All.Can
Changing cancer care together

All.Can Global Summit

"Improving efficiency in cancer care through multi-stakeholder collaboration"

Thursday, 27 May, 15:00 - 17:15 (CEST)

#AllCanGlobalSummit

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All.Can is a multi-stakeholder initiative involving patient, clinical, academic and industry experts as well as policymakers. We aim to help define better solutions for sustainable cancer care and improve patient outcomes in the future. The All.Can initiative is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors) and Baxter and Illumina (contributors), with additional non-financial (in kind) support from Helpsy, Intacare and Goings-On.

Harnessing data for better cancer care: All.Can’s policy report findings

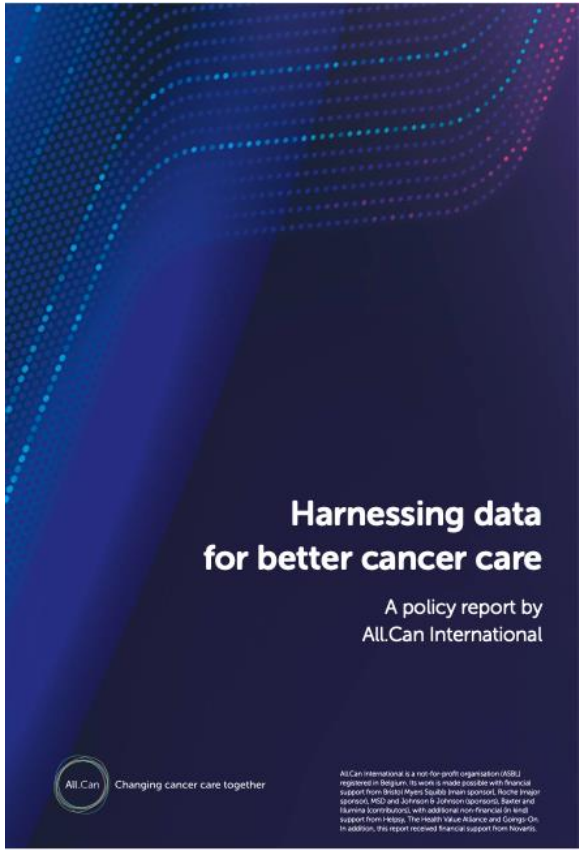
Matthew Hickey

CEO of The Health Value Alliance

Head of Cancer AXA Health UK

Co-Chair All.Can Research and Evidence Working Group

Co-Author All.Can Data Policy Report



Harnessing data
for better cancer care

A policy report by
All.Can International

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.

New report by All.Can

The report provides policymakers, care providers and decision-makers with a view on how to ensure that high-quality health data are systematically collected and used to improve care and patient outcomes

Why this report?

The COVID pandemic legacy

- Focused the world’s attention on the potential role of data in addressing some of the biggest challenges in healthcare
- Caused a backlog of cases that will require a greater focus on building efficient, sustainable cancer care systems that can deliver optimal outcomes to patients

Data: an integral part of post-COVID recovery

- Digitalisation agenda key part of all countries’ post-COVID recovery plans
- Opportunity to ‘get this right’ and address longstanding hurdles to optimising the role of data in driving high-quality and efficient cancer care.

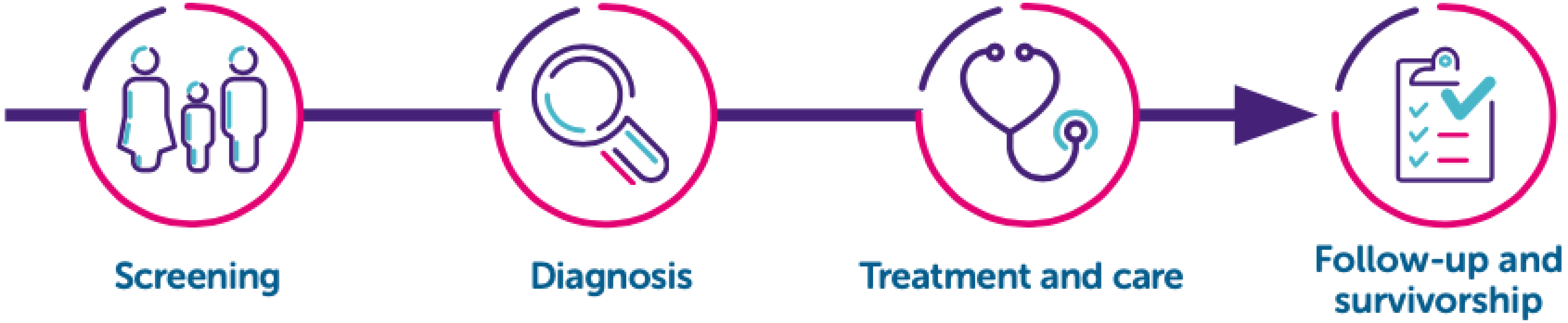
An External Advisory Committee provided expert guidance to the project:

- **Fatima Cardoso**, Advanced Breast Cancer Global Alliance
- **Sybo Dijkstra**, DigitalEurope
- **Nigel Hughes,** European Health Data and Evidence Network (EHDEN) & Janssen
- **Adrian Jonas,** The National Institute for Health and Care Excellence (NICE)
- **Sabrina Montante,** Istituto Superiore di Sanità
- **Francesco Pignatti,** The European Medicines Agency (EMA) (observer)
- **Ray Pinto,** DigitalEurope
- **David Roder,** University of South Australia
- **Abdullahi Sheriff,** MSD

The health data ecosystem is complex, constantly evolving, and health data are ill-defined

The report focuses on key data challenges and opportunities **across the cancer care pathway**, focusing in particular on:

- Cancer registry data
- Data from electronic health records and medical records
- Genomic data and
- Patient-generated health data, including PROMS and Patient Experience



Defining health data

Health data:

'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'.[1]

1. Data Saves Lives. 2020. Overview: Health Data. Available from: https://datasaveslives.eu/health-data-overview [Accessed 22/10/20]

Harnessing data

We are still far from fully harnessing the potential of data to transform cancer care due to **fundamental and common challenges** - none of which are insurmountable!

The Health Data Ecosystem

Challenges inherent in data

Challenges with data systems

What is preventing us from fully harnessing data in cancer care?

Challenges embedding data into clinical practice

Challenges drawing insights from data

Addressing challenges inherent in data

Challenges:

- Poor quality
- Data not being representative of entire populations (inequity and bias)
- Lack of data on the patient perspective

What can policymakers do?

- **Create national data quality standards** and regularly audit data systems against these measures
- **Demand greater equity** in cancer research and care. Ensure representation of people of different races and ethnicities, sex and cancer types in cancer data sets
- **Systematically collect data that are most relevant to patients** in key national data sets and use them to evaluate healthcare system and provider performance

Addressing challenges with data systems

Challenges:

- Limited interoperability of data sets
- Inconsistent use of data governance frameworks
- Low patient trust

What can policymakers do?

- **Develop common data standards,** specifications and processes for data collection
- **Build harmonised data governance legislation** to facilitate health data linking and sharing between providers, using **national health data codes of conduct**
- **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 health data,** so they may act as their own data 'gatekeepers'

Addressing challenges embedding data into clinical practice

Challenges:

- Limited actionability of data
- Poor integration of data insights into clinical decision-making
- High burden of data collection on care teams

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.

Addressing challenges in drawing insights from data

Challenges:

- poorly validated algorithms and inadequate analytical methodologies
- lack of trust in artificial intelligence

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 are standardised, transparent and subject to **rigorous evaluations** of clinical safety and effectiveness
- the insights drawn from data analysis are of **high quality.**

Call to action

We need to think of data as both **an investment and 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.

Commitment needed from policymakers:

- To embed optimal use of data across all facets of cancer care, in all settings, for all cancer patients.

Thank you for your attention!

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To find out more about All.Can, visit www.all-can.org

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