

# Harnessing data for better cancer care

A policy report by  
All.Can International



Changing cancer care together

All.Can International is a not-for-profit organisation (ASBL) registered in Belgium. Its work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors), Baxter and Illumina (contributors), with additional non-financial (in kind) support from Helpsy, The Health Value Alliance and Goings-On. In addition, this report received financial support from Novartis.

## About All.Can

All.Can is an international, multi-stakeholder, non-profit organisation aiming to identify ways we can optimise the use of resources in cancer care to improve patient outcomes. All.Can brings together representatives from patient organisations, policymakers, healthcare professionals, research and industry. It is made up of All.Can International as well as All.Can national initiatives established in 18 countries (at the time of writing).

## About this report

This report aims to offer policymakers, care providers and decision-makers a forward-looking view of opportunities for optimising the use of data to improve efficiency in cancer care. It starts by defining data and investigating the current role of data in cancer care. It then describes where data have contributed to improving patient outcomes and efficiency across the cancer care pathway, focusing in particular on their role in addressing inefficiencies viewed as important to cancer patients and their caregivers, based on previous All.Can research. The report then discusses the challenges that remain in optimising the use of data and provides recommendations for policymakers to overcome these challenges.

## Methodology

This report is based on a structured analysis of peer-reviewed and grey literature, 16 expert interviews and consultation with the All.Can Data Working Group and the External Advisory Committee.

The report does not attempt to cover all facets of the complex ecosystem of data in healthcare. For reasons of feasibility, it focuses on data generated during routine clinical care. Data collected in clinical trials are out of scope.

The report and its contents fully respect All.Can's core principle of being non-promotional and do not include references to any specific products. A full description of the research methodology is available on the All.Can website: [www.all-can.org/what-we-do/research/data-paper-project/](http://www.all-can.org/what-we-do/research/data-paper-project/).

## Authors

This report has been produced by The Health Policy Partnership and The Health Value Alliance on behalf of All.Can International. Its creation was led by the All.Can Data Working Group, made up of All.Can International members. The authors are grateful for the expert advice received from our External Advisory Committee on iterative versions of this report and to contributors who were interviewed for the project.

## Disclaimer

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In alignment with its statutes and bylaws, all activities and outputs of All.Can represent consensus of members, who have full editorial control.

In addition to the support provided by the companies listed above, Novartis has contributed financially to the development of this policy report.



## All.Can Data Working Group

**Sangeeta Agrawal**, Helpsy Health  
**Antonella Cardone**, European Cancer Patient Coalition

**Ivana Cattaneo**, Novartis  
**Dave Duplay**, Vital Options International

**Caroline Falciola**, F. Hoffmann-La Roche

**Alex Filicevas**, World Bladder Cancer Patient Coalition; All.Can president

**Stefan Gijssels**, Digestive Cancers Europe

**Petra Hoogendoorn**, Goings-On

**Agnieszka Krukowska**, Johnson & Johnson

**Laura McDonald**, Bristol Myers Squibb

**Jan van Meerbeek**, Antwerp University Hospital

**Matthijs Van Meerveld**, Merck Sharp & Dohme

**Borna Mueller**, F. Hoffmann-La Roche

**Vivek Muthu**, Marivek Consulting

**Kathy Oliver**, International Brain Tumour Alliance

**Titta Rosvall-Puplett**, Bristol Myers Squibb

**Christobel Saunders**, University of Western Australia

**Julian Shepelev**, Baxter Healthcare

**Puneet Singhal**, Merck Sharp & Dohme

**Henriette Thole**, Novartis

**Veronica Zilli**, Johnson & Johnson

**Matthew Hickey**, The Health Value Alliance

**Shannon Boldon**, The Health Policy Partnership

**Suzanne Wait**, The Health Policy Partnership

## External Advisory Committee

**Fatima Cardoso**, Advanced Breast Cancer Global Alliance

**Sybo Dijkstra**, DigitalEurope

**Nigel Hughes**, Janssen and European Health Data and Evidence Network

**Adrian Jonas**, National Institute for Health and Care Excellence

**Sabrina Montante**, Istituto Superiore di Sanità

**Ray Pinto**, DigitalEurope

**David Roder**, University of South Australia

**Abdullahi Sheriff**, GE Healthcare Europe

**Francesco Pignatti**, European Medicines Agency (observer role)

## Independent contributors

**Miriam Gargesi**, Illumina

**Dipak Kalra**, European Institute for Innovation through Health Data

**Gregory Katz**, University of Paris School of Medicine, PromTime

**Steve Laws**, Varian Medical Systems

**Volker Liebenberg**, Illumina

**Laura O'Hanlon**, Myriad Genetics

All affiliations correct at the time of writing.

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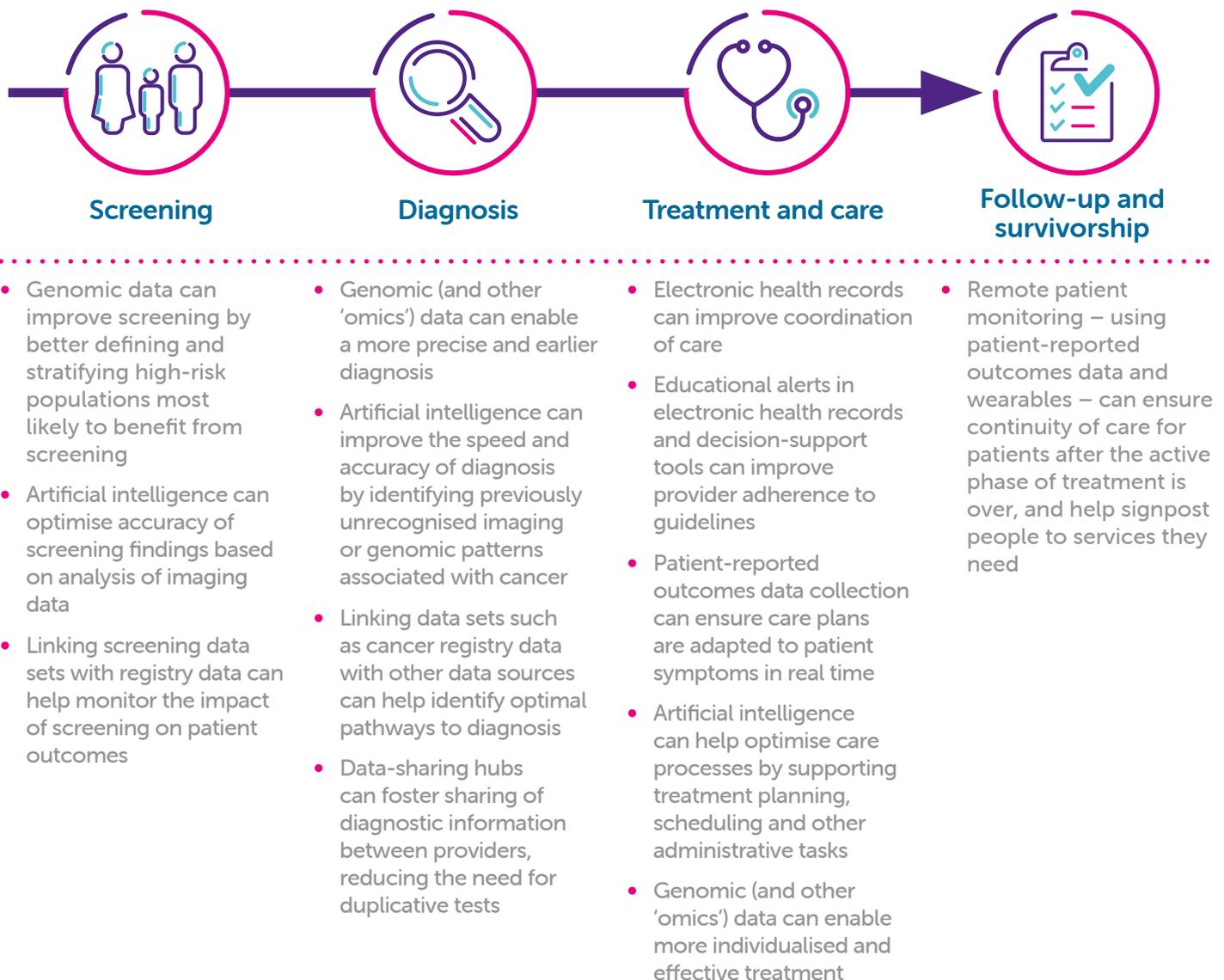
# Executive summary

## Data are central to quality, innovation and overall efficiency in cancer care

Over the past decades there has been considerable progress in cancer care, with many advances enabled by high-quality data. Having timely access to data has become essential to driving meaningful research, enabling efficient models of care, and improving quality and outcomes for patients.

Innovations in the way we use and collect data, as well as our ability to draw insights from data, offer the potential to improve efficiency at every stage of the care pathway (Figure a).

**Figure a.** Summary overview of the role of data in driving efficiency at every stage of the cancer care pathway



This figure summarises literature review findings from chapter 4, and does not aim to cover the entire realm of data in cancer care.

## We are still far from fully harnessing the potential of data to transform cancer care

The notion of ‘data rich, information poor’ rings true in cancer care, and many data challenges persist: in data themselves, the systems used to collect them, integrating data into clinical care and using data to draw meaningful insights to drive change.

Common challenges with cancer data include (but are not limited to) those outlined in **Figure b**.

## Overcoming existing challenges is integral to ensuring sustainability of cancer care

The COVID-19 pandemic has focused the world’s attention on the role of data in addressing some of the biggest challenges in healthcare and, equally, in cancer care. As we look to post-pandemic recovery, policymakers are presented with a unique opportunity to build more sustainable, resilient and efficient systems of care, leaving nobody behind. Addressing the challenges in data is essential to achieving this goal.

**Figure b.** Challenges to achieving the optimal use of data in cancer care

Challenges inherent in data	Challenges with data systems	Challenges to embedding data into clinical practice	Challenges in drawing insights from data
<p>Poor data quality</p> <p>Data not representative of entire population (inequity and bias)</p> <p>Lack of data reflecting the patient perspective and outcomes that matter most to individuals</p>	<p>Data siloes hindering the ability to link data across different data systems</p> <p>Limited interoperability, further hampering data linkage</p> <p>Inconsistent use of data governance frameworks</p>	<p>Data that cannot be actioned or that have limited use in guiding cancer care</p> <p>Poor integration of data insights into clinical decision-making</p> <p>Low patient trust in appropriate use of their health data or privacy protection</p> <p>High burden of data collection, leading to limited buy-in from healthcare professionals</p>	<p>Inadequate analytical methodologies, poorly validated artificial intelligence algorithms and inherent biases with data analysis</p> <p>Poor timeliness, relevance and granularity of data, limiting multi-stakeholder use</p> <p>Limited use of data to drive value-based healthcare at scale</p>



# Call to action

As part of the digitisation agenda, policymakers must implement lasting changes across systems of care and policy frameworks to enable data to achieve their full potential for the benefit of all people with cancer. Commitment is needed to embed optimal use of data across all facets of cancer care, in all settings, for all people living with and beyond cancer.

## Data quality

- **Create national cancer data quality standards** and build them into regular, mandatory auditing of cancer care.
- **Implement technological solutions for automatic data entry**, minimising the risk of human error and administrative burden on care teams.

## Data equity

- **Demand greater equity in cancer research and care** by ensuring appropriate representation of people of different races and ethnicities, sex and cancer types in cancer data sets.
- **Hold institutions accountable for providing equitable cancer care** by capturing performance on key quality indicators according to patients' race, ethnicity, sex and socioeconomic status in accreditation systems.
- **Ensure proportionate allocation of funds towards specialist cancer registries** to collect data on populations of cancer patients for whom data are less available.

## Patient-relevant data collection

- **Encourage systematic and standardised collection of patient-generated health data**, such as measures of patient-reported outcomes and patient experience, in key national health data sets.
- **Include these data in regular monitoring and performance evaluations** of cancer care to guide improvements to care most relevant to patients.

## Interoperability

- **Develop common data standards, specifications and processes** to improve the national and international interoperability of data sets.
- **Scale-up existing national and international initiatives** on data standardisation and interoperability.

## Health data governance

- **Build harmonised data governance legislation to facilitate health data linking and sharing between providers**, and ideally between countries.
- **Enable the creation of federated data networks** when national and international data linkages are not possible.
- **Invest in creating national health data codes of conduct** to facilitate the safe use of health data, limiting barriers to data sharing while protecting patient privacy.

## Data burden on healthcare professionals

- **Build in positive incentives for data collection and use across the cancer care pathway**, to foster a culture of value-based healthcare.
- **Embed data-analytic solutions into care processes** to enable rapid processing and feedback of data insights to clinical teams to guide decision-making.
- **Provide appropriate funding and resourcing to train and upskill** the healthcare workforce so that they keep pace with innovations in data collection and use.

## Patient trust

- **Create public awareness and education campaigns** to convey the power of meaningful data to better manage cancer care.
- **Engage with patients to discuss how data are being used**, and address misconceptions around the nefarious use of health data.
- **Continuously adapt legislation** and tools to give citizens appropriate control over their own health data, so they may act as their own data 'gatekeepers'.

## Drawing insights from data

- **Apply appropriate regulatory standards** to fundamentally protect citizens' rights and values by ensuring that:
  - data sets from which insights are drawn are adequate, equitable and sufficiently representative to train artificial intelligence algorithms while minimising potential biases
  - the analytics used (including artificial intelligence algorithms) are standardised, transparent and subject to rigorous evaluations of clinical safety and effectiveness
  - the insights drawn from data analysis are of high quality.



# 1 | Introduction

Cancer care is advancing at a speed never seen before, and data are at the core of many of these advances.

With an increasingly rich array of data at our disposal, we are seeing the potential for more accurate diagnosis, personalised treatment and better insights on the impact of treatment and care for patients. Mobile applications and smart devices now enable the collection of health data in a person's daily life outside of the clinical setting, allowing for remote monitoring and identifying critical health events sooner. Advances in data analytics, facilitated by artificial intelligence (AI), machine learning and improvements in data processing, are helping us solve some of the most complex challenges in healthcare at a scale and speed that were previously impossible. Many of these advances are still in early stages of implementation, but could be transformational to the future of cancer care.

The COVID-19 pandemic has had a dramatic impact on cancer care, but it has also demonstrated the importance of data and digital solutions to addressing challenges. Many countries saw partial or complete disruption to their cancer services – and it will be some time before they fully recover.<sup>1</sup> Healthcare systems around the world rapidly deployed and expanded telemedicine and remote monitoring systems to ensure continuity of care.<sup>2</sup> The pandemic also accelerated the use of data to reconfigure cancer services, improve patient monitoring and fast-track decisions on regulation, reimbursement and funding.<sup>2</sup>

**It is important to recognise that significant barriers still hinder our ability to fully harness the power of data to improve patient care.** The notion of 'data rich, information poor' is true for many healthcare systems. Data siloes, a lack of interoperability, unclear actionability of existing data, complex data governance, and limited ability to re-use data for other purposes are all ongoing challenges in many countries.<sup>3-5</sup> Moreover, we often fall short in our ability to analyse and extract meaningful insights from the data available to guide decision-making.

**All of these challenges must be addressed as a matter of urgency if we are to build sustainable healthcare systems that can continue to improve care for people with cancer.** Pressures on healthcare resources have only increased in the wake of the COVID-19 pandemic. In this context, optimal efficiency of care must be a core goal of any healthcare system – ensuring resources are being used to deliver the best possible outcomes for patients.



# 2 | Health data

**'Without data to guide cancer care,  
we are travelling blind.'**

**Stefan Gjissels**  
Digestive Cancers Europe

## Defining health data

It is estimated that 30% of the world's stored data are health data.<sup>7</sup> Health data is a broad term that can be defined in a number of ways. In this report, we have used the definition proposed by the Data Saves Lives initiative:

'[Health data are] any data describing a person's health, their healthcare or anything affecting any health issues or diseases they may have. This includes information created by health and care professionals, as well as information generated by patients; from illnesses monitored through mobile applications and smart devices, to screening tests and nutritional data.'<sup>8</sup>

Unless specified otherwise, when we say 'data', we mean health data generated during routine clinical cancer care, as opposed to within the context of a clinical trial.

An increasing number of health data are being generated, facilitated by new technologies and the digitalisation of our societies. Collectively, these make up a complex health data ecosystem, which is constantly evolving (**Figure 1**).<sup>9</sup>

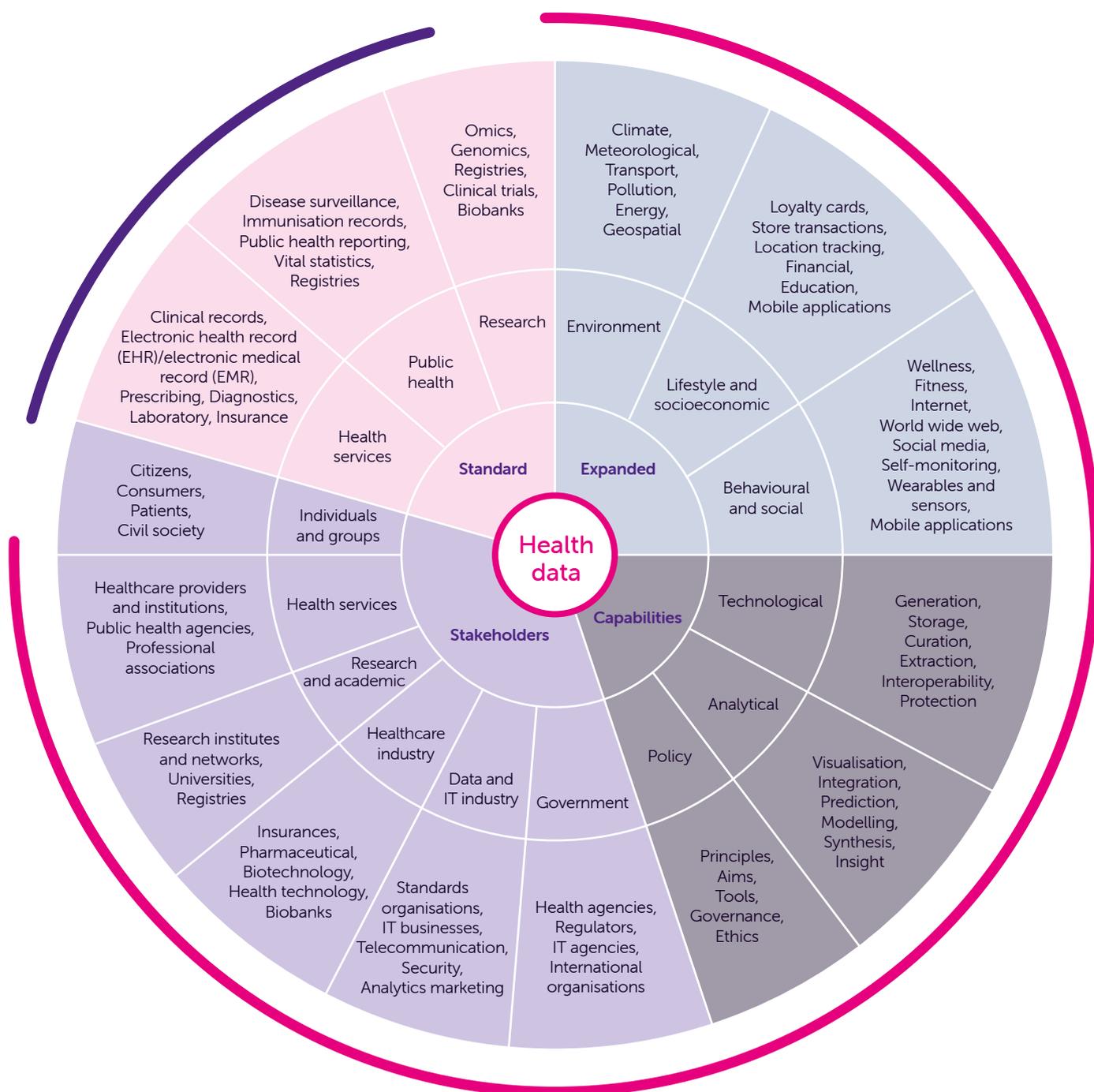
## Use of data and data analytics

Data can be used for multiple purposes, with both 'primary' and 'secondary' uses.

**Primary use of data is when data are used to directly support the delivery of care to the individual from whom they were collected.** A typical example of this is the use of imaging data to help determine a person's diagnosis, or patient-reported outcomes data to help measure the impact of a given intervention on their quality of life.

**Secondary use of data involves using data beyond direct patient care and healthcare delivery.** It includes using health data for analysis, research, quality and safety evaluations, commercial activities etc. Data collected on individuals are analysed for purposes other than their own care.<sup>10</sup>

**Figure 1.** Example of a health data ecosystem<sup>9</sup>



**Note:** This figure shows a non-exhaustive view of health data sources, to illustrate a 'typical' healthcare ecosystem, the vastness of data it contains and complexity in the connections between the sources. Adapted from 'Policy implications of big data in the health sector'. *Bulletin of the World Health Organization*: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.



Secondary use may also involve aggregating data from many different sources and analysing them to gain insights that can support better decision-making.<sup>8</sup>

For example, linking cancer registry data to population demographics can help identify populations disproportionately affected by cancer. This allows the development of targeted prevention programmes focusing on high-risk populations.<sup>11</sup> Similarly, quality indicators aggregated across different hospitals can be analysed to help identify disparities in quality of care and guide interventions to improve outcomes for patients.

Data are only useful if we can apply the right analytics to derive insights from them.<sup>12</sup> Even the best data do not translate into actionable insights in the absence of robust data analytics tools to extract, analyse and interpret them appropriately. AI is a rapidly growing field within data analytics, defined as the capability of a computer program to perform tasks or reasoning processes that we usually associate with intelligence in a human being.<sup>13</sup> Its application, combined with significant advances in data processing speeds, can allow us to derive actionable insights from vast amounts of data in a way that was previously impossible. AI is still in the early stages of development, but its use is being explored in many areas of cancer care.

## Data in cancer care

The cancer data ecosystem is complex and evolving, and data within it have multiple dimensions and facets.

Data can be examined in terms of:

- **contents** – what they describe and what information they provide (e.g. pathology data tell us the size of a tumour and how advanced it is) or the perspective they represent (e.g. patient-generated health data)
- **how they are collected and stored** – e.g. in cancer registries or electronic health records
- **their intended use and insights that can be derived from them** – e.g. to guide treatment or monitor for possible side effects in an individual patient, or to help understand variations in quality of care in a given hospital or across healthcare systems.

This report focuses on four types of data most relevant to cancer care:

- cancer registry data
- electronic health records data
- genomic data\*
- patient-generated health data.

These data types are described in **Box 1**.

\*Please note: for reasons of feasibility, we chose to focus on genomic data and not all kinds of 'omics' data in this report.



## Box 1 Types of data assessed in this report

### Cancer registry data

Cancer registries combine demographic data with key information on cancer cases (e.g. tumour size, stage at diagnosis, treatment modality).<sup>5 14 15</sup> This enables tracking of cancer epidemiology at a population level over time.<sup>14 16</sup> Registries obtain data from a variety of sources, including hospitals, laboratories, patients and others.<sup>17 18</sup> They play an important role in enabling the aggregation of population data to identify and track trends in cancer incidence, prevalence, prognosis, survival and patterns of care, as well as gaining a better understanding of the root causes of cancer and populations at risk. They also help track the burden of cancer over time to inform national cancer control efforts and policies.<sup>19 20</sup>

### Electronic medical records and electronic health records data

When a person visits their clinician, various data are collected in a medical record by the doctor and hospital staff, including medical history, family health history and any test results. These records are often only accessible within the facility where the information was collected, and are increasingly stored in an electronic format, as electronic medical records (EMRs).<sup>21 22</sup> EMRs from different settings can be linked together to form a central electronic health record (EHR) system. An EHR provides a record of a patient's history of interactions with the healthcare system over a period of time. It allows all providers engaged in a patient's care to access this information securely via a shared data system.<sup>3 16 23 24</sup>

Data included in EHRs can vary depending on the data system used and the ability to capture different data types (e.g. storing imaging data as well as text data). They may include: administrative data, demographic data, genomic data, doctors' notes, vital signs, medical history, diagnosis, medications, immunisation history, allergies, imaging data, laboratory data and other test results.<sup>3 25-28</sup> One challenge with EHRs is that different systems can have different data fields as well as the ability to record unstructured (non-menu-based) data. The resulting lack of conformity can make integration of data from different EMRs difficult.



## Genomic data

Genomics is the study of different aspects of human genes and their functions – including genetics (variations in DNA sequence and their function), transcriptomics (variations in RNA sequence and their function) and epigenetics (modifications of gene expression rather than genetic code alterations).<sup>29</sup>

Genomic data are collected from a person's tumour, the surrounding tissue (e.g. through tissue biopsy), blood or other bodily fluids.<sup>29 30</sup> These data can help determine a person's predisposition to cancer, define tumour characteristics, personalise treatment and assess a tumour's response to treatment.<sup>31 32</sup>

The different components of genomics have wide applicability in cancer care, and their application is expected to further increase in the years to come.<sup>29</sup>

## Patient-generated health data

Patient-generated health data are data gathered from patients to help track their health concerns and health status.<sup>33</sup> They include health and treatment history, patient-reported outcome measures, patient-reported experience measures and biometric data (e.g. cholesterol levels, step count, heart rate) obtained from sensors, smartphones and wearables.<sup>27 33-35</sup>

- **Patient-reported outcome measures (PROMs)**

PROMs are a form of patient-generated health data designed to measure the patient's own views of their health status, from a single symptom (e.g. pain) to a comprehensive assessment of their level of impairment, disability, health-related quality of life and holistic needs.<sup>36 37</sup> PROMs can be either generic (applicable to any given condition) or condition-specific (assessing outcomes relevant to a particular condition).<sup>37</sup> They can be collected on paper, electronically (ePROMs), via smart devices or by healthcare professionals contacting patients.<sup>36 38</sup>

- **Patient-reported experience measures (PREMs)**

PREMs are designed to look at different aspects of the care process and how they affect the patient's experience.<sup>36 37</sup> They can also vary in complexity, from a single question to detailed assessments.

# 3 | Defining efficiency in cancer care

‘Somewhat like the term “data”, the term “efficiency” has become ubiquitous in health policy debates in recent years – yet, like data, it is often poorly defined. All.Can has conducted considerable research to help define efficiency, looking at it from the patient perspective.’

**Alex Filicevas**

World Bladder Cancer Patient Coalition

## Efficiency in cancer care

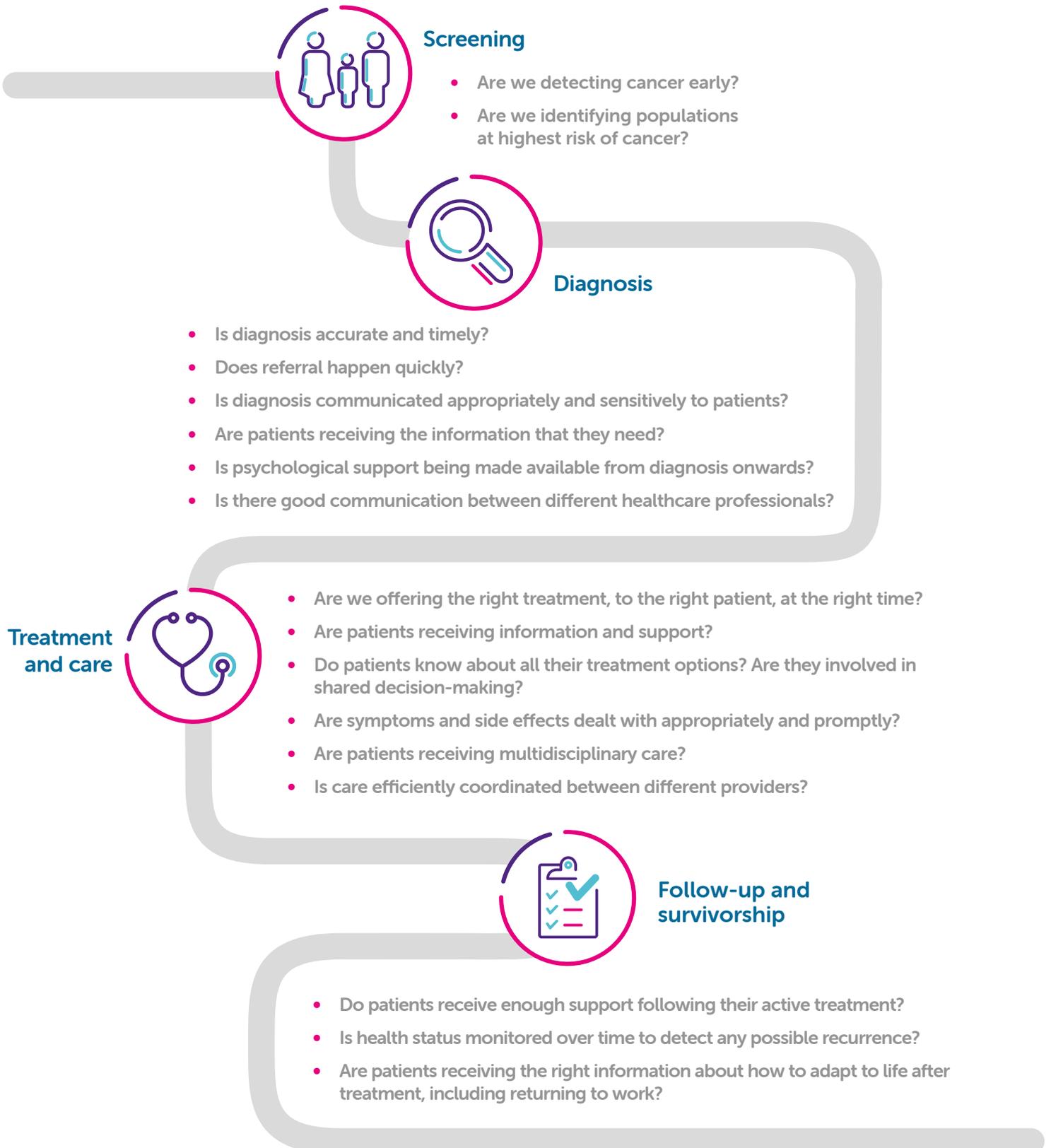
All.Can’s definition of efficiency takes a patient-centred approach – focusing on what matters to patients throughout their cancer care. Efficient cancer care should:

- **improve outcomes for patients** – through the delivery of accessible, patient-centric, evidence-based and high-quality cancer care that achieves best possible outcomes for all cancer patients individually and collectively with the resources at hand
- **optimise allocation of resources** – use available resources in such a way as to achieve optimal outcomes across the system. Resources should be distributed equitably across the population
- **use data to continuously learn** – newly available data should be used to contribute to an adaptive and learning healthcare system that strives for continuous improvement to benefit cancer patients and their families.

## Efficiency across the cancer care pathway

In our previous research, we asked patients and caregivers where they had experienced inefficiencies at different stages of their diagnosis and care.<sup>6</sup> Drawing from these insights, we have defined some of the key challenges that need to be addressed from the patient perspective at each stage of the care pathway (**Figure 2**).

**Figure 2.** A framework for improving efficiency of cancer care from the patient perspective<sup>6</sup>

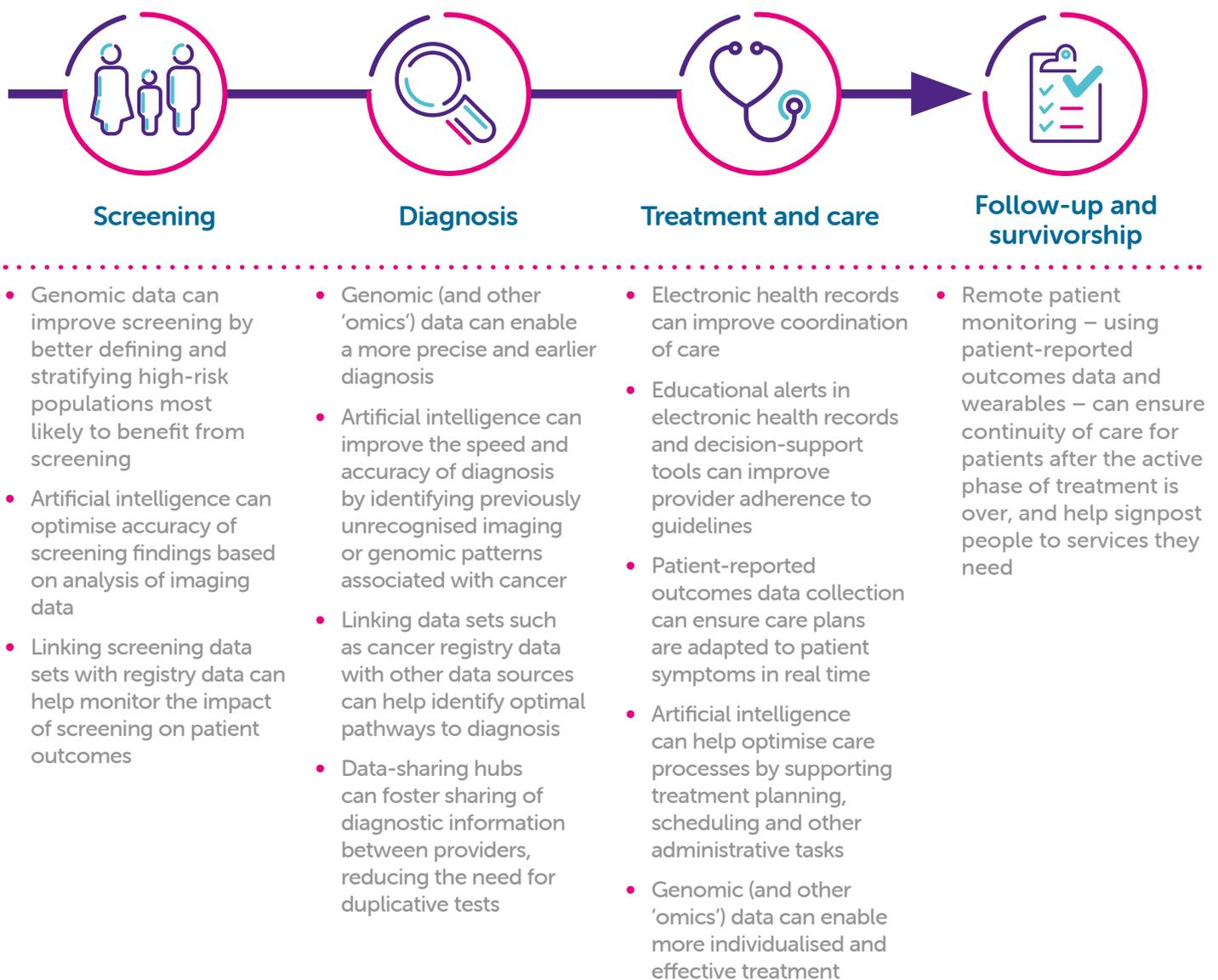


# 4 | The role of data in driving efficiency in cancer care

**‘Having good data is everything. We need good data on individual patients, we need good data on how our teams and hospitals are functioning, and we must be able to compare these data to ensure that if there are variations in patient outcomes... we can look at the reasons [and] correct them.’**

**Christobel Saunders**  
University of Western Australia

**Figure 3.** Summary overview of the role of data in driving efficiency at every stage of the cancer care pathway





## Screening

**Cancer screening aims to detect illness at the earliest stage possible, before symptoms develop and when effective treatment options are still available.<sup>39</sup>**

Advances in our understanding of genetics in cancer have led to the development of targeted screening programmes, which can identify individuals at high risk of developing cancer. Gene mutations have been associated with over 50 hereditary cancers. The presence of one or more of these mutations places a person at a higher lifetime risk of developing cancer.<sup>29 36</sup> Targeted screening can allow healthcare professionals to offer individuals risk-reducing, often lifesaving, interventions.<sup>40</sup> These may include more frequent screening, lifestyle and behavioural changes or preventive treatments, such as aspirin in colorectal cancer prevention or preventive surgery in breast cancer.<sup>41 42</sup>

**A common example of genetic screening in cancer is screening for mutations in the *BRCA* genes, which place people at a higher risk of breast and ovarian cancer.<sup>43-45</sup> Targeted *BRCA* screening in high-risk populations is now underway in several countries. People with an identified mutation are offered preventive approaches, genetic counselling and, if they develop cancer, targeted treatment.<sup>46</sup>**

**Another example is the use of genetic data to better define and stratify high-risk populations in cancer screening programmes.** For example, using genetic data to more accurately define groups at risk of colorectal cancer can help identify people at highest risk.<sup>47</sup> This helps to avoid unnecessary investigations and procedures for those in the lower-risk groups and creates greater efficiency in diagnosis.<sup>43 47</sup> However, this approach to screening is not yet widely adopted.<sup>47</sup>

**Data analytics tools, such as AI, have also played a role in improving the potential reach and efficiency of screening.** For example, in skin cancer, the use of AI for image recognition is expanding the potential of image-based screening. AI can process people's images of skin lesions uploaded to a smartphone application. It can distinguish between harmful melanoma and benign moles with accuracy similar to that of a dermatologist.<sup>48-50</sup> Researchers have suggested that combining human and AI capabilities to classify skin cancers may offer a superior, and more resource-efficient, option for large-scale skin cancer screening.<sup>48 51</sup>



**AI is also being used to interpret imaging results in cancer screening.** In breast cancer, AI can improve analysis of mammography results, with initial studies showing a greater accuracy in diagnosis by reducing common image interpretation errors (i.e. false negatives and false positives).<sup>52</sup> AI is also beginning to be used to interpret computed tomography (CT) scans in lung cancer screening to alleviate capacity issues and enhance the quality of interpretation.<sup>53 54</sup>

**Lastly, valuable information can be gained by linking screening data sets with other data.** For example, linking registry data with cancer screening data sets allows monitoring of outcomes over time and provides important information on the impact of screening on early detection and survival.<sup>11 19 55</sup>

## Diagnosis

**Accurate diagnosis is essential to direct patients as quickly as possible to treatments that are most likely to be effective for their individual characteristics.**<sup>56-59</sup>

**Genomic data are increasingly being used to detect cancer early and personalise diagnosis.**<sup>60 61</sup> In paediatric brain tumours, genomic tumour profiling has helped to identify disease-specific patient subgroups that can exhibit distinct clinical outcomes. This provides the information needed to personalise care pathways for individual patients, with tailored therapies, improved clinical management and better survival.<sup>62</sup> This personalised approach is especially important in treating children with brain tumours, given the risk of comorbidities and long-term side effects from conventional treatments.<sup>62</sup>

**Data analytic tools are also expanding what was previously possible in cancer diagnosis, by revolutionising our ability to extract insights from vast data sources.** We are now in an era where machines can process a large amount of diagnostic data and detect patterns of use in clinical decision-making.<sup>63</sup> AI has shown early successes in improving the speed and accuracy of diagnostics by identifying previously unrecognised imaging and genomic patterns associated with cancer. Knowledge of these patterns has allowed for better tumour segmentation and, in some cases, the ability to tailor care pathways to very specific types of cancer based on the person's genetic make-up.<sup>13 49 63</sup>



The power of data analytics to extract diagnostic insights is perfectly illustrated by the use of liquid biopsies in diagnosis. Liquid biopsies can detect circulating tumour DNA (ctDNA) in a sample of a person's blood, which can indicate the presence of cancer, often before any clinical signs or symptoms are apparent.<sup>64-67</sup> Some liquid biopsies can detect up to 50 cancer types in a simple blood test.<sup>64</sup> As these biopsies yield enormous amounts of genomic data, they rely heavily on machine learning algorithms for interpretation.<sup>64</sup> A number of countries are currently conducting pilot studies on integrating liquid biopsies for early cancer detection into clinical practice.<sup>68</sup>

**Aggregating and linking data sets can also provide enhanced information to guide diagnostic pathways.** For example, by linking cancer registry data with other sources (e.g. emergency room or general practitioner records), we can identify the routes through which patients are most commonly diagnosed with cancer.<sup>69</sup> In the UK, this approach has been used with great success to develop strategies to encourage early diagnosis (**Case study 1**).<sup>69</sup> Centralised diagnostic data-sharing hubs, which link data from different cancer treatment centres, could also prevent inefficiencies in the diagnostic pathway (**Case study 2**).

# 1

## Case study

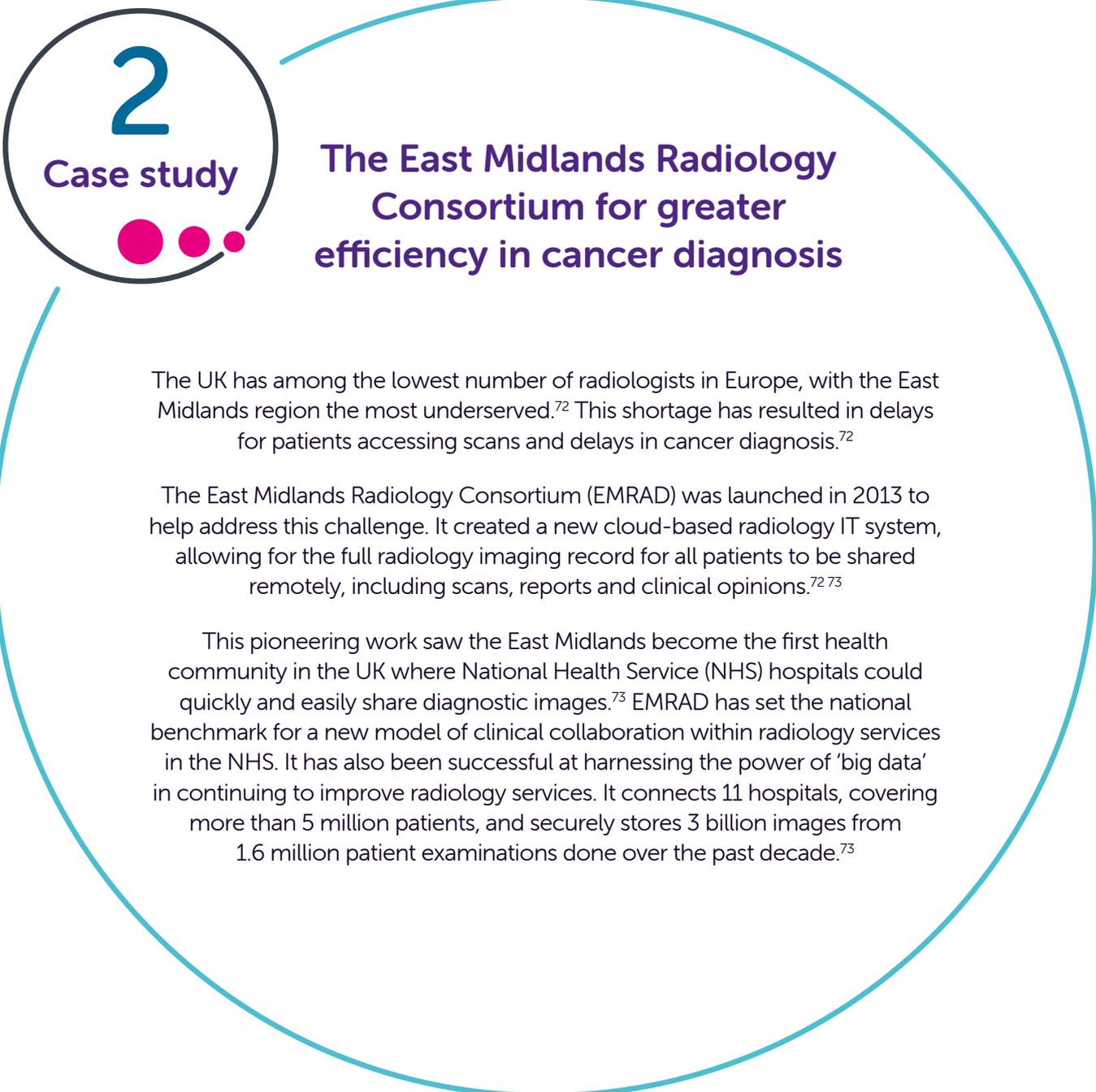
### The Routes to Diagnosis Programme in the UK to improve early diagnosis of cancer

Cancer survival in England is below the European average – partially attributed to people being diagnosed with cancer at a later stage of disease progression.<sup>70 71</sup> The Routes to Diagnosis Programme, created by the National Cancer Intelligence Network in partnership with Cancer Research UK, aimed to better understand the setting where cancer patients in England are most commonly diagnosed by linking different national cancer data sets.<sup>70 71</sup>

The project linked data from: administrative hospital episode statistics, cancer waiting times data, cancer screening programme data and cancer registration data.<sup>70</sup> It also examined demographic, organisational, service and personal reasons for delayed diagnosis.<sup>70 71</sup> The analysis included all cancers diagnosed in England between 2006 and 2016, equating to over 3 million diagnoses.<sup>69 70</sup>

Findings led to a major shift in understanding about where most cancer patients are diagnosed. Researchers found that far too many individuals were first diagnosed in an emergency department. This is significant, because these individuals tend to be at a later stage of cancer, and their survival is expected to be worse as a result.<sup>69</sup>

Insights gained from the programme helped to drive improvement efforts focused on reducing the proportion of cancers diagnosed as an emergency, and highlighted opportunities for improvement in primary and secondary care.<sup>69 70</sup>



# 2

## Case study



### The East Midlands Radiology Consortium for greater efficiency in cancer diagnosis

The UK has among the lowest number of radiologists in Europe, with the East Midlands region the most underserved.<sup>72</sup> This shortage has resulted in delays for patients accessing scans and delays in cancer diagnosis.<sup>72</sup>

The East Midlands Radiology Consortium (EMRAD) was launched in 2013 to help address this challenge. It created a new cloud-based radiology IT system, allowing for the full radiology imaging record for all patients to be shared remotely, including scans, reports and clinical opinions.<sup>72,73</sup>

This pioneering work saw the East Midlands become the first health community in the UK where National Health Service (NHS) hospitals could quickly and easily share diagnostic images.<sup>73</sup> EMRAD has set the national benchmark for a new model of clinical collaboration within radiology services in the NHS. It has also been successful at harnessing the power of 'big data' in continuing to improve radiology services. It connects 11 hospitals, covering more than 5 million patients, and securely stores 3 billion images from 1.6 million patient examinations done over the past decade.<sup>73</sup>



## Treatment and care

Cancer care involves engagement from multiple providers, and decisions about a person's care should ideally build on cumulative knowledge about them acquired over time.

An essential starting point for this data-driven approach is to have functioning EHRs in place, providing a holistic record of a person's interactions with the healthcare system over time, as well as patient-relevant outcomes data.<sup>3</sup> Sharing records across different institutions and providers helps avoid duplication of services and inappropriate interventions, and can facilitate treatment decision-making. Overall, this can improve care coordination and safeguard patients' time and energy as they navigate the system.<sup>3</sup> Interestingly, integrating educational alerts and decision-support tools into EHRs, facilitated by AI, has been shown to improve provider adherence to evidence-based guidelines, and thus improve quality of care.<sup>27,74</sup>

Genomic data can help predict with greater accuracy whether a person is more likely to respond to a specific therapy. This allows for reduced exposure to harmful treatments and avoidance of adverse effects.<sup>32</sup> In lung cancer, for example, tumour profiling can indicate whether a tumour has the *EGFR* gene mutation, which would make the person eligible for targeted therapies called *EGFR* inhibitors.<sup>75</sup> Genomic data can also help predict the risk of recurrence for certain cancers, providing physicians with better information to select optimal treatments early on.<sup>76</sup>

**'Cancer is a complex disease; it is different for everybody. Ensuring that we have cancer data that are relevant to each individual is vital in enabling the personalisation of treatment and care.'**

**Matthew Hickey**

The Health Value Alliance

**'Specialists from various fields involved in the treatment process should consult each other, and medical information should be gathered in one place [in the system] and be readily available to appropriate physicians.'**

**Participant**

All.Can Patient Survey (2018)

Routine collection of patient-generated health data can also help care teams better understand patient needs over time and adjust care plans accordingly. For example, regular monitoring of patients using PROMs may help the care team make necessary adjustments or cease a given treatment if the benefit to the patient is being outweighed by negative effects. PROMs can also lead to additional interventions and support to meet patients' needs over time – such as signposting to psychological support, physiotherapy, nutritional services or pain management. Using PROMs data in this way has been shown to improve quality of life and survival, lessen resource utilisation, and reduce emergency room visits and hospitalisations.<sup>77-82</sup> Remote monitoring using PROMs has become especially important during the COVID-19 pandemic (**Case study 3**).

3

Case study



## Using PROMs to effectively monitor cancer patients with COVID-19

People with cancer have an increased risk of complications and death related to COVID-19 infection during and after cancer treatment.<sup>83</sup> The Gustave Roussy Cancer Institute in France has been using a remote telemonitoring system, called CAPRI COVID-19, to identify possible COVID-19 cases early. The system also collects daily symptom reports from people with cancer and confirmed COVID-19 who are self-isolating at home.

The programme was initially set up to monitor patients with cancer undergoing oral therapy and was adapted during the pandemic. It allows for 24/7 patient communication through secure messaging. An online application enables patients to provide information specific to COVID-19 (PROMs) and presents care teams with a complete view of individual electronic patient medical records.<sup>83</sup> The programme is managed by four nurse navigators, who monitor these reports and arrange admission to emergency care or COVID-19 wards if needed.<sup>83</sup>

CAPRI COVID-19 has proven to be an efficient way to reduce patient exposure to COVID-19 and to care for those affected. It allows patients to be screened, while respecting quarantine requirements.<sup>83</sup>



Cancer treatments such as chemotherapy or radiotherapy often involve several cycles, and remote monitoring of patients in between can help detect critical health events. Remote, real-life symptom monitoring through collection of patient-generated health data via smartphones, sensors and wearables allows care teams to detect critical health events sooner and improve patient survival.<sup>38 77 84</sup> Suspicious symptoms trigger an alert for the care team, who can intervene between control visits.<sup>35 84</sup>

For example, a sudden change in a patient's physical activity levels during active treatment may indicate that they are experiencing acute toxicities, such as renal insufficiency, pneumonitis or gastritis, or a condition such as cancer-related fatigue.<sup>33</sup> Declining step count during cancer treatment has been associated with an increased risk of hospitalisation (**Case study 4**).<sup>27 35</sup>

4

Case study



## Using step count to detect chemotherapy-related toxicity in cancer patients

Physical activity can be a powerful predictor of long-term clinical outcomes in cancer, as symptoms such as pain, anxiety, fatigue or disturbed sleep patterns may all manifest as changes in physical activity. For example, step count tends to decline during treatment or following surgery, and is associated with an increased risk of hospitalisation; an increase in step count corresponds to decrease in pain, improved quality of life and more favourable clinical outcomes.<sup>35</sup>

In a pilot study of adult patients with cancer receiving chemotherapy, daily steps were monitored by a smartphone accelerometer to detect possible treatment-related toxicities.<sup>35 85</sup> When a decline in step count was greater than 15% on a given day, health teams were alerted via a smartphone application to check whether the person was experiencing treatment-related toxicities.<sup>35 85</sup> Overall, 30% of people were flagged for a drop in step count; among 60%, treatment-related toxicities could be managed over the phone, and 27.5% received urgent medical interventions.<sup>35 85</sup>

The study yielded strong patient engagement and satisfaction.

Aggregated data, such as patient-generated health data or registry data, can also be used to help inform better cancer care. PROMs data can serve as a powerful indicator of performance and care quality in a given hospital. Data can be compared across institutions to identify the root causes of any erosion of outcomes and drive patient-centred improvement efforts.<sup>36 38 81 86</sup>

Specialist cancer registries can help track the quality and management of cancer care across selected healthcare institutions. This can help to identify where quality improvement work is needed (**Case study 5**).<sup>11 18 87 88</sup> Specialist registries can also be used to monitor the effectiveness and safety of medicines by providing real-world data on wider patient populations in real-world settings. These data can also be used by physicians to inform their patients about the potential toxicity of medicines.<sup>89</sup>

5

Case study



## Improving quality of lung cancer care through a cancer registry

The Dutch Lung Cancer Audit for Lung Oncology (DLCA-L) registry was set up in 2017 to enable clinical auditing in lung cancer. It tracks quality indicators, patient and tumour characteristics, and real-world use of immunotherapy.<sup>90</sup>

The registry collects data from non-small-cell lung cancer (NSCLC) and small-cell lung cancer (SCLC) patients and had been adopted by all hospitals in the Netherlands in 2020.<sup>90</sup> It has become a valuable and comprehensive data source, providing excellent insights into hospital processes and outcomes of lung cancer care as well as real-world information on the use of (systemic) therapies.<sup>90</sup> Based on the DLCA-L data, 15 quality indicators were established to improve processes and clinical outcomes in lung cancer. Also as a result, brain imaging at diagnosis of stage III NSCLC increased from 80% in 2017 to 90% in 2019, and variations in care between hospitals were reduced.<sup>90</sup>



**The role of data analytics and AI is also being explored in improving efficiency in cancer treatment.**<sup>91</sup> AI has been successfully applied to various aspects of treatment. This includes more accurately determining tumour size and the number and location of metastases to better guide management.<sup>63</sup>

**AI may also enhance the capability of clinical decision-support tools, which can be used to aid physicians' decision-making and adherence to evidence-based guidelines.** Physicians are expected to keep up to date with an increasing amount of information. AI can help retrieve relevant medical knowledge and present it in a structured way to help evidence-based decision-making on treatment options.<sup>13</sup> Insights derived from AI can also aid in detecting patients at risk of complications or health deterioration.<sup>13</sup>

**Furthermore, AI may be helpful when managing administrative tasks, freeing up time for healthcare professionals to focus on patient care.** AI can help release practitioners from low-value-added administrative tasks and increase the time they have to focus on patients.<sup>13</sup> AI has found applications in scheduling, hospital admissions, discharge and capacity management, optimising processes in the operating room and emergency department, and moving patients between wards – leading to shorter waiting times, improved processes and better patient outcomes.<sup>13 92</sup>



## Follow-up and survivorship

Cancer is increasingly becoming a chronic condition. Patients' needs during follow-up care and survivorship may be significant – but often, they are not well met.<sup>6</sup>

People may experience long-term consequences of cancer and treatment, which can include fatigue, mental health issues and pain, and can persist for more than ten years after treatment. Such late effects of cancer or treatment can cause disruption to a person's work, as well as social isolation and financial difficulties.<sup>93</sup>

Remote patient monitoring can be an important tool to ensure continuity of care for patients after the phase of active treatment is over. It provides a cost-effective means of ensuring that a person's needs are being identified and addressed when they no longer have frequent interactions with their cancer care team. In some cases, it may improve their quality of life or even survival, compared with standard follow-up procedures (**Case study 6**).<sup>6 94-96</sup>

PROMs data, if collected on a regular basis, may provide helpful information on symptoms and late effects, and enable clinical teams to address the evolving needs of each patient.<sup>34</sup> Data on sleep patterns, mobility and cognitive functioning can also serve as useful predictors of health status.<sup>35</sup> Tracking these measures can help a person's recovery and encourage self-care.<sup>97</sup> This is still a new area of care and more research is needed to develop safe and effective follow-up systems that exploit modern technology.<sup>98</sup> This is expected to be an area of increased importance in future, especially in the context of the COVID-19 pandemic, during which the use of telehealth services dramatically increased.<sup>99</sup>

**'I had fantastic doctors, but I do feel that after the initial push to get through chemotherapy, radiation and surgery, the amount of support and concern seems to taper off.'**

**Participant**  
All.Can Patient Survey (2018)

# 6

## Case study



## Lung cancer follow-up and relapse detection using remote monitoring

Routine follow-up care for lung cancer patients commonly involves clinical assessments and imaging at standard intervals, often every 3–6 months. This may leave relapsing patients without medical input for weeks between appointments.<sup>95</sup> Repeated imaging is also costly and may increase patients' anxiety.<sup>96</sup> At least 75% of lung cancer relapses are symptomatic, and these symptoms could be monitored to improve and personalise follow-up care.<sup>100</sup>

Researchers in France developed a web-based algorithm to help oncologists intervene at the first signs of a potential relapse.<sup>95,96</sup> Lung cancer patients were asked to rate their symptoms every week using a short online form. The algorithm processed these symptom scores and emailed oncologists if there were signs of a potential relapse. The algorithm has now been built into a web and mobile application called Moovcare®. It offers significant improvements in overall survival, relapse detection and healthcare costs for people with lung cancer when compared with standard follow-up care.<sup>100-102</sup>

# 5 | Challenges and opportunities

**'It is clear that data and the insights we draw from them have the potential to transform cancer care and ultimately benefit cancer patients. If this potential is to be fully realised, some common challenges must first be overcome.'**

**Antonella Cardone**  
European Cancer Patient Coalition

The potential of data to improve care and outcomes for patients across the entire cancer pathway is tremendous. Yet it is important to recognise that the implementation of data innovations in cancer care is in its infancy, and significant challenges remain. These are illustrated in **Figure 4** and described in more detail in this chapter.

**Figure 4.** Challenges to achieving the optimal use of data in cancer care

Challenges inherent in data	Challenges with data systems	Challenges to embedding data into clinical practice	Challenges in drawing insights from data
<p>Poor data quality</p> <p>Data not representative of entire population (inequity and bias)</p> <p>Lack of data reflecting the patient perspective and outcomes that matter most to individuals</p>	<p>Data siloes hindering the ability to link data across different data systems</p> <p>Limited interoperability, further hampering data linkage</p> <p>Inconsistent use of data governance frameworks</p>	<p>Data that cannot be actioned or that have limited use in guiding cancer care</p> <p>Poor integration of data insights into clinical decision-making</p> <p>Low patient trust in appropriate use of their health data or privacy protection</p> <p>High burden of data collection, leading to limited buy-in from healthcare professionals</p>	<p>Inadequate analytical methodologies, poorly validated AI algorithms and inherent biases with data analysis</p> <p>Poor timeliness, relevance and granularity of data, limiting multi-stakeholder use</p> <p>Limited use of data to drive value-based healthcare at scale</p>

## Challenges inherent in data

### Data quality

It is common for data quality in cancer to vary across data sets.<sup>103</sup> Without high-quality data, data sets can be rendered untrustworthy and unusable.<sup>104</sup> It is therefore vital to ensure that robust quality control mechanisms are in place. These mechanisms can safeguard the quality of data collected and help maximise their role in decision-making.

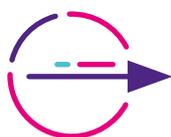
Most data quality issues arise at the point of data entry. To mitigate this, data systems should become more fit for purpose for those inputting data, and automated processes for data entry and managing data quality should be used.<sup>103 104</sup> Healthcare professionals should be offered ongoing training on data input and be given user-friendly software platforms to minimise the burden associated with data entry.

**'We have established a Data and Analytics Methods and Standards Programme, which will provide a clear framework to improve the rigour, transparency and consistency with which real-world data quality is assessed. This is to allow these important data to be used reliably in our appraisals of health innovations.'**

**Adrian Jonas**

National Institute for Health and Care Excellence

## What can policymakers do?



- Create national cancer data quality standards and build them into regular, mandatory auditing of cancer care.
- Implement technological solutions for automatic data entry, minimising the risk of human error and the administrative burden on care teams.

## Data equity

Equity is an important consideration when looking at available data. Inequities in data can take several forms, introducing biases in the availability of data about certain populations defined by race, ethnicity or socioeconomic status, as well as varying amounts of data available for different types of cancer.

Traditionally, data collection has favoured Caucasian and Western populations.<sup>105</sup> For example, in genomics, the focus of research on primarily Caucasian populations in high-income countries restricts its global applicability.<sup>105</sup> Without data specific to given populations, it is difficult to know the impact of health interventions on those groups.

Creating greater equity in data collection should be built into an overarching focus on equity across cancer services. Initiatives aiming to create culturally appropriate healthcare services should be encouraged. Examples include the use of 'equity scorecards' or dashboards to capture performance on key quality indicators according to patients' race, ethnicity and socioeconomic status.<sup>106</sup>

It is also important to recognise that data can be biased towards different types of cancer. Because most cancer registries do not collect data on cancer recurrence, information is particularly scarce on people with metastatic cancers.<sup>107</sup> These data need to be incorporated into existing cancer registries, because their absence leads to limited access to research, clinical trials and treatment advances for affected individuals.<sup>107</sup>

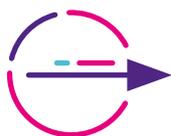
**'Most cancer registries currently only record cancer diagnoses and deaths; they do not record cancer recurrence. As a result, we do not know how many people have advanced or metastatic cancer.'**

**Fatima Cardoso**  
Advanced Breast Cancer  
Global Alliance



There are also important data gaps in rare cancers. This is mainly owing to low patient numbers and has traditionally resulted in limited research opportunities or innovations in this area.<sup>108</sup> To redress this imbalance, a number of targeted initiatives are underway. At the EU level, the European Reference Networks for Rare Cancers were set up to improve the quality of diagnosis and care and facilitate cross-border access to specialist care. Sharing of data across countries has been an integral part of the networks and has facilitated cross-country research and data collection in centralised registries.<sup>109 110</sup>

## What can policymakers do?



- **Demand greater equity in cancer research and care** by ensuring appropriate representation of people of different races and ethnicities, sex and cancer types in cancer data sets.
- **Hold institutions accountable for providing equitable cancer care** by capturing performance on key quality indicators according to patients' race, ethnicity, sex and socioeconomic status in accreditation systems.
- **Ensure proportionate allocation of funds towards specialist cancer registries** to collect data on different populations of cancer patients for whom data are less available.

## Patient-relevant data collection

Patient-generated health data are vital to understanding patients' perspective on the quality and value of their care, yet such data are not consistently collected or used.<sup>111</sup> As a result, we cannot gain a complete picture of how healthcare systems are performing from the point of view of the people they are designed to serve, and how cancer care can be adapted to be more patient-centred. We are also missing important opportunities afforded by PROMs data. By allowing us to analyse variations in care, PROMs can guide where in the care pathway improvements are needed. They also enable continuous monitoring of individual patients' health status and alert care teams when patients' health is declining.

The importance of collecting more patient-generated health data is being increasingly recognised. For example, the PaRIS initiative from the Organisation for Economic Co-Operation and Development (OECD) aims to accelerate and standardise the use of PROMs and PREMs data in the assessment of healthcare system performance. It will also allow for cross-country comparison (**Case study 7**).<sup>112</sup> The International Consortium for Health Outcomes Measurement (ICHOM) is another body leading global efforts to standardise PROMs data sets and data collection for benchmarking of hospitals and clinics around the world.<sup>113</sup>

## What can policymakers do?



- Encourage systematic and standardised collection of patient-generated health data, such as measures of patient-reported outcomes and patient-reported experiences, in key national health data sets.
- Include these data in regular monitoring and performance evaluations of cancer care to guide improvements to care most relevant to patients.



7

Case study



## The PaRIS initiative: measuring healthcare system performance based on patient-centredness

Launched by the OECD, the Patient Reported Indicators Surveys (PaRIS) initiative aims to make healthcare systems more patient-centred through internationally comparable PROMs and PREMs data collection. Initially, PaRIS will focus on breast cancer. It will fill a critical information gap and ultimately lead to the creation of new international benchmarks of health system performance based on patient-centredness.<sup>112</sup>



## Challenges with data systems

### Interoperability

It is essential to combine data from across the cancer care pathway, to fully understand the impact of interventions on patients and integrate them into secondary research.<sup>111</sup> At present, our ability to link data is often challenged by data being stored across different institutions in the care pathway (hospitals, clinics, insurers), data sets having limited interoperability, and data privacy rules preventing data sharing between institutions and countries.<sup>111 114 115</sup> As a result, few countries regularly link key national health data sets across the care pathway to monitor the quality of care and system performance.<sup>5 103 112</sup>

Recognising the importance of data linking in cancer care, many countries have invested in initiatives to make the practice more widespread. In New South Wales, Australia, data linking across key cancer data sets has resulted in successful service monitoring and improvements (**Case study 8**).

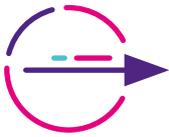
In cases where data linking into a centralised database is not possible (e.g. due to legal or technical barriers), a federated data model could serve as an alternative.<sup>13 116</sup> This is especially pertinent in data sharing across borders to facilitate research (**Case study 9**). This model allows data sets to be accessed remotely, without movement of data from their secure location of origin.<sup>117</sup> This model is being used ever more widely, due to a complicated data privacy landscape in healthcare, especially involving sensitive data that must remain inside their country or institution of origin (e.g. genomic data).<sup>117</sup>

**‘The data we collect tend to reside in different systems, which often don’t talk to each other. Unless we can gather all the bits of information from the patient journey and merge them together, we cannot fully improve care for our cancer patients.’**

**Christobel Saunders**  
University of Western  
Australia

An example is the European Health Data and Evidence Network (EHDEN), an emerging, federated, EU-wide programme to analyse real-world data for healthcare decision-making.<sup>13 116</sup> The World Economic Forum is also invested in federated data models as a solution to cross-country data sharing and has developed an initiative called the Breaking Barriers to Health Data Project. This aims to create a federated data model to share genomic data globally.<sup>117 118</sup>

## What can policymakers do?



- **Develop common data standards, specifications and processes** to improve the national and international interoperability of data sets.
- **Scale-up existing national and international initiatives** on data standardisation and interoperability.



# 8

## Case study



### The use of linked data in service monitoring and improvement in New South Wales, Australia

In 2011, an initiative called the Reporting of Better Cancer Outcomes (RBCO) was launched to continuously monitor and evaluate treatment outcomes and performance of cancer services by harnessing linked cancer data.

RBCO involves linking data from the New South Wales cancer registry, inpatient and emergency department records, screening registries, state-wide radiotherapy data, medical and pharmaceutical benefits claims, and reported causes of death. Data are analysed to assess performance trends. This information is then fed back to clinical networks, services and administrations for service improvement.

The initiative has placed a focus on improving outcomes for priority groups such as Aboriginal peoples and Torres Strait Islanders, culturally and linguistically diverse groups, and residents of remote or socioeconomically disadvantaged areas. It has resulted in improvements to cancer services and patient outcomes, including consolidation of surgical treatments at specialist hospitals for a number of cancer types. It has also helped to identify variations in cancer service delivery and increased the use of patient-reported measures.

# 9

## Case study



### **HONEUR: a federated data network for real-world data analysis and evidence sharing**

The Haematology Outcomes Network in Europe (HONEUR) was launched to increase the knowledge and understanding of haematological cancers and improve outcomes for patients across Europe by harnessing the power of data analytics.<sup>119</sup>

The network is run as a federated model, where the data stay at the respective sites and the analysis is executed at the local data sources. It uses the common data model called OMOP (observational medical outcomes partnership), ensuring participating sites maintain local governance and can initiate their own research questions. No patient-level data are stored on the HONEUR portal – only aggregated results of a research question can be shared securely.<sup>120</sup>

HONEUR is a secure, collaborative platform that allows for the analysis of data on multiple data sets with methodological and statistical possibilities.<sup>120</sup>

It increases the value of the data by enabling their re-use across a wide range of research studies, and encourages publication of results so that insights can contribute towards improving patient outcomes. It currently enables participants across Europe to analyse 23,000 data sets in haematological malignancies.<sup>120</sup>

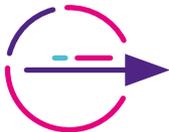
## Health data governance

Health data governance frameworks are essential for a safe and coordinated approach to optimising use of data within countries.<sup>5</sup> Data governance strategies help define how an organisation, or a country, manages its data assets, protects patient information and uses these data to guide decision-making.<sup>121</sup>

In the past, countries have been slow to adapt governance frameworks to harness data in health. Many are still developing their policies and regulations defining governance, citing barriers such as gaps in funding, leadership and technical expertise, and competing priorities within the health system, as reasons for slow progress.<sup>5,9</sup>

However, several promising initiatives have been launched in this area. The legislative proposal for the European Health Data Space, for example, will enhance cross-border data governance within the EU.<sup>122</sup> The Findata initiative in Finland, meanwhile, provides a legislative framework for the secondary use of health data for research purposes across the country, acting as a data permit authority and making health data available to different sectors for research and innovation (**Case study 10**).<sup>123</sup>

### What can policymakers do?



- Build harmonised data governance legislation to facilitate health data linking and sharing between providers, and ideally between countries.
- Enable the creation of federated data networks when national and international data linkages are not possible.
- Invest in creating national health data codes of conduct to facilitate the safe use of health data, limiting barriers to data sharing while protecting patient privacy.

# 10

Case study



## Findata: legislation to facilitate secondary use of health data

In 2019, Finland passed legislation to facilitate the secondary use of Finnish social and health data, representing one of the first implementations of the European General Data Protection Regulation for the secondary use of data.<sup>124 125</sup> Findata expands access and use of social and health data beyond the traditional areas of research and statistics, to sectors including management, development, innovation, education, planning, and steering and supervision work. It allows access to data from national social and healthcare registers, data from patient systems in primary care, and specialist healthcare and social services.<sup>124 125</sup>

Data can be accessed for secondary research purposes, such as statistics, scientific research and other activities. Access is controlled by a central authority – making it easier for individuals, companies and organisations to apply and access the data.<sup>124 125</sup>



## Challenges embedding data into clinical practice

### Data burden on healthcare professionals

It is important to make data collection as simple and efficient as possible for clinicians, to minimise the burden of data collection. Time-consuming data collection processes can act as a perverse incentive to clinicians in recording and using data.<sup>36 38 126</sup>

For example, the American Medical Association attributed difficulties with EHRs and their design as a contributing factor to physician burnout and wasted time. Issues such as lack of integration into provider workflows and EHRs being optimised for provider billing instead of patient care were identified.<sup>127</sup>

Designing data systems with the physician and patient in mind can be instrumental in increasing engagement from these vital stakeholders.<sup>127</sup> Where possible, technological solutions should be utilised to automate data collection and minimise the administrative burden it can place on care teams.

**Data should be presented to clinical teams in a clear way that makes it evident how they can be actioned to improve patient care.** Intuitive displays and dashboards enable care teams to rapidly assess and interpret data findings during a consultation, and use these to optimise patient care in real time. Data analytics and AI can process large amounts of data to gain actionable insights, and intuitively display these back to care teams.<sup>13</sup> Training and upskilling the workforce on how to use these tools and interpret results will support their effective use.<sup>13</sup>

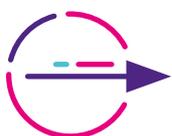
**'One of the most important aspects for clinicians is that the data being collected are meaningful – something they can act on to improve patient outcomes.'**

**Jan Van Meerveld**  
Antwerp University Hospital



Lastly, it is essential to create a positive data-sharing culture. Resistance to data sharing, such as fears of ‘naming and shaming’ or reputational impact, can be overcome by building positive incentives for data sharing into the care pathway.<sup>111</sup> In France, as part of initiatives to foster value-based healthcare, doctors were financially rewarded for sharing data on patient outcomes with what they called a ‘transparency fee’. The fee was set at €30 for health outcomes data shared, regardless of the actual outcome achieved. This created a healthy incentive for data transparency on health outcomes.<sup>128 129</sup>

## What can policymakers do?



- **Build in positive incentives for data collection and use across the cancer care pathway**, to foster a culture of value-based healthcare.
- **Embed data-analytic solutions into care processes** to enable rapid processing and feedback of data insights to clinical teams to guide decision-making.
- **Provide appropriate funding and resourcing to train and upskill** the healthcare workforce so that they keep pace with innovations in data collection and use.



## Patient trust

Opinion studies often show that both patients and the general public support sharing personal health data for research purposes.<sup>130 131</sup> For example, 73% of EU citizens want to share health data on the condition that it is done securely, and that data are accessible only by authorised parties.<sup>8</sup> At the same time, citizens are becoming increasingly aware of the risks associated with sharing their data and have significant concerns around data privacy and confidentiality.<sup>131</sup>

**Building public trust is essential.** Each person should know how their health data may be used, the goals of research involving their data, and how they can opt out.<sup>131</sup> Fostering transparency in data use across cancer care helps to build public trust in data systems.

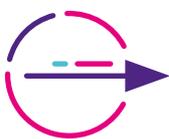
**Continued conversations, education and an open dialogue with patients and the general public are important to ensure their data privacy and confidentiality concerns are being met.** This can be achieved through initiatives such as Data Saves Lives, which creates patient and public dialogue about the importance of health data across Europe.<sup>132</sup>

**'We must all do more to promote patient and public awareness about why their data, including data they themselves collect, are vital to improve healthcare and accelerate research. We also have to make clear how these uses of data can be undertaken in trustworthy ways.'**

**Dipak Kalra**

European Institute  
for Innovation through  
Health Data

## What can policymakers do?



- **Create public awareness and education campaigns** to convey the power of meaningful data to better manage cancer care.
- **Engage with patients to discuss how data are being used,** and address misconceptions around the nefarious use of health data.
- **Continuously adapt legislation** and tools to give citizens appropriate control over their own health data, so they may act as their own data 'gatekeepers'.



## Challenges in drawing insights from data

Data analytics are necessary for extracting insights from vast pools of structured and unstructured data. The field of AI, in particular, is rapidly evolving and still in early stages of development in cancer, and there are many barriers to its everyday use.<sup>63 91</sup>

**A lack of trust in AI is a main factor holding back its implementation.**<sup>133</sup> Many stakeholders have expressed concerns over ethical issues with AI (such as biases) and validity of the data that underpin AI algorithms.<sup>13</sup> Many AI models replicate biases in existing data sets, therefore AI-based support tools that are used to guide patient care will need careful auditing and quality controls to avoid racial bias or other potential harms due to system shortcomings.<sup>127</sup> As AI relies heavily on data availability and requires large volumes of data, poor quality or lack of data availability limit our ability to develop AI-driven health data analysis solutions.<sup>13</sup>

**AI requires highly technical knowledge and expertise for its appropriate use.** Healthcare professional buy-in and support for AI is currently lacking and many have not used AI in their day-to-day work.<sup>13</sup> Upskilling of the current workforce is needed.

**Governments recognise the importance of AI for improving healthcare.** There have been an increasing number of aspirations, frameworks, targets and standards on the use of AI, and subsequent investment in AI research, from governments and other stakeholders globally (**Case study 11**).<sup>133</sup>

## What can policymakers do?



- **Apply appropriate regulatory standards** to fundamentally protect citizens' rights and values by ensuring that:
  - data sets from which insights are drawn are adequate, equitable and sufficiently representative to train artificial intelligence algorithms while minimising potential biases
  - the analytics used (including artificial intelligence algorithms) are standardised, transparent and subject to rigorous evaluations of clinical safety and effectiveness
  - the insights drawn from data analysis are of high quality.



# 11

## Case study



### The ATHENA project: harnessing the power of AI for secondary use of data to advance precision medicine in cancer care

The ATHENA (Augmenting THERapeutic Effectiveness through Novel Analytics) data science innovation project, launched in 2020 and funded by the Flemish government's Agency for Innovation and Entrepreneurship, aims to improve cancer care insights by using machine learning to analyse combined Omics and Non-Omics (OnO) patient-level data. The project is applying these methods in bladder cancer and multiple myeloma.

It will run until mid-2023.

ATHENA facilitates the re-use of clinical data for secondary research by using a federated data network model for data analytics. Data remain local, under governance of the data custodian (in this case, the hospital), and the analysis is brought to the data. Only query results will go back to a central location and no patient-level data leave the hospital.

ATHENA uses an AI system and supports research organisations and biomedical companies to analyse the data. It was conceived with the aim to advance medical science, for the development of new treatments and to accelerate clinical research. In a later phase, hospitals around Europe can join the initiative, potentially increasing the volume of data as well as the robustness of the insights.

# 6 | Conclusion

**'We need to think of data as an investment, but also as an innovation. Having the correct data systems in place, to be able to harness their value, is as important to the future of cancer care as new medicines and other advances.'**

**Vivek Muthu**

Marivek Healthcare Consulting

Recent advances in data and data analytics have led to transformational changes in the way we deliver cancer care. Still, we are only on the cusp of exploiting their full potential, and historical challenges that have hampered progress in this area persist.

Quality cancer care relies on us taking a data-driven approach to decision-making – for each individual patient, for the population as a whole, and across all steps in the care pathway. This can only happen if we invest in making sure the data we collect are of the highest quality and relevance. We need to make appropriate linkages between existing data systems and use the right tools to draw insights from them. Finally, we need to build data into continuous improvement measures at an individual, organisational and national level.

The COVID-19 pandemic has focused the world's attention on the role of data in addressing some of the biggest challenges in healthcare and, equally, in cancer care. As we look to post-pandemic recovery, we have a unique opportunity to build more sustainable, resilient and efficient systems of care, leaving nobody behind.

Addressing the challenges in data is essential to achieving this goal. As part of the digitisation agenda, policymakers must implement lasting changes across systems of care and policy frameworks to enable data to achieve their full potential for the benefit of all people with cancer. Commitment is needed to embed optimal use of data across all facets of cancer care, in all settings, for all people living with and beyond cancer.

# Glossary

The definitions of terms used in this report are either those widely adopted (referenced as appropriate) or All.Can's internal definitions.

**Artificial intelligence (AI):** the capability of a computer program to perform tasks or reasoning processes that we usually associate with intelligence in a human being. AI is used in healthcare to manage large data sets, gain insights and extract patterns from vast amounts of data.<sup>13</sup>

**Big data:** extensive collections of data, also called repositories. In healthcare, big data describes large healthcare databases or networks of interconnected healthcare databases coming from multiple organisations.<sup>22</sup>

**Big data analytics:** the use of advanced analytic techniques against very large, diverse data sets that include structured, semi-structured and unstructured data, from different sources and in different sizes.<sup>134</sup>

**Data governance:** defining, implementing and monitoring strategies, policies and shared decision-making over the management and use of data assets.<sup>135</sup>

**Digital health literacy:** the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.<sup>136</sup>

**Electronic health record (EHR):** organised set of health data which can be accessed electronically. EHRs contain a diversity of data, the most frequent being medical records from

general practitioners, specialists, hospitals, pharmacies, prescription data and sometimes lifestyle-related information.<sup>16</sup>

**Electronic medical record (EMR):** computerised medical record created by an organisation that delivers care, such as a hospital or physician's office, for each patient of that organisation.<sup>21</sup>

**Federated data models:** models in which data sets are analysed remotely, without movement of data from their secure location of origin.<sup>117</sup>

**Genomics:** the study of different aspects of human genes and their functions, including genetics (variations in DNA sequence and their function), transcriptomics (variations in RNA sequence and their function) and epigenetics (modifications of gene expression rather than genetic code alterations).<sup>29</sup>

**Late effects:** a health problem that occurs months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental and social problems and metastatic cancers.<sup>137</sup>

**Machine learning:** a branch of artificial intelligence that focuses on the development of computer programs and mathematical algorithms that can process data and use them to learn for themselves over time without being programmed to do so.<sup>63 138</sup>

**Patient-generated health data:** data gathered from patients to help track health concerns and health status.<sup>33</sup> They can originate from a variety of sources, including self-reported health and treatment histories, patient-reported outcomes and digital biomarkers.<sup>27 33-35</sup>

**Patient-reported outcome measures (PROMs):** tools used to measure patient-reported outcomes. They collect information on how a patient sees their own health or the impact of a given intervention on their health.<sup>36 38</sup>

**Patient-reported experience measures (PREMs):** tools that measure a patient's view and experience while receiving care. They are designed to look at aspects of the care process and how it impacts the patient experience. They are an indirect indicator of quality of care.<sup>36 37</sup>

**Personalised medicine:** the characterisation of individuals' phenotypes (observable characteristics and traits) and genotypes (e.g. molecular profiling, medical imaging, lifestyle data). It can be used to tailor a therapeutic strategy to the person, determine the person's predisposition to disease or deliver timely and targeted prevention.<sup>31 32</sup>

**Primary use of health data:** the use of data to support the delivery of care to the individual for whom they are collected.

**Registry:** an organised system that uses observational study methods to collect uniform data to evaluate specified outcomes for a given population. Registries serve a predetermined scientific, clinical or policy purpose.<sup>5</sup>

**Secondary use of health data:** the use of data beyond direct patient care and healthcare delivery (for analysis, research, quality and safety evaluations, commercial activities etc.) with the data collected on individuals being analysed for purposes other than their own care.<sup>10</sup>

**Survivorship:** focuses on health and the physical, psychological, social and economic issues affecting people after their primary treatment for cancer is over.<sup>139</sup>

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