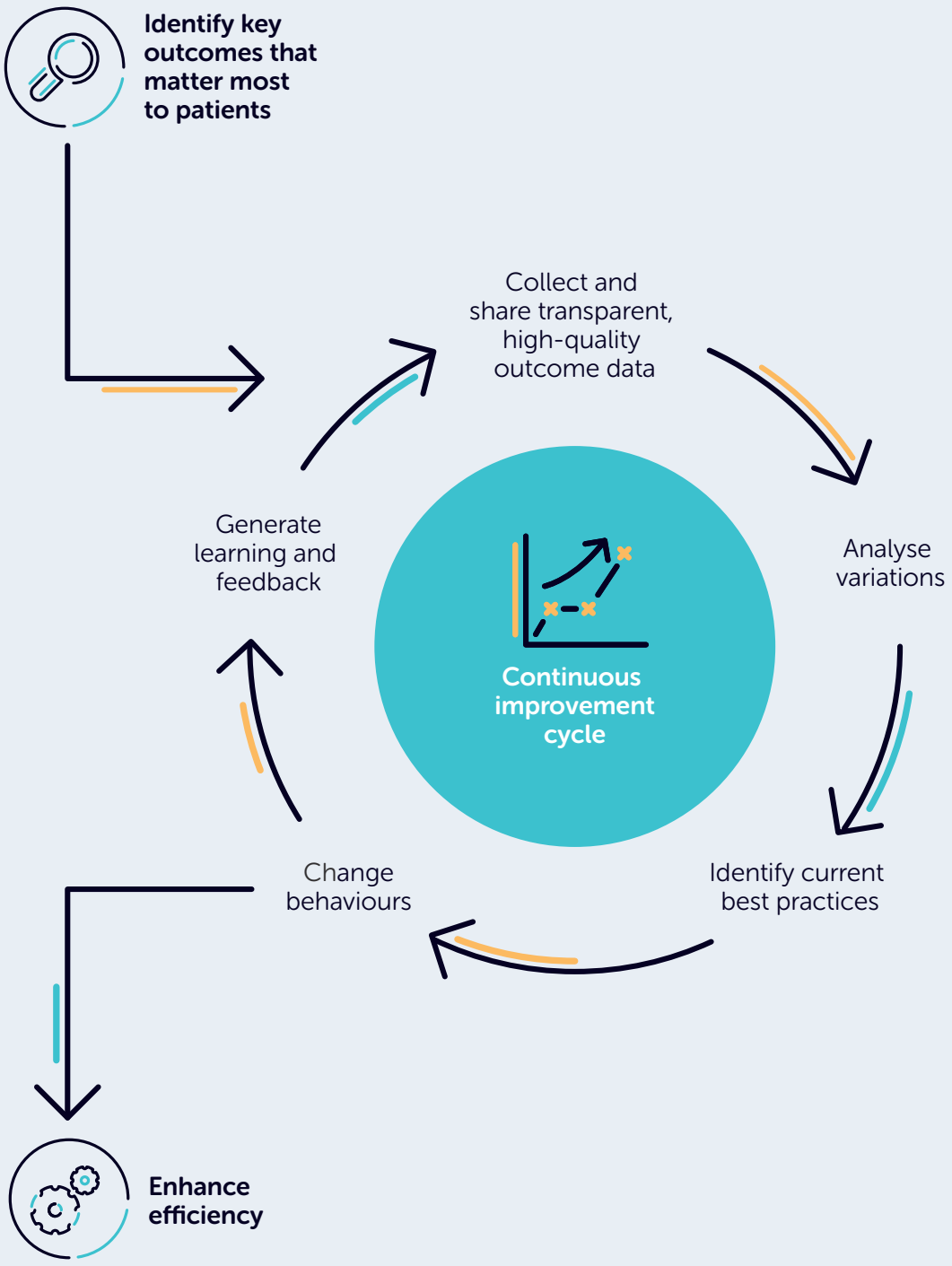
As was illustrated in the PROCHE example previously cited, data should drive efforts to improve efficiency. Transparent data collection enables a cycle of continuous improvement and a constant refocus of resources to deliver what matters most to patients.

First, we should collect data on actual use of care, map the variation in care patterns and compare against patient-relevant outcomes data.

Second, we can identify current best practices in cancer care providing most value to patients, by cancer type and other individual patient characteristics. We can then change the way we provide care, and continuously enhance its efficiency.

This is illustrated in **Figure 2**.

Figure 2. Data driving improved health outcomes within existing resources[43]



Adapted from Soderlund et al. 2012[43]

A prominent example of putting this cycle of continuous improvement into practice is the Martini prostate cancer clinic in Germany (see Box 3).

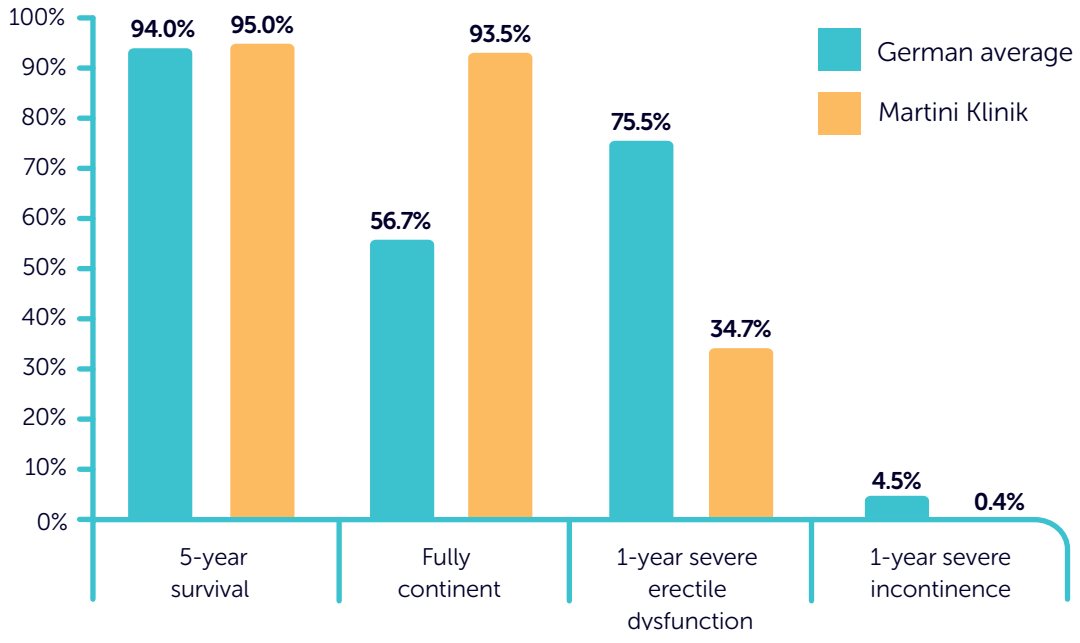
Box 3. Data driving continuous improvement in prostate cancer: The Martini Klinik in Germany[44,45]

Typically, prostate specific antigen (PSA) levels are used as a primary measure of the impact of surgery for prostate cancer – whereas outcomes such as rates of incontinence or erectile dysfunction are less often collected.

The Martini Klinik Centre of Excellence in Prostate Cancer in Hamburg recognised this gap. The clinic started engaging prostate cancer patients in defining the most meaningful outcomes from prostate cancer surgery. This effort led to the systematic collection of patient-relevant outcomes – including rates of incontinence and erectile dysfunction for every surgery performed within the clinic. Data analysis results are fed back to the care team, so that they can continually assess and improve their own performance. All data are also integrated into a web-based information system open to public viewing. This helps other prostate cancer patients understand the potential impact of different care options and actively engage with their physicians about the outcomes they can expect.

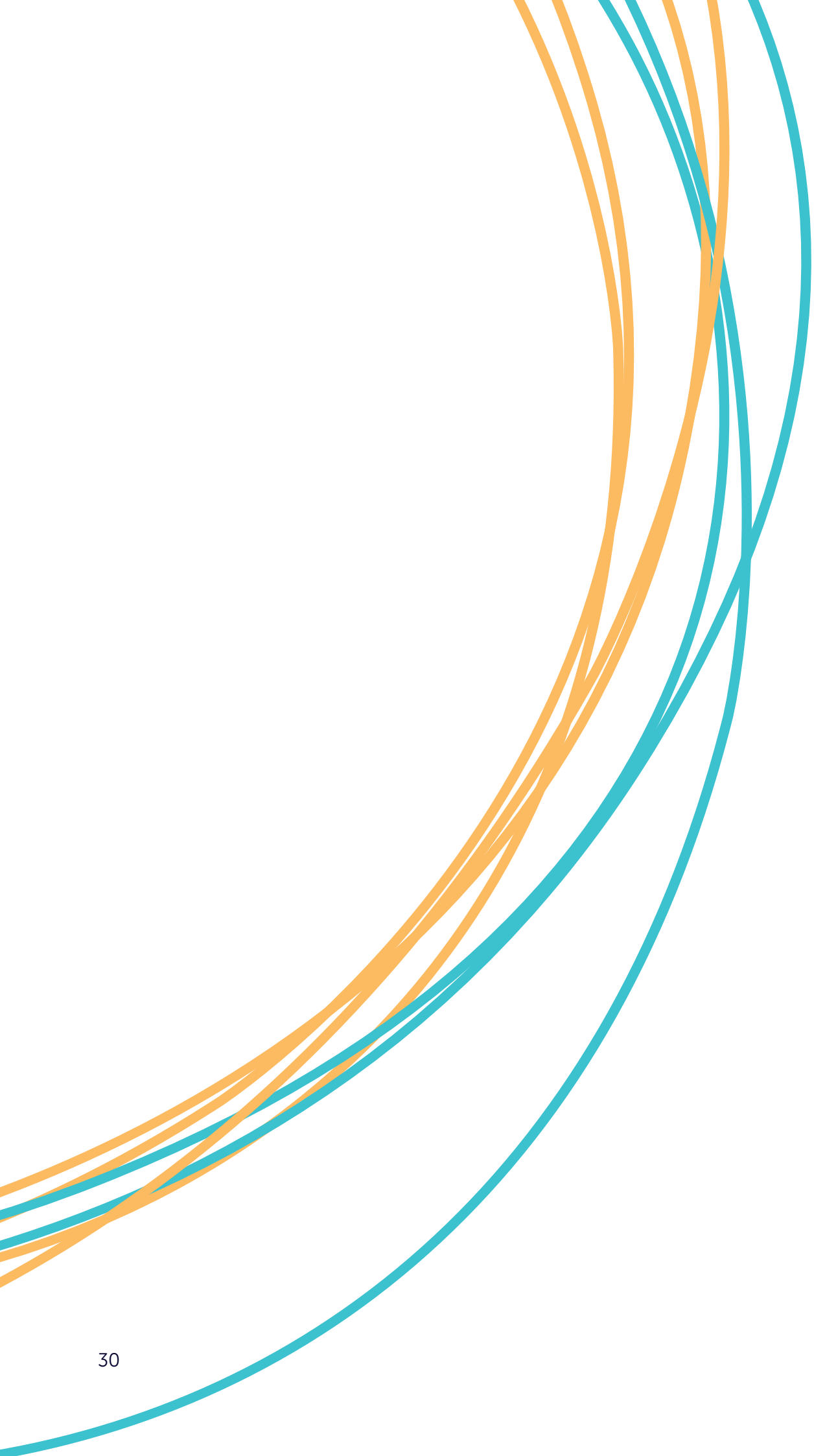
The clinic's survival rates are similar to other providers in Germany; however, its performance on other patient-relevant outcomes is well above the national average – as illustrated in **Figure 3** below.

Figure 3: Patient outcomes: German average vs. Martini Klinik[44,45]



In summary, driving efficiency is not a cost-cutting exercise. It is about finding adaptive ways to eliminate wasteful and ineffective practices, thereby improving outcomes for patients and making the best use of resources available.

This requires the collection and analysis of comprehensive cost and outcomes data. These data may then be used to drive continuous improvement and strengthen accountability across the entire cancer pathway.



Section 03
Improving efficiency in cancer care: opportunities for change

Defining inefficiencies requires a look across the entire spectrum of cancer care to try to identify practices, interventions or processes that do not provide meaningful benefits for patients with the resources used. This is no small task – as inefficiencies may occur at the system, institutional or individual level – and at every step along the cancer care pathway.

Invariably, strategies to improve efficiency will involve some level of judgment, and prioritisation, as to where efforts are most needed and can have the greatest impact.

Identifying and correcting inefficiencies: where do we start?

The most common understanding of inefficiency is in terms of medical overuse, or 'care in the absence of a clear medical basis for use or when the benefit of therapy does not outweigh risks.'[46] This definition was the basis for the Choosing Wisely campaign, which aims to promote patient-physician conversations to avoid medical tests and procedures that provide no clinical value to patients, and eliminate inefficient practices as a result.[47]

Through the campaign, leading professional societies from the US,[47-51] Canada,[52] Australia,[53] the UK[54] and Germany[55] have published lists of practices that should be removed from clinical practice. These practices are either inefficient, obsolete, offer little or no clinical benefit to patients, or are even potentially harmful (see **Box 4**).

Box 4. Creating 'do not do' lists for cancer care – the Choosing Wisely campaign

The Choosing Wisely campaign[48,49,52-54] was launched in 2009 by the American Board of Internal Medicine in the United States in efforts to reduce waste and avoid risks associated with unnecessary treatment.

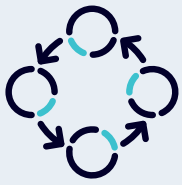
Since 2011, the American Society of Clinical Oncology (ASCO) applied the Choosing Wisely campaign to cancer care,[50,51] and many other cancer-related professional societies in the US[48,49] have followed suit. The campaign has also been adopted in Canada,[52] Australia,[53] the UK[54] and Germany[55] – although it is not specific to oncology.

A consolidated list of approaches deemed 'inefficient' in cancer care by existing Choosing Wisely campaigns is provided in **Appendix 1**.

A whole-system view on inefficiencies

The Choosing Wisely campaign focuses on specific inefficient practices across cancer care. A broader perspective on inefficiencies may involve thinking of those that may be potentially occurring at the level of the system, care setting (e.g. primary care practice or hospital), or individual. Some examples of potential inefficiencies at each level are featured in **Table 1**.

Table 1: Levels of inefficiency and selected examples

Level of inefficiency[56]	*Examples of possible inefficiencies*
 System	• perverse incentives for healthcare providers • suboptimal mix between private and public funding • mismatch of personnel skills to patient needs • inadequate provision of primary care and prevention • regional variations in quality or access to care[7]
 Institution	• unnecessary use of expensive technologies and care • insufficient data collection and optimisation of IT • uni-disciplinary (as opposed to multidisciplinary) care decisions
 Individual	• poor doctor–patient communication, leading to unclear treatment goals • low adherence to medication • overtreatment and undertreatment • poor support for caregivers • missed appointments • duplication or use of redundant interventions • medication errors

In addition, judging efficiency requires us to ask different questions depending on whether one is looking at screening, diagnosis, treatment or follow-up care.

For example, screening programmes may be considered efficient if they help reach populations at highest risk of cancer, enable earlier diagnosis and improve outcomes. Follow-up care may be considered efficient if it helps prevent complications from treatment and helps patients adapt to living beyond the phase of active treatment (**Figure 4**).

This section presents a number of case studies that illustrate where inefficiencies exist and where efficiencies may be gained – with positive examples of implementation.

These examples have been drawn from the published literature, and are by no means meant to be either exhaustive or representative of all potential inefficiencies across the cancer care spectrum, or proposed solutions to address them.

Instead, they are intended as a starting point for further exploration, and illustrate the tremendous potential and scope for greater efficiency across cancer care.

Two transversal themes are then explored in subsequent sections: person-centred care and the potential for personalised care (see **Section 4**), and the role of data in improving efficiency (see **Section 5**).

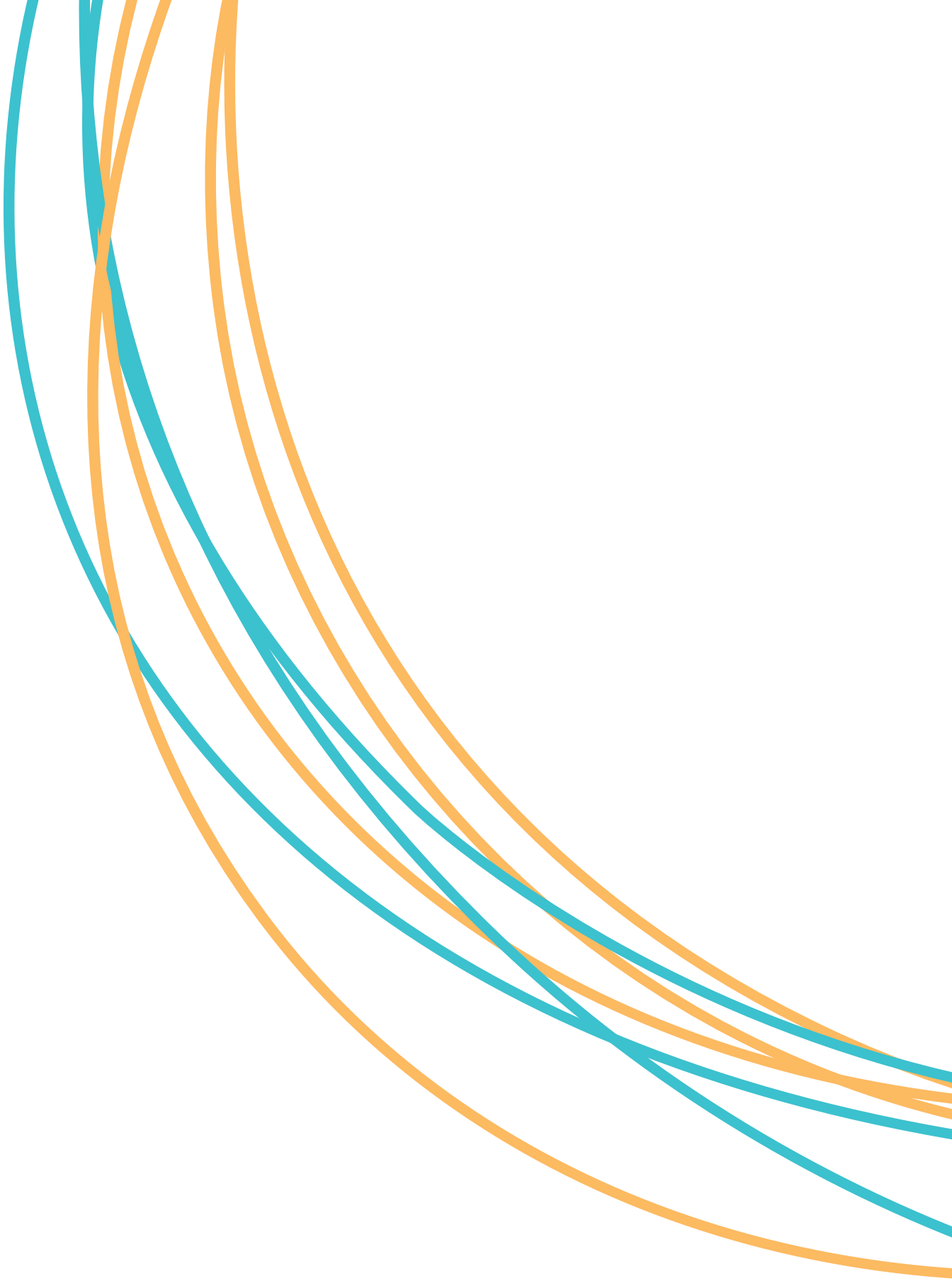
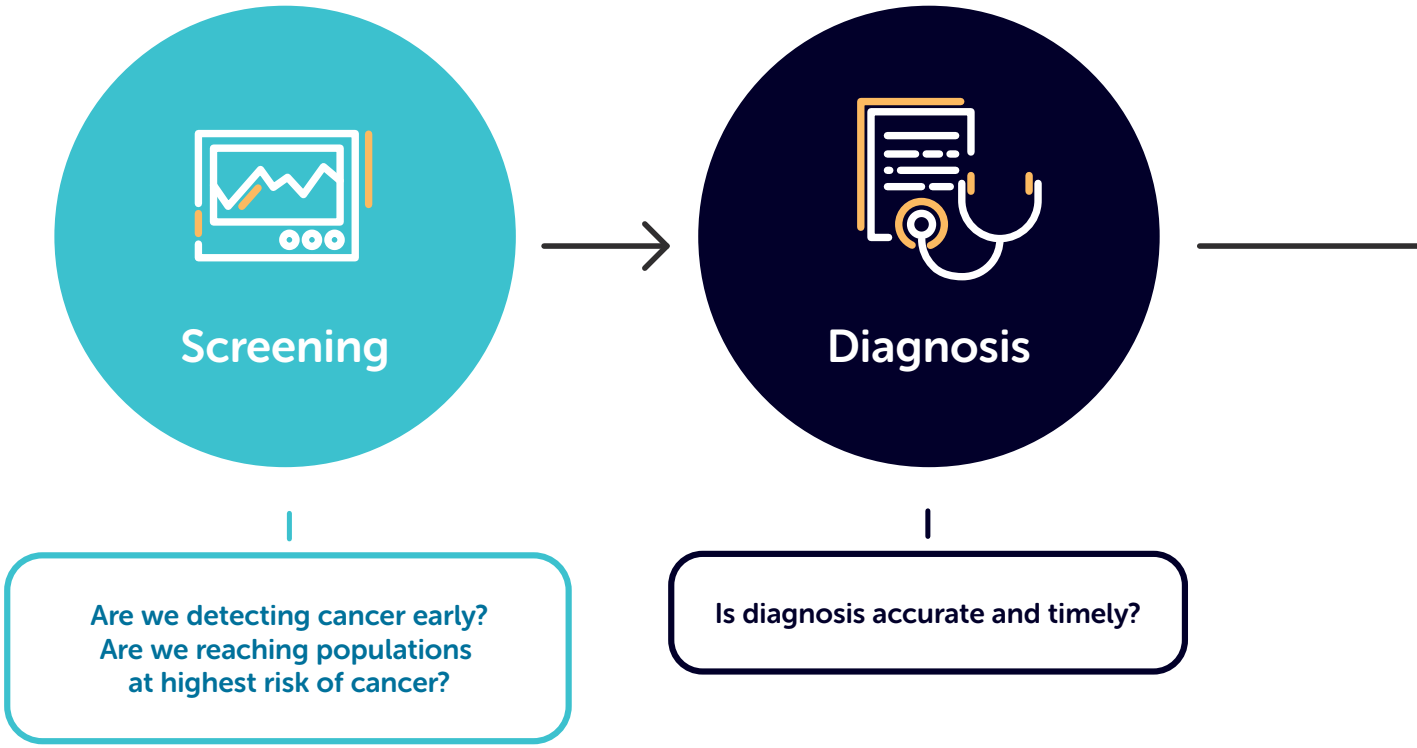


Figure 4: A framework for improving the efficiency of cancer care

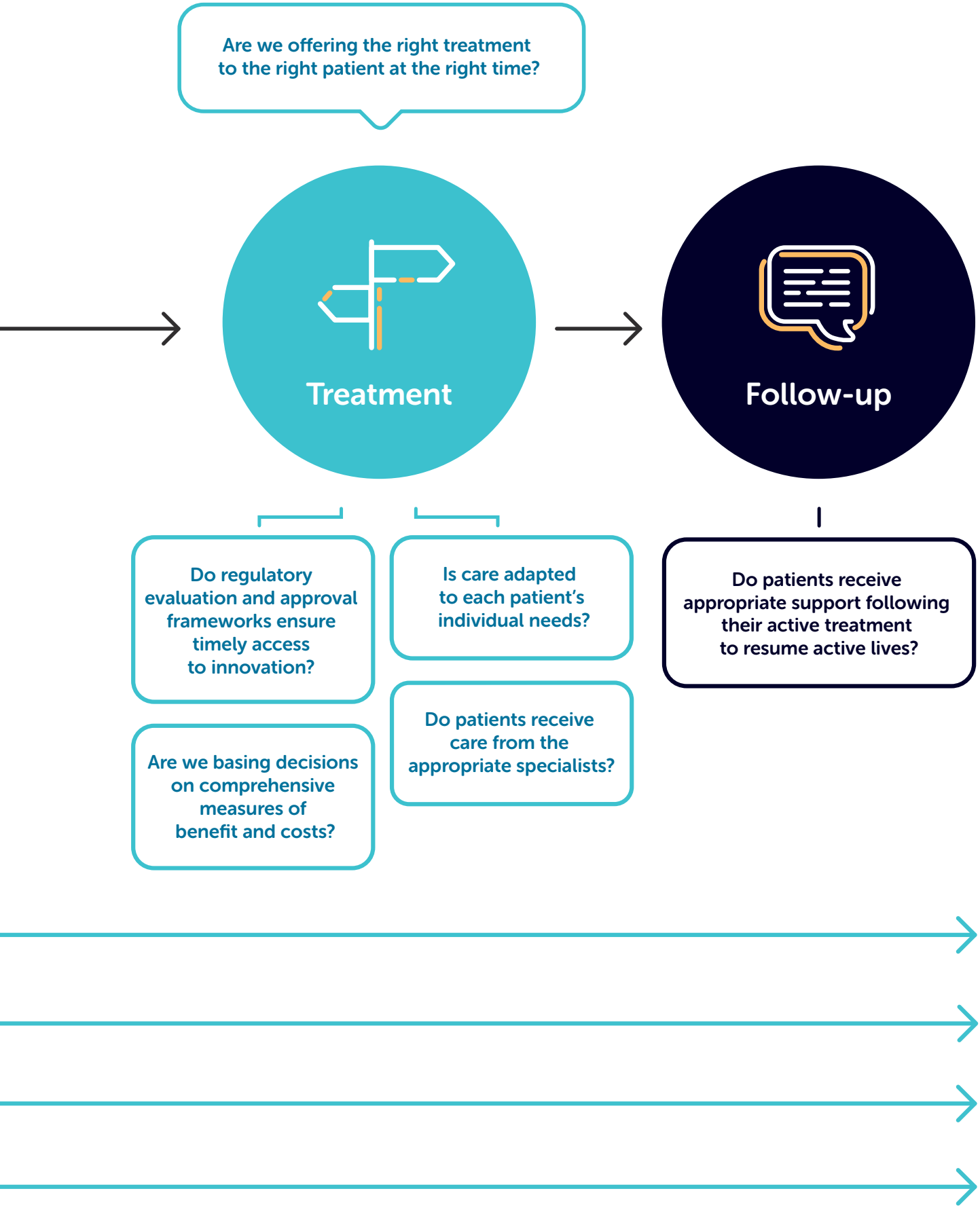


Are we placing patients at the heart of all decisions?

Are we providing seamless, well-coordinated multidisciplinary care?

Do we measure and understand the impact of given interventions on costs and outcomes?

Are there system-wide accountability mechanisms for outcomes?


Are we offering the right treatment to the right patient at the right time?
Treatment
Follow-up
Do regulatory evaluation and approval frameworks ensure timely access to innovation?
Is care adapted to each patient's individual needs?
Do patients receive appropriate support following their active treatment to resume active lives?
Are we basing decisions on comprehensive measures of benefit and costs?
Do patients receive care from the appropriate specialists?

Workforce planning

Is the current healthcare provider skill mix most able to meet the needs of cancer patients over the course of their care? Is there continuity of care? Are we avoiding duplication?

The need for a multidisciplinary approach has been broadly recognised as being critical to improving standards throughout the entire cancer care pathway.[29,57,58] However, it is not applied systematically, often due to lack of available personnel or remuneration for involved clinicians. This represents a clear missed opportunity to improve patient care (see **Box 5**).

Cancer nurse specialists (CNS) play a key role within the multidisciplinary team. CNS provide vital support to patients and their families, ensuring continuity of care and avoiding unnecessary hospitalisations for patients. CNS may also help free up time for oncology specialists, therefore speeding up care pathways and allowing for more patients to be seen.[59] Yet despite this, a number of countries still do not have formalised specialist oncology nurse roles, although steps to change this are being made by the European Oncology Nursing Society.[60]

Box 5: Multidisciplinary care – unfulfilled potential

Despite being recommended in many policies and guidelines, multidisciplinary team (MDT) models may not be fully implemented due to funding and resource shortages. Physicians, for example, are often not remunerated for the time they spend on the MDT. In many countries, the roles needed to offer patients the psychosocial and non-clinical support simply do not exist, or are inadequately funded in hospitals.

Recognising this issue, health insurance companies in Switzerland, for example, have introduced a special reimbursement tariff to ensure health professionals are paid for their input into MDTs.

In Belgium, the government offers specific financing for roles such as oncology nurses, onco-psychologists, social workers and data managers to encourage an MDT approach in cancer centres. The funding to provide this extra manpower is explicitly foreseen in the Belgian national cancer plan.[61]

Screening

Are we decreasing the number of cancers diagnosed at a late stage? Are we reaching high-risk populations? Are we avoiding over-diagnosis?

Cancer screening – particularly in prostate,[62–64] breast[65] and cervical[66] cancer – may help detect cancer at an early stage. Yet an unintended consequence of increased cancer screening rates over the past few decades has been over-diagnosis (false positives and over-investigation). This leads to overtreatment of low-risk cancers, which would otherwise not have developed into a serious health problem for patients.[67–70]

Over-treatment not only represents an inefficient use of health resources, but it may also produce long-term physical and psychological side effects for patients. In the case of prostate cancer, this can include erectile dysfunction and incontinence from repeated biopsy or unnecessary surgical interventions.[71] Active surveillance programmes have been introduced as a means of countering the risk of over-treatment in prostate cancer (see **Box 6**).

Box 6. Reducing the risks of overtreatment from population screening – active surveillance for men with low-risk prostate cancer

Active surveillance has emerged as an effective way of managing the care of men diagnosed with low-risk prostate cancer.[71]

It uses regular prostate-specific antigen tests and prostate biopsies to monitor patients, and switches them onto active treatment when the monitoring data indicate that it is needed.

The biggest study on active surveillance of low-risk prostate cancer is the Prostate Cancer Research International Active Surveillance (PRIAS) project. Implemented since 2006, it has encouraged doctors in 17 countries to keep low-risk prostate cancer patients under active surveillance and avoid starting unnecessary active treatment. The PRIAS pilot study (2012),[63] secondary evaluation with an expanded patient pool (2013),[64] and the 10-year follow-up study (2016),[62] all show that active surveillance is a safe treatment option for men with low-risk prostate cancer. One issue for patients, however, is discomfort due to repeated biopsies. Ways to safely reduce the need for repeated biopsies are therefore currently being explored.[72]

Diagnosis

Is diagnosis accurate and timely? Is it identifying patients with cancer correctly and referring them to appropriate treatment?

Diagnosis is intended to correctly identify people who have cancer, with the aim of directing patients in a timely fashion towards the most appropriate and effective care pathways possible.[73] However, misdiagnosis or late diagnosis is a common problem with many cancers. This may lead to delays in treatment, poorer outcomes and higher costs.[74] For example, the costs of managing a case of breast cancer diagnosed at the most advanced (metastatic) stage are over twice those of managing a case detected at early stages, and the chances of five year survival are four times lower.[75]

In Denmark and the UK, general practitioners (GPs) play a gatekeeper role to specialist care and are therefore the first point of contact for any patient presenting with possible symptoms. It was found that restrictive referral patterns for patients with cancer previously recommended to GPs exacerbated the risk of later diagnosis. Both countries therefore designed strategies to expedite suspected cancer patients into diagnostic pathways (see **Box 7**).

Box 7. Avoiding late diagnosis — early referral pathways in Denmark and the UK

Cancer patients may present with typical symptoms at early stages of their condition, which general practitioners (GPs) may not often pick up, potentially leading to late diagnosis.

The Danish early referral pathway was set up in 2012 to allow GPs to refer patients with serious and non-specific symptoms and signs of cancer for early specialist diagnosis, in addition to those with predefined specific alarm symptoms of cancer.[76] In the year following implementation, 16.2% of the patients referred through the new criteria were found to have cancer.[77]

Similarly, in the UK, Macmillan Cancer Support pointed out the problem of late diagnosis in the UK in its report, Cancer in the UK 2014.[78] In response, the National Institute for Health and Care Excellence (NICE) expanded its early referral criteria for adults,[79] children and young adults,[80] to include 'non-specific features of cancer' for urgent referrals to ensure timely diagnosis.

Specialising care

Do patients receive care from the appropriate specialists? Are appropriate accreditation systems, professional training and care pathways in place to ensure that patients are treated in centres with sufficient expertise?

As was mentioned previously, established care pathways may facilitate appropriate and timely referral for patients with cancer. In addition, there is ample evidence demonstrating that the centralisation of cancer care into specialist centres of excellence improves outcomes for patients.[81]

The importance of specialist diagnosis and treatment is particularly acute in the case of rare cancers, which represent 22% of all new diagnoses of cancer in Europe.[82] Patients often face many challenges finding healthcare practitioners with the necessary expertise to treat their cancer if it is rare. A significant number of cases are misdiagnosed, often resulting in errors in initial treatment. This leads to compromised outcomes and inappropriate use of existing resources.[82]

In light of this, Rare Cancers Europe (RCE) has recommended that rare cancers be treated within designated centres of expertise. The implementation of the European Reference Networks (ERNs) is a positive development in this regard (see **Box 8**).

Box 8. Building of expertise in specific cancers: European Reference Networks

The European Reference Networks (ERNs) aim to promote pan-European collaboration to achieve more efficient therapy management for rare diseases including rare cancers. The initiative aims, for example, to promote exchange of diagnostic materials[20,81] and information,[19,20,83,85] develop high-quality laboratory[85] guidelines, improve real-world data collection[19,29,83,85] and create training and education tools for health professionals.[85]

Since 2013, the European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment (ExPO-r-NeT) has been delivering highly specialised paediatric cancer care by pooling expert knowledge and facilitating fluid health information exchange. It has allowed paediatric cancer experts to work much more closely than ever before, and continues to fight inequalities in childhood cancer survival across Europe.[86,87]

The launch of the EU Joint Action on Rare Cancers[88] in November 2016 is expected to further strengthen collaboration and expansion of ERNs in several cancers. A range of partners from major European scientific societies, patient advocacy organisations and medical institutions are already working on the development of ERNs in rare adult solid cancers, blood disease and paediatric cancers.

Follow-up care

Do patients receive appropriate support following their active treatment, enabling them to resume active lives? Is appropriate support given to them to self-manage their condition as needed and avoid unnecessary admissions to hospital?

Advances in diagnosis and treatment have transformed cancer care into a chronic condition for many patients, leading to a growing population of cancer 'survivors'. These patients require long-term monitoring and follow-up care beyond the so-called active treatment phase, whilst also adjusting to living with cancer, not just physically but also in terms of returning to work and everyday life.[89] Yet patients often lack a clear point of contact in primary care in case of any post-treatment issues, which may lead to avoidable hospitalisations, not to mention significant distress for patients (see **Box 9**).

A further issue with follow-up is that many patients are subject to unnecessary imaging and tests.[90] Web-based platforms that tailor the need for tests to individual data may represent an efficient way of providing patients with follow-up care (see **Box 10**).

Box 9. The need for appropriate follow-up care for cancer patients

A 2015 report from the UK found that supporting people with cancer beyond their initial treatment costs the NHS at least £1.4 billion per year, excluding end-of-life care. At least £130 million of this sum is spent on inpatient hospital care. Instead, patients should be receiving long-term support and management in a community setting, which may have prevented the need for emergency hospital admissions. Investing in appropriate follow-up care for cancer patients through personalised care planning may result in savings of £420 million per year.[91]

Box 10. Exploiting the potential of web-based approaches to provide follow-up care for lung cancer patients

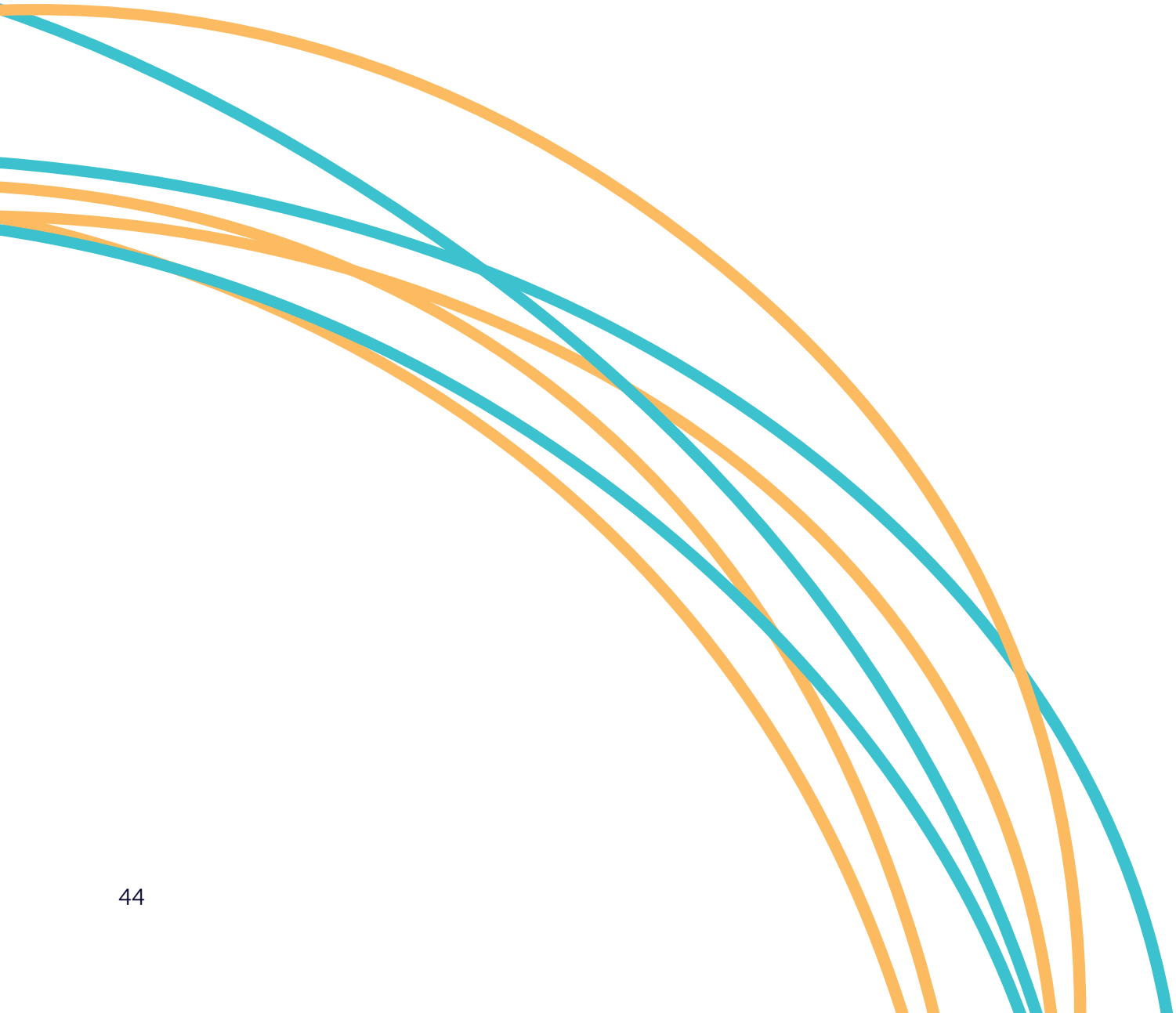
A recent clinical trial found that patients with late stage lung cancer using a web application follow-up system had longer survival and better quality of life than patients receiving standard imaging tests as part of their follow-up. The study took place in the US, France and other European countries.

Patients using the web-based follow-up system submitted self-reported symptoms weekly, either on their own or through their caregivers. The application analysed these symptoms using an algorithm to determine which patients needed to be called in for imaging tests. By comparison, 'usual care' patients were subject to standard tests following a fixed schedule, exposing them to potentially unnecessary radiation and possibly unnecessary costs.

The trial was stopped because of the huge survival difference in lung cancer patients shown early in the trial: 75% for those who received care based on the weekly web-application follow-up system compared to 49% for those who received standard care. Web-application users also reported a higher quality of life because they only had to receive tests when deemed necessary.[92]

Section 04

Tailoring cancer care to individual patient needs: a building block to efficient cancer care



Any effort to improve efficiency must start with an understanding of what outcomes are most important to patients – and then direct resources towards achieving these. It follows that the views of patients and caregivers, or their representatives, should be taken into consideration and be the foundation of how we plan, evaluate and deliver cancer care – creating the basis for a person-centred, and whole-person, approach to cancer care.

At an individual patient level, this means tailoring care around patients' individual needs. It also means trying to always optimise outcomes for each individual patient, ideally finding **'the right treatment for the right patient at the right time'** – the notion of personalised care. We will address each of these in turn.

Person-centred care

Listening to patients is critical. Care decisions should be based not just on patients' clinical needs, but also their psychological and emotional needs as well.

This has implications at the individual patient level, but also in the overarching planning of cancer care services, where patient organisations may provide a critical perspective on where the greatest unmet needs may lie.

As was illustrated by the PROCHE programme described earlier in this report, listening to patients and adapting care delivery to their individual needs may not only result in better outcomes, but may also improve efficiency. Patient needs are not just clinical, but also psychological and emotional.[93] A telling example of this may be found in the case of paediatric imaging – which also proves that often, it is small and inexpensive things that can make the most difference to patients, and achieve the greatest results (see **Box 11**).

Box 11. Adapting care to paediatric patients – patient-centred innovation in imaging

Many children find the experience of undergoing imaging tests, such as MRI, frightening. The intimidating, cold, grey machines with loud noises only add to the anxiety from already being ill. Up to 80% of paediatric patients must be sedated to carry out these tests. If an anaesthesiologist is unavailable to provide sedation, the scan must be rescheduled – creating anxiety for the child and his or her family all over again.

To address this situation, GE Healthcare re-designed their imaging machines by painting them in enjoyable themes such as a rocket ship or pirate adventure. This low-tech innovation helped improve paediatric patients' perception of the imaging tests drastically from something terrifying into an adventure. The number of children needing sedation dropped, more patients could be scanned per day and overall patient satisfaction scores went up by 90%.[94]

Another area where the notion of person-centred or a 'whole-patient' care is critical is palliative care. Palliative care is a holistic approach to care which aims to prevent and relieve the physical and emotional pain associated with life-threatening illness for patients and their caregivers.[95] Palliative care has been shown to have considerable benefits for patients and their caregivers in terms of quality of life.[96]

Traditionally, palliative care is considered to be part of end-of-life care and its availability varies considerably between countries. However, it is increasingly recommended to introduce it early as an integral part of the care of patients with advanced stage cancers to provide symptom relief and management beyond the end-of-life care concept.[97] This has significant benefits for patients and may also offer potential economic advantages (see **Box 12**).

Box 12. Early palliative care – Improved patient outcomes and reduced costs to the system

A randomised trial for lung cancer patients with a heavy burden of symptoms[98] found that those who received early and scheduled palliative care with standard cancer care reported **higher quality of life, improved mood and longer survival periods** despite having less aggressive treatment than those who only received late and sporadic palliative care with standard oncologic care. Although no economic analysis was conducted within this trial, analyses of it have found that palliative care is usually found to be less costly compared to conventional care, particularly in terms of inpatient care.[99,100]

'Patients are deeply concerned about efficiency – and know exactly where their care is inefficient and wasteful. Their views must not only be respected and heard, but translated into action.'

Gilliosa Spurrier,
Melanoma Patient Network Europe

Personalised care: providing the right treatment to the right patient at the right time

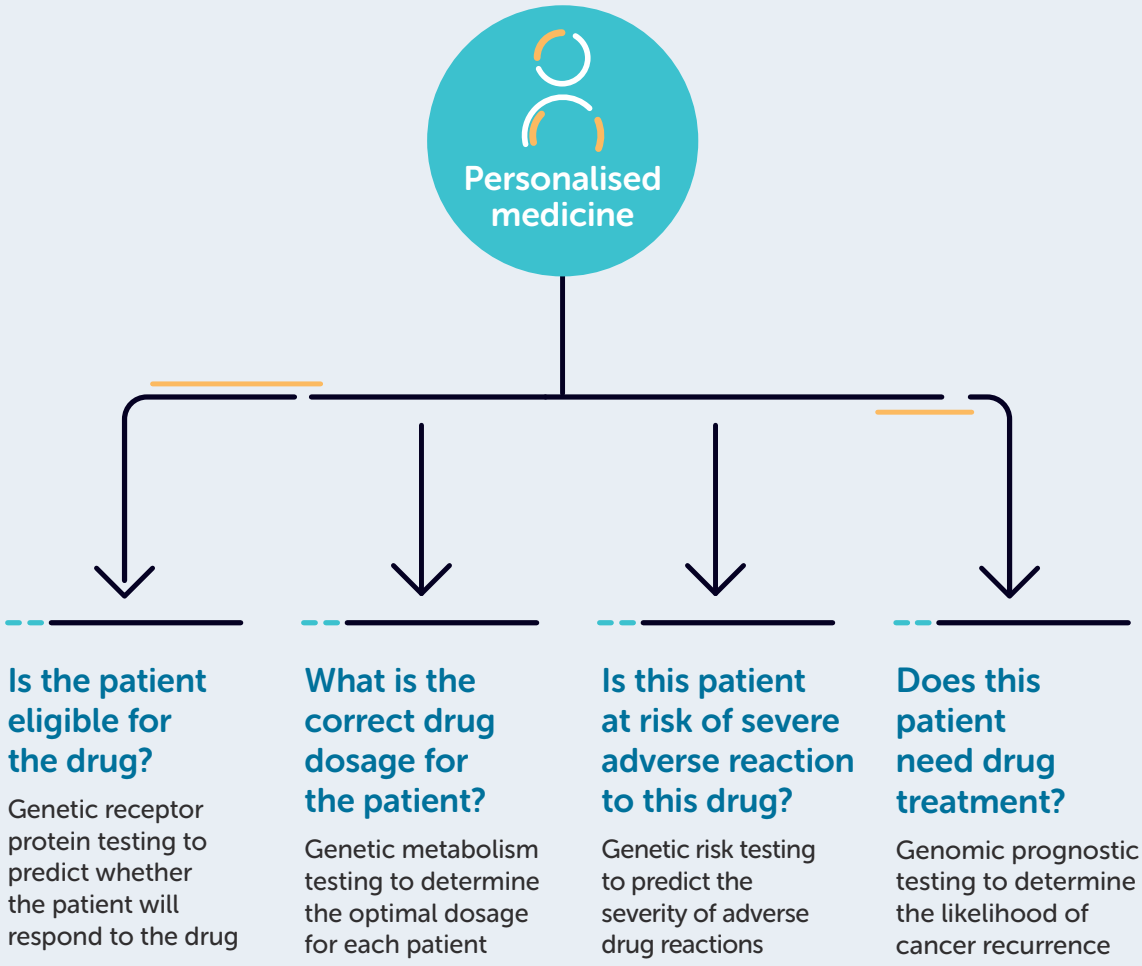
‘With advances in our understanding of the genetic profile of cancers, physicians will, one day, be able to prescribe the most appropriate treatment, at the best dose, corresponding to each individual patient’s genetic profile. We are not there yet – but we should always try to make sure that we are limiting the use of ineffective drugs in patients and reducing avoidable toxicity.’

Professor Thomas Szucs, University of Basel

The past decade has seen incredible advances in our ability to characterise the genetic and biological profile of individual cancers, including identification and understanding of key tumour receptors and pathways modulating the immune system. This has led to the development of new therapies directly targeting these new tumour markers. We now have a better understanding of the interplay between how cancers develop and how they kill normal cells; how cancer cells interact with their microenvironment and the critical role of the immune system in these pathways.

In parallel, the field of diagnostics has grown considerably, offering considerable potential to identify the most appropriate treatment for patients based on given genetic and clinical factors. Ultimately, this is leading to an increased potential for effective and safe treatments to be given to each patient. The growing potential of diagnostics to help us tailor treatment to individual characteristics is illustrated in **Figure 5**.

Figure 5. Ways in which one may personalise treatment



Adapted from Hogarth 2016[101]

Despite the excitement surrounding its potential, it is important to recognise that the science of 'personalised medicine' is still evolving. Individualising treatment is not always possible, nor are decisions straightforward. The presence or absence of a given biomarker may be an important consideration in guiding treatment decisions, but it may not be the only consideration.

The role of patients and citizens – their ability to understand, process and act on health information ('health literacy') – becomes even more important with personalised care. It is a precondition for finding the right treatment for the right patient, and ensuring that physicians and patients take treatment decisions together to reflect a patient's personal preferences and objectives.

All key stakeholders should work together to ensure the appropriate organisational and testing infrastructure is in place to support the effective application of current and future scientific and technological advances. Important steps should include:

1) **Defining and ensuring standards** for the testing of biomarkers and diagnostic accuracy to minimise the number of false positives and false negatives (i.e. optimise the predictive ability of biomarkers and other predictive tests), as the application of personalised medicine can incur substantial costs.[102]

2) **Encouraging clinical studies** to ensure that the use of a personalised approach results in better outcomes for patients, with acceptable toxicity.[102]

3) **Centralising and streamlining research efforts through public-private partnerships** to eliminate unnecessary duplication in research[102] and help accelerate patient access to care and information as a result (e.g. the US Cancer Moonshot Initiative[103]).

Regulatory and reimbursement agencies also have an important role to play. They can ensure that the appropriate tests are reimbursed to enable physicians to put evidence-based guidelines into practice and to use personalised approaches as appropriately and efficiently as possible (see **Box 13**).

Box 13. Resolving regulatory incongruence – the need for alignment between regulatory and reimbursement policies on the use of personalised medicines

Current scientific techniques allow us to identify, in the case of some anticancer medicines, which patients may present a higher risk of toxicity than others based on a specific genetic mutation. If these data are available at the time of approval, regulatory authorities will often request that this risk be clearly specified in the prescribing information (or label) for the given medicine.

However, at the moment diagnostic tests undergo a different approval and reimbursement process than their 'companion' medicines.

What may also occur is that a given medicine is reimbursed, but its companion diagnostic is not – or vice versa. As a result, physicians may not be able to obtain the necessary information to select patients who are most likely to benefit from a given medicine, and medicines for which an effective diagnostic exists may be given to patients without knowing if they are most likely to respond.[104]

The new in-vitro diagnostics regulation that is being put into place will hopefully resolve some of these issues, as tests that are required for medicines to work will be linked to similar approval pathways. The new regulation is expected to be implemented fully within five years.[105]

Section 05
The role of data in driving efficiency across cancer care

Reliable data on costs and outcomes are, as has been mentioned previously, the starting point for creating a continuous cycle of improvement focused on interventions that offer the greater potential efficiencies for patients and the system overall. Although ongoing challenges exist, the collection and exploitation of real-world data and advances in 'big data' analytics are likely to play a critical role in helping us understand what happens to patients across the whole cancer pathway, and in identifying potential areas of inefficiency or waste – as well as areas of potential efficiency.

We already collect a lot of information in healthcare administrative databases. Unfortunately, not all of these data are useful, and several mutually-reinforcing factors make it difficult to collect meaningful outcomes and cost data across the entire cancer care pathway[41] (see **Box 14**).

Box 14. Limitations to obtaining comprehensive data across the entire care pathway:

- **Care is decentralised** across different providers, with often separate databases using different templates for data collection. Within Europe, only three countries (Denmark, Finland and Sweden) have national health registries which allow the entire care pathway of patients to be traced across different conditions.[106]
- **Information (IT) systems are inadequate and fragmented.**[107] This is compounded in many countries by privacy restrictions on merging datasets; lack of uniform data collection practices;[106] heavy emphasis on tracking billing and reimbursement information; and difficulties in linking datasets based on a unique patient identifier in many healthcare systems.[108]
- **Patient data and hospital budgets are siloed.**[109,110] This encourages a short-term perspective on investment decisions and limited accountability across the entire care pathway. For example, it may not be possible to measure whether a given intervention has any impact on reducing length of hospital stays or readmissions down the line.
- **Data collection is often not a natural part of clinical workflow,** and we must make efforts to utilise user-centred design when creating real-world data collection systems, in order to avoid imposing additional burden on clinicians.[111]
- **Governance standards for data ownership, accessibility, and patient privacy are still in early development.**[112] In 2016, the European Union reformed the outdated General Data Protection Regulation[113] to promote international cooperation with higher standards of data security in the new era of big data.[114,115] The reformed General Data Protection Regulation now offers what is known as 'the right to explanation', which will come into effect in 2018. This stipulates that, when any entity makes an automated data-based decision regarding a person, the person has 'the right to obtain human intervention to express his or her point of view, to obtain an explanation of the decision reached after such assessment and to challenge the decision.'[113]

Notwithstanding these limitations, advances in data analytics have vastly increased our potential for using health data to identify what works and what does not.

These advances help us implement adaptive and meaningful changes across the healthcare system. Two critical developments are the collection of real-world data and the use of big data analytics.

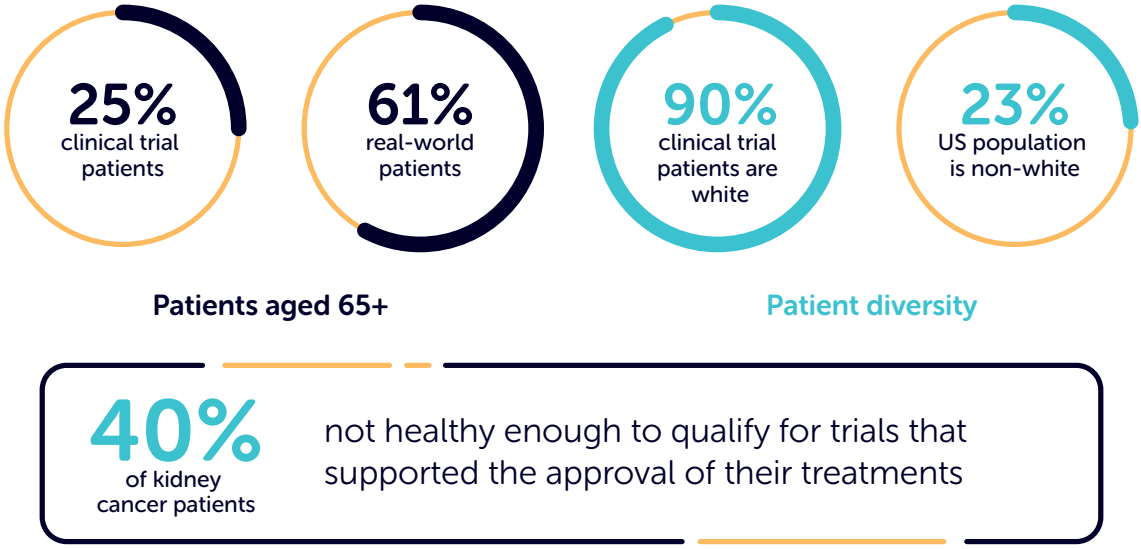
Real-world data

Real-world data refers to data generated outside of randomised clinical trials,[106] for example patient care records, disease registries, observational studies or registries to ensure medicines are used in accordance with their prescribed indication.[112] They offer a chance to observe and demonstrate how a given intervention, be it screening, diagnosis, a medicine or device, works in 'real life' settings with unselected patient populations.[106,116]

Real-world data are an important complement to clinical trial data, as patient populations included in clinical trials are often not representative of an entire cancer patient population, as they have to meet specific inclusion and exclusion criteria[117–119] (see **Figure 6**).

Figure 6. Differences between real-world patients and those often enrolled in clinical trials

Everyday patients tend to be older, less healthy, and more diverse than clinical trial patients.



Adapted from the American Society of Clinical Oncology 2016[118]

Real-world data are particularly important in the case of rare cancers, where small numbers of patients with any given rare cancer often make it challenging to conduct large-scale trials able to yield a strong evidence base on efficacy and safety.

For example, consolidating data from electronic records and collaboration between countries may allow collection of sufficiently large amounts of real-world data to help inform the management of rare cancers.[120]

The collection of real-world data has become increasingly important in the evaluation of new cancer medicines, as part of 'coverage with evidence' or outcomes-based reimbursement schemes.[106,116,121] Outcomes-based reimbursement allows patients to receive new interventions whilst data on their impact in clinical practice – outcomes and costs – is being collected. For payers, this creates the potential for a more flexible pricing environment. It lays the foundation for identifying and eliminating medicines that are not as effective as others based on real-world data collected over time. Similarly, it prioritises those that offer the greatest value to patients based on these data.[122] Real-world data may also be useful to re-evaluate older interventions over time, as new data may reveal that these options no longer represent 'best practice' for patients.

Despite their potential, it is important to recognise that many national outcomes-based reimbursement schemes are still in pilot phase because of technical, structural, financial and political barriers.[122] To overcome them, the ADAPT-SMART platform (Accelerated Development of Appropriate Patient Therapies: a Sustainable, Multi-stakeholder Approach from Research to Treatment-outcomes) provides a consensus framework for outcomes-based reimbursement. This project is part of Innovative Medicines Initiative 2 (IMI2).[123] The European Medicines Agency (EMA) recently launched the Medicines Adaptive Pathway to Patients (MAPP) based on the ADAPT-SMART platform to foster an outcomes-based approach to invest in innovation (see **Box 15**).

Box 15. The European Medicines Agency Medicines Adaptive Pathway to Patients: an outcomes-based approach to invest in innovation[124]

On 1 August 2016, the EMA launched the **Medicines Adaptive Pathway to Patients (MAPP**) to accelerate patient access to innovative therapies and decide further investment based on their outcomes. It builds on the ADAPT-SMART platform under the Innovative Medicines Initiative 2.

Drug development through MAPP initially targets a well-defined small group of patients, and allows the early introduction of promising medicines within this population, whilst gathering real-world data from existing disease registries or compassionate use programmes. Data are then collected in an iterative way both from real-world settings and clinical trials to decide whether to continue the initial licensing and to potentially expand the use of the drug to a wider group of patients. This complements EMA's parallel initiative to measure the real-world impact of medicines in order to encourage their safe and effective use.[125]

The EMA emphasises the importance of involving both patient representatives and health technology assessment (HTA) bodies to facilitate discussions during the adaptive processes. To ensure transparency, the EMA gives clear criteria for patient representatives[126] to invite to the discussion. The EMA calls for patient input in many areas: for example, whether the patient outcomes measured are relevant to patients, and whether new methods are needed to capture patient-relevant outcomes.

Big data analytics

Big data analytics is a field that is likely to transform our ability to scrutinise and improve the quality and efficiency of cancer care.

- Big data may be defined as: 'large amounts of different types of data produced with high velocity from a high number of various types of sources.'[127]
- Big data analytics refers to the systematic use of big data to make decisions.

We now have the computing power to simultaneously collect and analyse massive amounts of data from different settings of care to generate real-world evidence without delay. These analyses may then help inform the improved management of cancers[120] and drive efficiency across the entire cancer care pathway.[107,112]

Big data analytics can be descriptive, predictive or prescriptive.[128]

Big, real-world data can help describe pathways of care. Pooling data across different settings may help improve our understanding of the epidemiology and management of cancers and help drive more targeted and effective prevention efforts.

The development of registries[106] may serve this purpose – with important European initiatives such as the PARENT Joint Action,[129] the European Network of Cancer Registries[130] and EMA Initiatives on Patient Registries.[131,132]

At a national level, one country that has invested heavily in data registries is Sweden – it has over 90 disease registries covering approximately 25% of annual health expenditure (see **Box 16**). Another interesting example is the Systemic Anti-Cancer Therapy Dataset (SACT) launched in the UK in April 2012; an effort to analyse across different cancer care settings the use and outcomes for all patients receiving anti-cancer medicines (see **Box 17**).

Box 16. Sweden: harnessing the power of data analytics for improving treatment pathways

Sweden's 90 disease registries store vast amounts of outcomes information, with relevant clinical societies playing a key role in defining and refining the criteria for nationwide data to be collected and analysed.[133]

One such example is the Swedish Childhood Cancer Registry, which has existed since the 1970s; Sweden has the highest childhood cancer survival rate in Europe (80%) and this rate is consistent across the country.

The transparent reporting of outcomes data from registries to health professionals and the public has contributed to improved outcomes and greater efficiency, as the registry data allow health professionals to identify interventions or practices that yield the highest value.[39] Individual-level cancer registry data dating back from 1958[134] is available upon request for research purposes.[135]

Box 17. The Systemic Anti-Cancer Therapy Dataset (SACT): map every cancer patient pathway[136]

In attempts to integrate real-world evidence to improve cancer outcomes, the UK launched the **Systemic Anti-Cancer Therapy Dataset (SACT)** in April 2012. It requires mandatory reporting of cancer outcomes and prescribed treatment regimens from all NHS hospitals in England, and attempts to map a complete patient care pathway with the outcomes reported. Using descriptive analytics, the initial mortality outcomes study for breast and lung cancer was published in September 2016.

The study assessed the real-world factors influencing 30-day mortality for breast and lung cancer patients in 2014 to help refine clinical decision-making processes at the national level. It also allowed a transparent comparison of mortality outcomes among different hospitals.

The results should promote reviewing the current care delivery for those with higher mortality rates, and show the importance of collecting outcomes data beyond clinical trials.

Analysing large volumes of real-life data across the entire care pathway will allow us to predict how to deliver better and more efficient cancer care.[137-139]

For example, analysing big health data at the national level can help improve population health surveillance by predicting patient population risks with higher precision,[128] leading to much more targeted investment in prevention or screening programmes.[112]

Similarly, it may help identify populations who benefit most from screening interventions, and help adapt outreach efforts to optimise the impact of existing screening programmes. An example of predictive analytics applied to cancer care may be found in the CancerLinQ™ system created by the American Society of Clinical Oncology (ASCO) in the United States (see **Box 18** and **Figure 7**).

Box 18. American Society of Clinical Oncology (ASCO) CancerLinQ™: a data network driving the continuous cycle of learning for oncologists

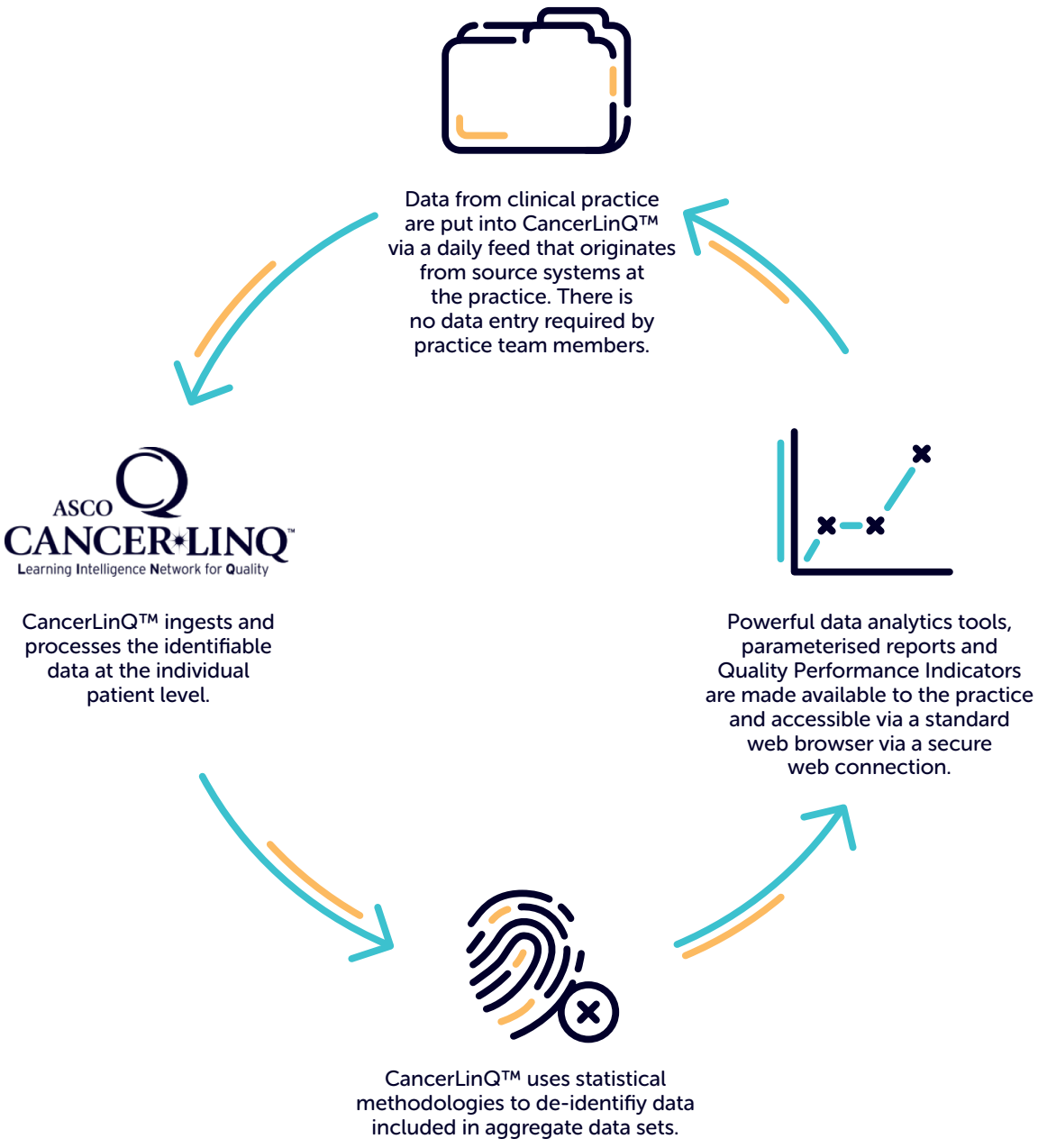
In June 2016, ASCO launched its big data initiative, **CancerLinQ™**.[140] Developed and led by doctors, CancerLinQ™ is a self-improving quality measurement and reporting system based on the daily feed and rapid analysis of unstructured clinical data, enriched with contextual information.[141] It aims to rapidly improve quality of care and patient outcomes using massive amounts of real-world patient data.

Currently, 58 oncology practices and 1,000 providers across the United States are collaborating to harness the power of 750,000 patient records and 40,000 leading oncologists.[140]

CancerLinQ™ will provide personalised insights for each patient by efficiently processing massive amounts of individual patient data and rapidly analysing complex trends. The real-time trend reports will be visually intuitive, present each patient's clinical event history, and continue to reflect up-to-date insights and findings.[118]

Figure 7. How CancerLinQ™ leverages big data analytics to drive cancer care quality improvement

CancerLinQ™ creates a continuous cycle of learning, beginning and ending with the patient.



Adapted from the American Society of Clinical Oncology 2016[118]

Finally, prescriptive analytics have the potential to transform cancer care from the current state of reactive care to predictive and preventive care.[112,142]

Healthcare providers can now prescribe highly personalised care plans with minimal side effects by comparing each patient, in real time, with many other patients with similar characteristics and medical history.[118,138]

Insights gained from analysing real-world data can also inform the redesign of care structures to achieve the most optimal patient outcomes with better resource allocation at a larger scale.[112,121]

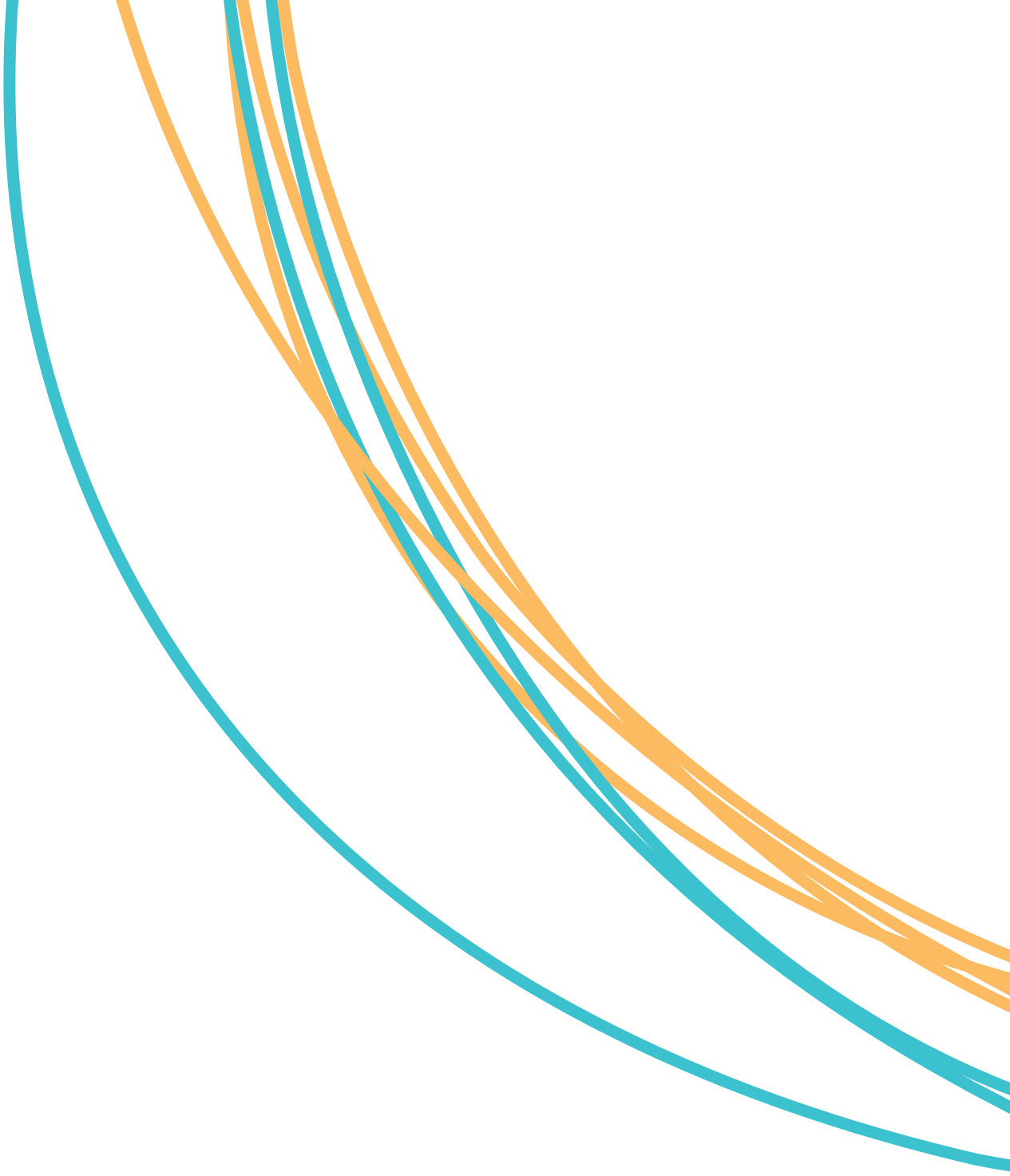
For example, providers already analyse large-volume patient health records to plan for patients who may need more intensive care than their peers.[85]

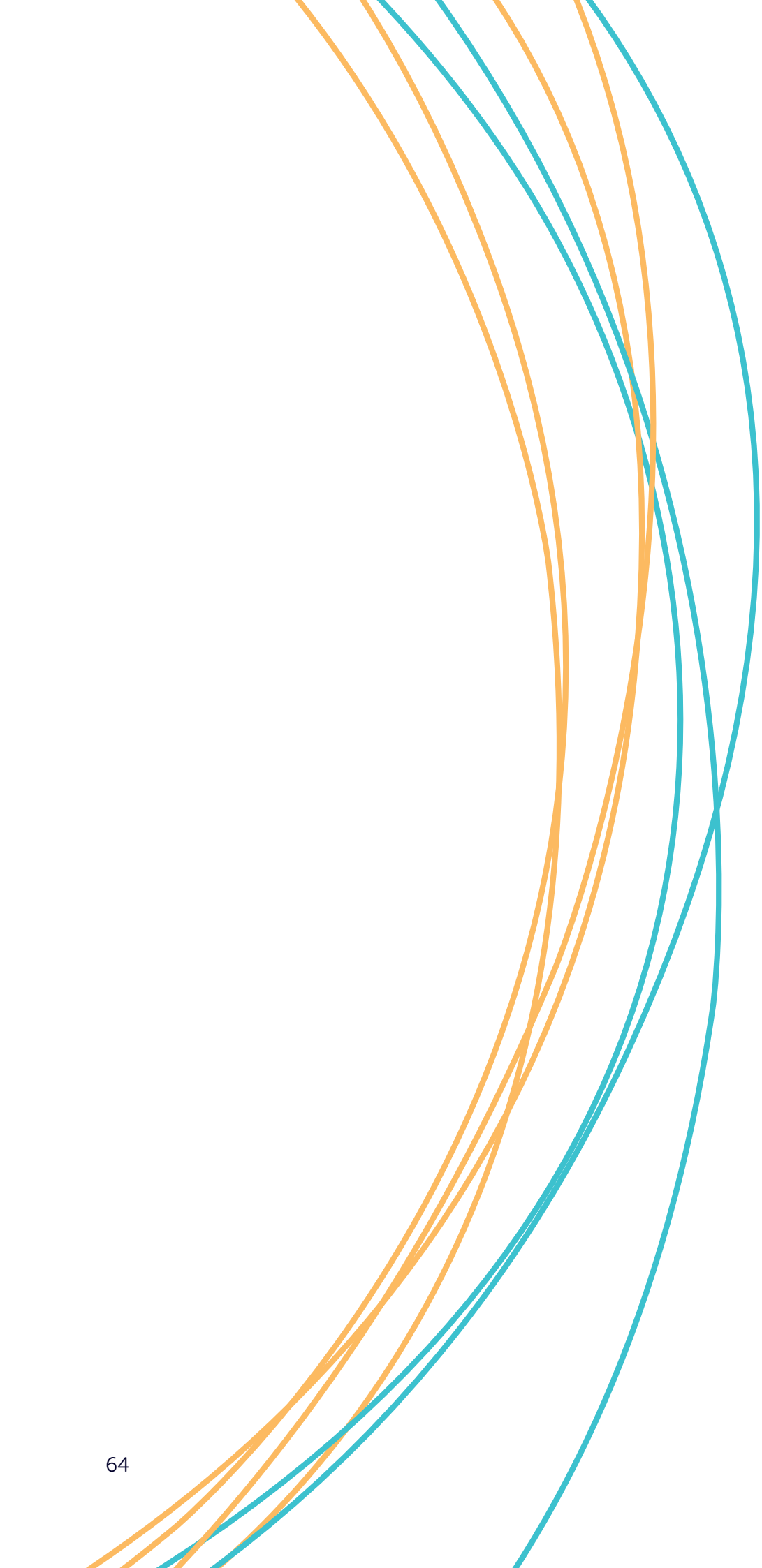
Hospitals can reduce waiting times by streamlining the points of longest delay within each care pathway.[143]

Finally, applying big data analytics may help accelerate the development of up-to-date clinical guidelines[139] and enable the personalisation of medicines, for example through genetic profiling.[112]

'We need to collect outcomes that matter to people in a standardised way. The data can then be used in real time to support people in the management of their own health and to drive co-production. Additionally, the data can be used to compare performance across providers, driving learning and improvement and it can enable the move away from payment based on volume to payment based on outcomes. To start, we need to bring together communities of cancer providers from across the globe that sign up to this idea – so that together we can implement standardised measurement and enable its use by patients and professionals.'

Thomas Kelley,
The International Consortium for Health Outcomes Measurement (ICHOM)





Section 06
Conclusions and key recommendations

Putting efficiency in practice: the way forward

'Inefficiencies in the system are a toxicity. There is no single formula for all countries that will deliver sustainable care, but we can agree on key principles, and make recommendations where efficiencies could be made to improve patient care.'

Lieve Wierinck, Member of the European Parliament

With the rising demand for high-quality cancer care and increasing financial pressures on our healthcare systems, there is an urgent need to rethink the way we allocate resources towards cancer care.

Creating greater efficiency across all aspects of cancer care today is a necessary step towards safeguarding its quality for future generations. This report has aimed to explore what is meant by efficiency in cancer care and provide illustrative examples of where inefficiencies exist and greater efficiency may be created – thereby improving outcomes for patients and making best use of available resources.

Improving efficiency is ultimately about change – and to make this happen, we need to instil a new culture of efficiency across all cancer policies and practices.

We need to take a whole system perspective of how we can improve efficiency across the entire care pathway, moving away from short-term investment decisions, siloed budgets and artificial segregation between different parts of the healthcare system. We need to invest in and exploit data to inform the right decisions. And critically, across everything we do, we need to make sure we are always focusing our efforts on delivering the best possible outcomes to patients – and be ready to scrutinise, and change, practices if they fall short of achieving this goal.

We all have a responsibility, and a shared interest, in improving efficiency in cancer care.

Political will is an essential starting point for this change to begin. National governments must be at the helm, as they ultimately drive decisions on the funding and allocation of resources. The European Union also has an important role of coordination and leadership to play. All stakeholders, however, have an essential role to play – industry, health professionals, regulators, governments and patients – and should be ready to make bold decisions if we want true change to occur. We must all accept that achieving efficiency may require compromises from each of us, and may even run contrary to our immediate interests.

Recognising the potential for greater efficiency in cancer care is simple. Implementation, however, is more challenging, and involves overcoming a number of system, technical, cultural and political barriers.

It would be unrealistic to think we can overhaul the way we deliver cancer care overnight. Yet, as has been shown in the previous sections, there are several promising examples of where inefficiencies have been identified and tackled. The question is how some of these approaches can be applied at scale and what each group of stakeholders – governments, regulatory and reimbursement agencies, industry, researchers, physicians, patients and caregivers – can do to enable this process.

Unfortunately, we currently lack practical models to guide the disinvestment from inefficient practices and reallocation of resources towards more efficient ones.

The notion of 'out with the old, in with the new' is conceptually appealing, but its implementation may be difficult in practice. Some authors have suggested that disinvestment decisions should be led by the same HTA agencies (or similar bodies) that advise on which new interventions should be funded, thereby ensuring a consistent evaluation framework to be used to guide both investment and disinvestment decisions.[144] However, we still need to explore feasible, evidence-based models of disinvestment that allow interventions (old and new) to be continuously re-evaluated in light of new data coming from clinical trials, registries and real-world data studies.[14] Creating accountability for these mechanisms will also be key.

Key recommendations

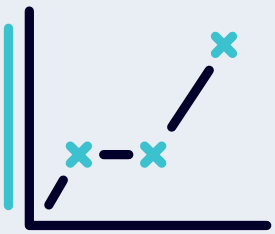
To reduce inefficiencies and ultimately protect the financial sustainability of high-quality cancer care for all European citizens, we need to:

01

Focus political will — to drive efficiency measures and strategic reinvestment across the entire cancer care pathway.

02

Place patient-relevant outcomes at the heart of everything we do — by including patients and their representatives in all aspects of cancer care planning, delivery, and evaluation. Across all aspects of cancer care, we must ensure that we are focusing on what matters most to patients.



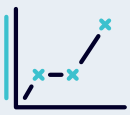
03

Invest in data — in the form of real-world data collection to capture variations in use of care and patient-relevant outcomes. We also need better linkages between health information systems and big data analytics to guide a continuous cycle of improvement, help target care more effectively and support technological and service innovation.

04

Create greater accountability — through measurement and public reporting of outcomes, outcomes-based reimbursement and built-in mechanisms to systematically identify and remove inefficiencies in cancer care.

What can policymakers do to help achieve more efficient cancer care?

	At the European level
 **Focus political will**	As a follow-up to the Cancer Control Joint Action, as well as the Economic and Financial Affairs Council's commitment to ensuring fiscal sustainability and access to good quality healthcare services for all,[1] collect good practices and explore models for creating greater efficiency in cancer care.
 **Place patient-relevant outcomes at the heart of everything we do**	Ensure that all health policies (i.e. in health promotion, prevention, and care) take account of the experience and perspectives of patients and citizens in healthcare. Empower patient organisations to help drive greater efficiency throughout the system, possibly in the form of a Choosing Wisely campaign driven by patients.
 **Invest in data**	Invest in public-private partnerships that aim to collect and merge real-world datasets across different countries. Map country-level variation in relevant cancer outcomes across countries, building for example on the EuroHOPE study, to compare variations of cancer care and outcomes, and drive improvement over time.[2]
 **Create greater accountability**	Within the European Semester, include credible measures of efficiency against which healthcare systems may be held accountable, and monitor progress against these measures over time, taking cancer care as an example.

At the national level

Make efficiency in cancer care a priority in national health policy and invest in a national consultation to identify existing inefficiencies.

Develop clear objectives to remedy these inefficiencies, with dedicated resources to ensure successful implementation.

Always involve patients or their representatives in all prioritisation decisions in national-level planning, purchasing and evaluation bodies (such as health technology assessment (HTA) agencies or their equivalents).

Ensure that care pathways are built around a clear understanding of patients' perspectives and experience.

Map regional variations in the use of care and patient-relevant outcomes across different cancers, and report these data back to individual practices or hospitals to promote adaptive improvements over time.

Explore the implementation of outcomes-based reimbursement schemes to encourage the development of new technologies that provide the greatest outcomes to patients.

Section 07
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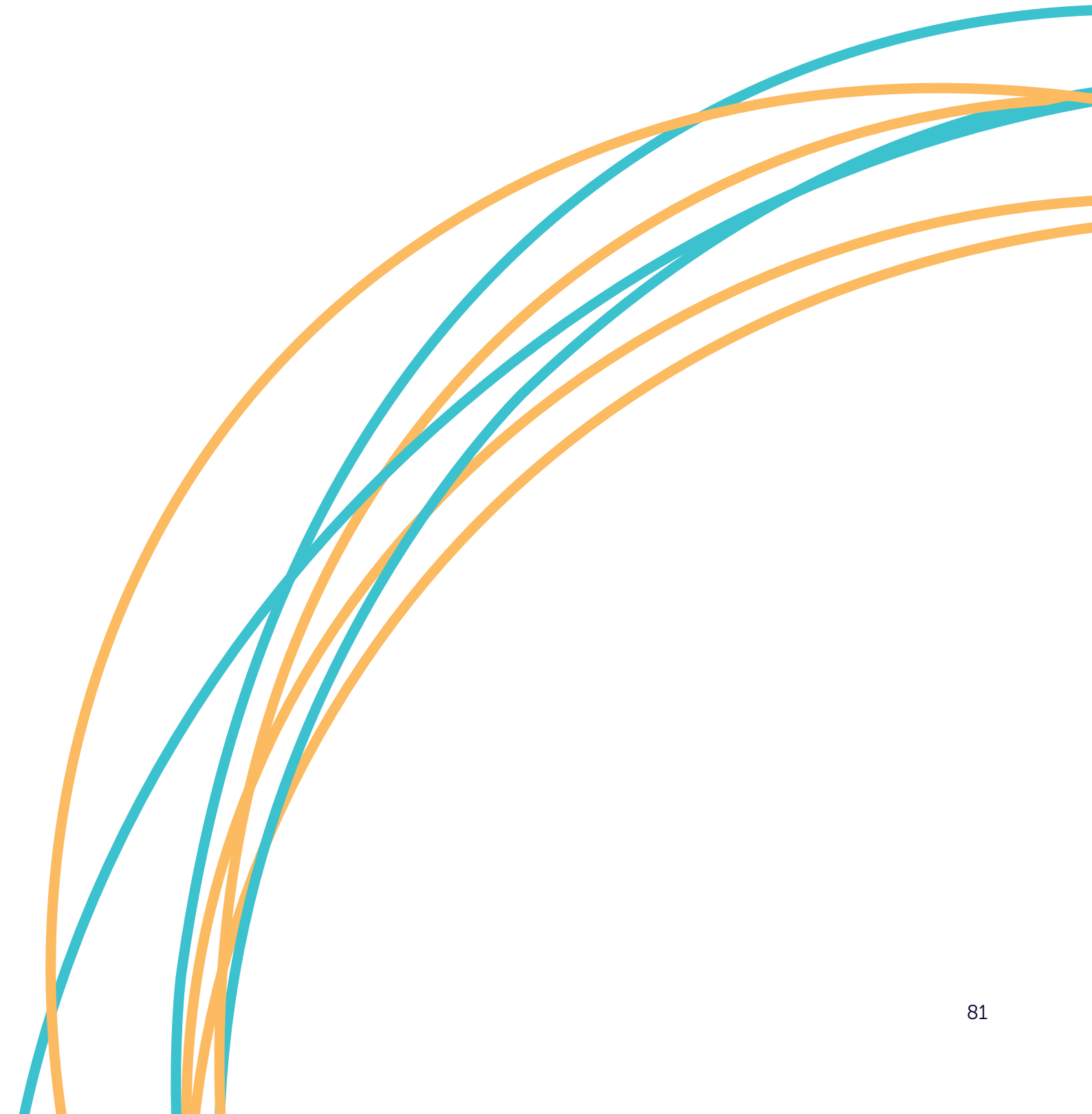

Appendix 1: Consolidated examples of clinical practices to discontinue or encourage in cancer care pathway

Note: This represents a first attempt at identifying areas of 'obsolescence' or clear 'do not do's' in cancer care, which have been identified by leading cancer professional societies in different Choosing Wisely campaigns in the US, Canada and Australia. This list is far from exhaustive, but gives an idea of where the focus of proposed 'de-listing' has been.

Screening and diagnosis

- Avoid using PET or PET-CT scanning as part of routine follow-up care to monitor for a cancer recurrence in asymptomatic patients who have finished initial treatment to eliminate the cancer unless there is high-level evidence that such imaging will change the outcome.[50]
- Don't perform prostate-specific antigen (PSA) testing for prostate cancer screening in men with no symptoms of the disease when they are expected to live less than 10 years.[50]
- Don't initiate management of low-risk prostate cancer without discussing active surveillance.[48]
- Don't perform PET, CT and radionuclide bone scans in the staging of early prostate cancer at low risk for metastasis.[51]
- Don't perform surveillance testing (biomarkers) or imaging (PET, CT and radionuclide bone scans) for asymptomatic individuals who have been treated for breast cancer with curative intent.[51]
- Don't perform routine cancer screening, or surveillance for a new primary cancer, in the majority of patients with metastatic disease.[52]
- Don't perform routine colonoscopic surveillance every year in patients following their colon cancer surgery; instead, frequency should be based on the findings of the prior colonoscopy and corresponding guidelines.[52]

Treatment

- Don't deliver care (e.g. follow-up) in a high-cost setting (e.g. inpatient, cancer centre) that could be delivered just as effectively in a lower-cost setting (e.g. primary care).[52]
- Don't routinely use extensive loco-regional therapy in most cancer situations where there is metastatic disease and minimal symptoms attributable to the primary tumour (e.g. colorectal cancer).[52]
- Don't give patients starting on a chemotherapy regimen that has a low or moderate risk of causing nausea and vomiting anti-emetic drugs intended for use with a regimen that has a high risk of causing nausea and vomiting.[50]

- Don't use cancer-directed therapy for solid tumour 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.[51]

- Don't 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 tumour-related symptoms.[50]

- Don't use a targeted therapy intended for use against a specific genetic aberration unless a patient's tumour cells have a specific biomarker that predicts an effective response to the targeted therapy.[50]

- Don't initiate whole breast radiotherapy as a part of breast conservation therapy in women aged ≥50 with early stage invasive breast cancer without considering shorter treatment schedules.[48]

- Don't routinely recommend proton beam therapy for prostate cancer outside of a prospective clinical trial or registry.[48]

- Don't routinely use intensity modulated radiation therapy (IMRT) to deliver whole breast radiotherapy as part of breast conservation therapy.[48]

- Don't use white cell stimulating factors for primary prevention of febrile neutropenia for patients with less than 20% risk for this complication.[51]

- Avoid chemotherapy and instead focus on symptom relief and palliative care in patients with advanced cancer unlikely to benefit from chemotherapy (e.g. performance status 3 or 4).[52]

- Don't initiate management in patients with low-risk prostate cancer (T1/T2, PSA < 10 ng/ml, and Gleason score < 7) without first discussing active surveillance.[52]

Survivorship (long-term care)

- Streamline interdisciplinary care structures and communication between oncology specialists and primary care providers.[145]

- Increase provision of stratified care (cancer aftercare services) based on supported self-management and shared decision making to fulfil unmet needs of patients.[146]

- Limit surveillance CT scans in asymptomatic patients after curative-intent treatment for aggressive lymphoma.[49]

- Don't order tests to detect recurrent cancer in asymptomatic patients if there is not a realistic expectation that early detection of recurrence can improve survival or quality of life.[52]

Palliative care (end-of-life care)

- Don't routinely use extended fractionation schemes (>10 fractions) for palliation of bone metastases.[48]

- Don't recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.[52]

- Don't delay or avoid palliative care for a patient with metastatic cancer because they are pursuing disease-directed treatment.[52]

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