

Harnessing data for better cancer care

Report summary



All.Can 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 the report

This is a summary of pages 1–9 of *Harnessing data for better cancer care: a policy report by All.Can International*. The full report is available on www.all-can.org/what-we-do/research/data-paper-project

The 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.

Authors

The 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 the report and to contributors who were interviewed for the project.

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).

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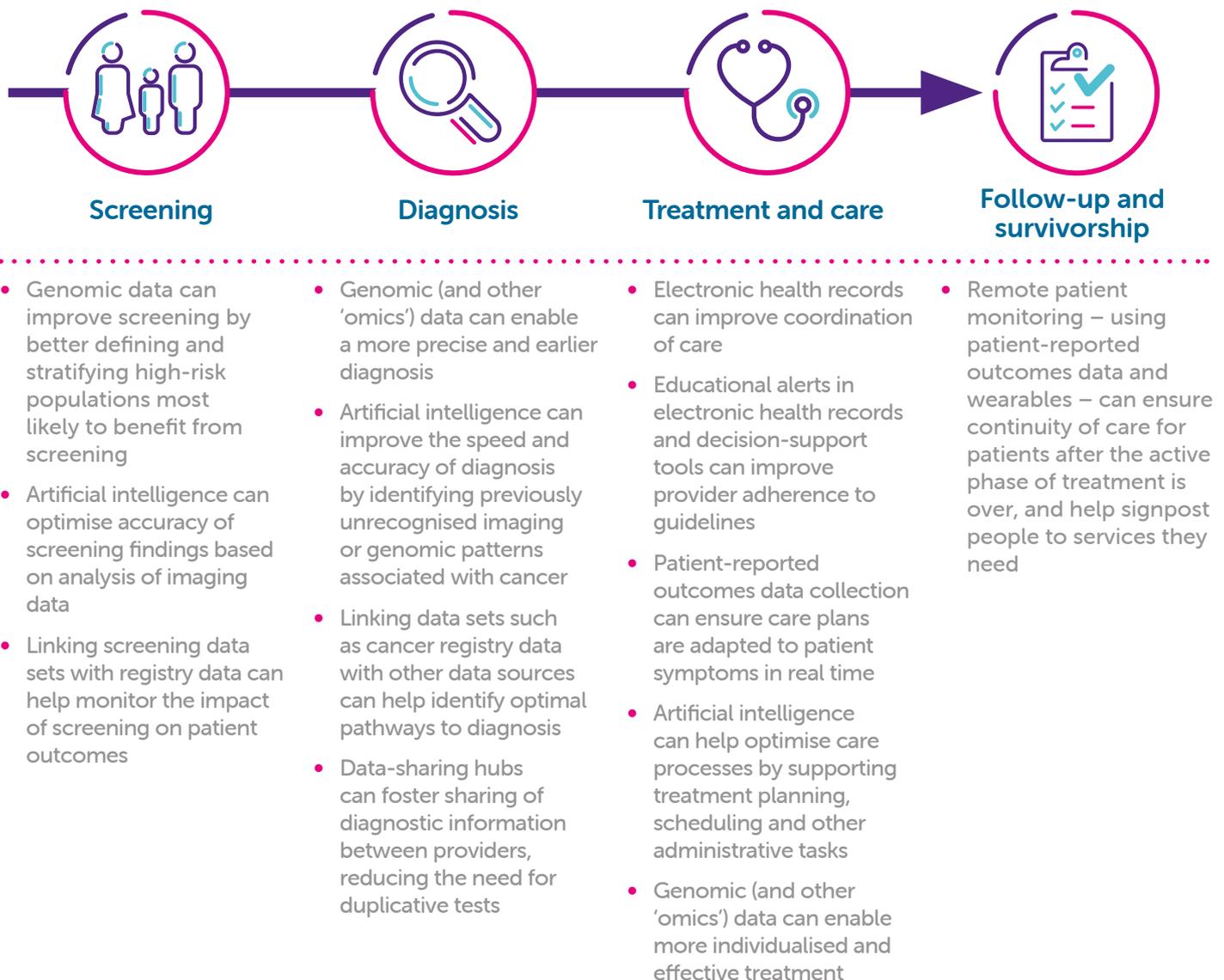
Executive summary

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 of the report, 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.

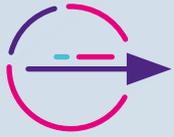
Common challenges with cancer data include (but are not limited to) those outlined in **Figure b**.

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.

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