Cancerworld

The potential of data to improve efficiency in cancer care

Adriana Albini / 5 October 2021

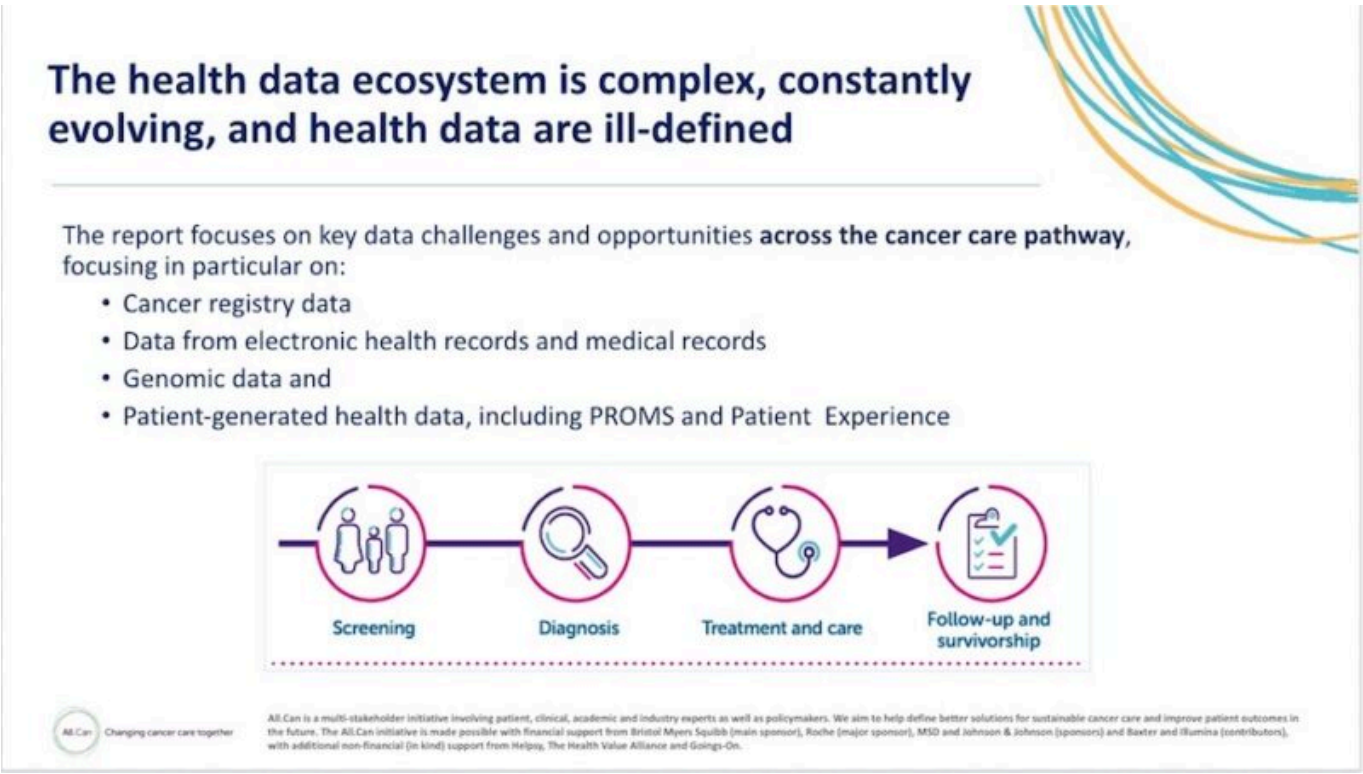
Dr Pietro Presti, CEO of Sharing Progress in Cancer Care, Turin, Italy, introduced this webinar focussing on the crucial role that high-quality data can play in improving cancer care and patient outcomes. There are many challenges to overcome in the collection and management of data, and standards to be defined, in order to achieve better transparency in the complex ecosystem of health data capturing, interpretation and actualisation.

The All.Can Data Report: findings and recommendations

Mr Matt Hickey, founder and CEO of the Health Value Alliance, founder of Intacare, and Co-Chair of the All.Can International Research and Evidence Working Group, presented the All.Can policy report 'Harnessing data for better cancer care'. The report, which took a year and a half to complete, presents the findings of a literature review and global stakeholder consultation programme, with the All.Can Data Working Group and an External Advisory Committee. The report aims to offer policymakers, care providers and decision-makers a view the opportunity data provides for improving efficiency and outcomes in cancer care. Additionally, how to ensure that high-quality health data are systematically collected to achieve this aim. The project was initiated and completed during the Covid crisis, which brought to the world's attention the potential role of data in addressing some of the biggest challenges in healthcare. The pandemic also caused a significant

backlog in cancer diagnosis and therapy. To address this backlog more efficient and sustainable care systems will be needed. There is a greater focus now on efficiency, on fast-track pathways, on ensuring that patients get minimal in-person interaction with hospitals. Data gathering and use are fundamental in ringing the necessary changes. The digitalisation agenda is an integral part of post-Covid recovery worldwide. It is important to harness the current opportunity to 'get this right' and address longstanding hurdles to optimising the role of data in driving high-quality and efficient cancer care.

The health data ecosystem is complex. It is constantly evolving and health data themselves are often ill-defined. The All.Can report highlights key challenges and opportunities across the cancer care pathway, such as: cancer registry data; data from electronic health records and medical records; genomic data and patient-generated health data, including PROMs and Patient Experience.



There are more than 700 registries worldwide collecting cancer data, but they are not combined or accessible, so the information often remains in siloes. Data also exists in a plethora health electronic records and medical records, be that in paper form, in digital form. The complexities associated with genomic data are considerable. Perhaps most importantly, patient-generated health data, such as patient reported outcomes measurement (PROMs) and patient experience (PREMs) must also be systematically collected, analysed and acted upon. For effective insights to be drawn, data that stems from across the whole of the cancer care continuum, from screening to diagnosis, treatment and care, follow-up and survivorship needs to be leveraged.

Defining health data

The very first challenge faced by the All.Can team was to define what data actually is. The formulation agreed upon was an all-encompassing definition proposed by the Data Saves Lives initiative: *'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*'.

The next step was to look at the data ecosystem, where it comes from and how it is how data is collected. Evident from this review was that we are not harnessing the full potential of data to transform cancer care. Also, that we have some fundamental and common challenges, but none of these are insurmountable.

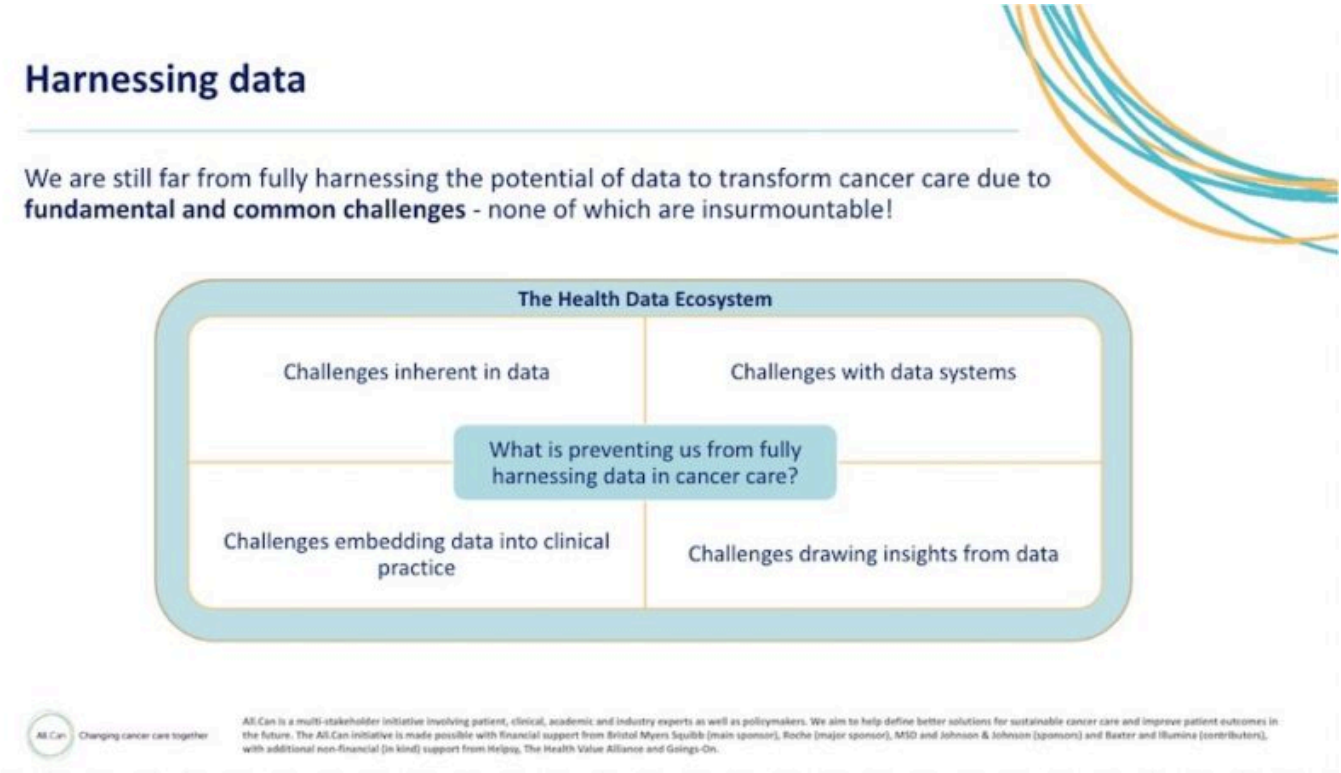
Challenges inherent in data: The benefit of any innovation can only truly be realized by the benefit to the patient, and so their voice is fundamental. However, there are inherent challenges in data. These include, poor quality, data not being representative of entire populations (inequity and bias), and a lack of data from the patient's perspective. To address this, policymakers need to create national data quality standards and ensure that there is a regular data audit program. This audit should include assessing and demanding greater equity in cancer research and care; ensuring people of different ethnicities, sex, and cancer types are fairly represented in the cancer data sets. As well as ensuring there is systematic collection of data that are most relevant to patients. These data also need to be developed into standard national data sets and used to evaluate healthcare system and provider performance.

Challenges with data systems: These include; limited interoperability of data sets; inconsistent use of data governance frameworks; and low patient trust, where the patient might ask, "What are you going to do with my data?". To overcome these obstacles, we need to develop common data standards, build harmonised data governance legislation to facilitate health data linking and sharing between providers. This will involve using national health data codes of conduct and engaging with patients to discuss how their data are being used. Insights can then be used to address misconceptions around the nefarious use of health data. Furthermore, legislation can then be constantly adapted and tools can be given to citizens to enable them to control their health data, effectively enabling them to be their own data 'gatekeepers'.

Challenges with embedding data into clinical practice: These include; the limited actionability of data: is it in real time? Does it help me make a decision today? Generally, there is poor integration of data-derived insights into clinical decision-making. Also, the high burden of data collection on care teams (another administrative burden) poses a challenge. To address this, policymakers need to: 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 real-time feedback and real-time insights for the decision maker at the point of care; and provide appropriate funding and resourcing to help train and upskill the health care workers so that they can keep pace with the innovations and utilise the data correctly.

Challenges in drawing insights from data: Poorly validated algorithms and inadequate analytical methodologies; lack of trust in artificial intelligence are key challenges here. Artificial Intelligence (AI) is becoming more and more embedded into mainstream oncology. Yet there remains inherent scepticism by many clinicians – how do we (or why should I) trust the machine? To address this, policy makers need to ensure appropriate regulatory standards are established that 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. And finally, the insights that are drawn are of high quality and have real-world applicability.

We also need to think of data as both an **investment and an innovation**. This will help ensure there is motivation to have the correct data systems in place, to be able to harness their value. Investment in data and data infrastructures is now considered to be as important to the future of cancer care as new medicines and other advances.



Next to speak was **Dr Abdullahi Sheriff**, Associate Vice President, Global Leader, Affordability and Sustainable Access Solutions, MSD, who presented a personal view on data standards.

A focus on transparent and inclusive standards

Transparent and robust data standards build trust, strengthen decision making, stimulate innovation and enable more sustainable and inclusive advancements in cancer care.The growing availability of real-world data holds exciting potential for driving sustained innovation for the benefit of patients and society.

The definition of **real-world data** (RWD) used at MSD is “data relating to patient health status and/or the delivery of health care that is routinely collected from a variety of sources, primarily outside the typical research setting.” Examples include: claims data, electronic medical records, prescription refill data, lab reports, physician notes, biomarkers and genomics data, patient registries and surveys, data from patient wearable devices, social media, etc. This is well depicted in the pie chart in the All.Can data report, which comprises all the various sources of data, from public health and standardized information data, through to personalized generated information, information about care, about stakeholders, et cetera.

Data is an integral part of the underlying cancer journey; it drives decisions at every step of the pathway, from prevention, through screening, diagnosis, care, and follow-up. Data exists across the whole of the cancer continuum, and innovations in the way we collect and use it have massive potential to help us improve efficiency in cancer care. Data is not just for the policymakers; we all use it. Whichever hat we are wearing – patient, clinician, regulator, academic, etc. – we look at data to plan a course of action, be it self-care, clinical, operational or financial. Yet, we are not always able to leverage data to make decisions. Why? It might be due to the quality, availability, and accessibility of the data. We need systems that enable us to access the data and, more importantly, to use it in the way that we want to, embedded into routine activity. There can be a disconnection between the data, how and where it exists, and how people live on a day-to-day basis, the range of decisions they need to make.

Inadequate data standardization can mean that we are not all looking at the same thing, and thus we cannot feel confident in the decisions we're making. Robust and inclusive data, underpinned by consistent standards, on the other hand, can help us make informed decisions. A good example of how this works in practice is the Transport for London map. Its data is underpinned by standards that allow travellers to easily navigate their journey through the system and find the most efficient route for their requirements. A wheelchair user, for instance, can identify step-free stations that provide easy access. If someone decides to do part of the journey by underground and part by bus, a combined map helps them plan their route successfully. Why can't we have an equivalent navigation system for cancer care? Inclusive and transparent data build trust. When we arrive at the airport, we need not worry about how we are going to reach central London. We can consult the map and choose what transport infrastructure to use. This makes us feel part of the system, it allows us to make objective and transparent decisions. We need an equivalent navigation system for cancer care. The Travel for London network chart allows us to use multiple routes because we can see our destination in context, in a more holistic manner. This provides a basis for inclusion and representation of all parties in the ecosystem. Whether or not we are a wheelchair user, whoever we are or where we come from, we find the information to make the decisions that best align to our desired journey. Having consistent standards empowers us to build a system that works, that we can all feel part of and that helps us navigate more effectively.

We are all decision-makers in healthcare, and we are diverse. We all look at the world differently and to make decisions we need inclusive data, that reflect the diversity of who we are, of where we're coming from and, consequently, of the kind of journeys that we may choose based on our worldview. As decision-makers, we need to be confident that the data we have is the right one and that the decisions we're able to make are the right ones. Confidence comes from trust. Trust that what we are seeing is right, that the judgements we're making are right and the actions we're able to take on the back of those judgments are also right. Confidence is further reinforced when the data we are looking at is transparent, inclusive, and we know where it comes from.

Establishing clear and consistent global standards will help to increase confidence among decision makers on quality, relevance, and reliability of data; ensure clarity and consistency for creators, innovators and consumers of data driven products and services; help generate public trust in the regulatory framework and in the decisions the relevant agencies make leveraging data. Transparency needs to span across the entire data lifecycle through to the end of life: transparency in how we generate, process, use, reuse, manage and curate data. We cannot just have transparency in one area and expect to build trust. People need to know where the data comes from and how is it used.

Health equity is fundamental, how do we make sure nobody is left behind? How do we create standards that everybody can engage with? Going back to the Transport for London example. It is designed for inclusivity and equity. For instance, we do not need a smartphone to navigate it, we can pick up a paper-printed map instead. How do we translate that in the context of cancer care? We need to use data to drive equity and embrace diversity and inclusivity, encourage participation, consultation, collaboration and, most importantly, empower the actors in the system because patients should not be afterthoughts in our design of healthcare system.

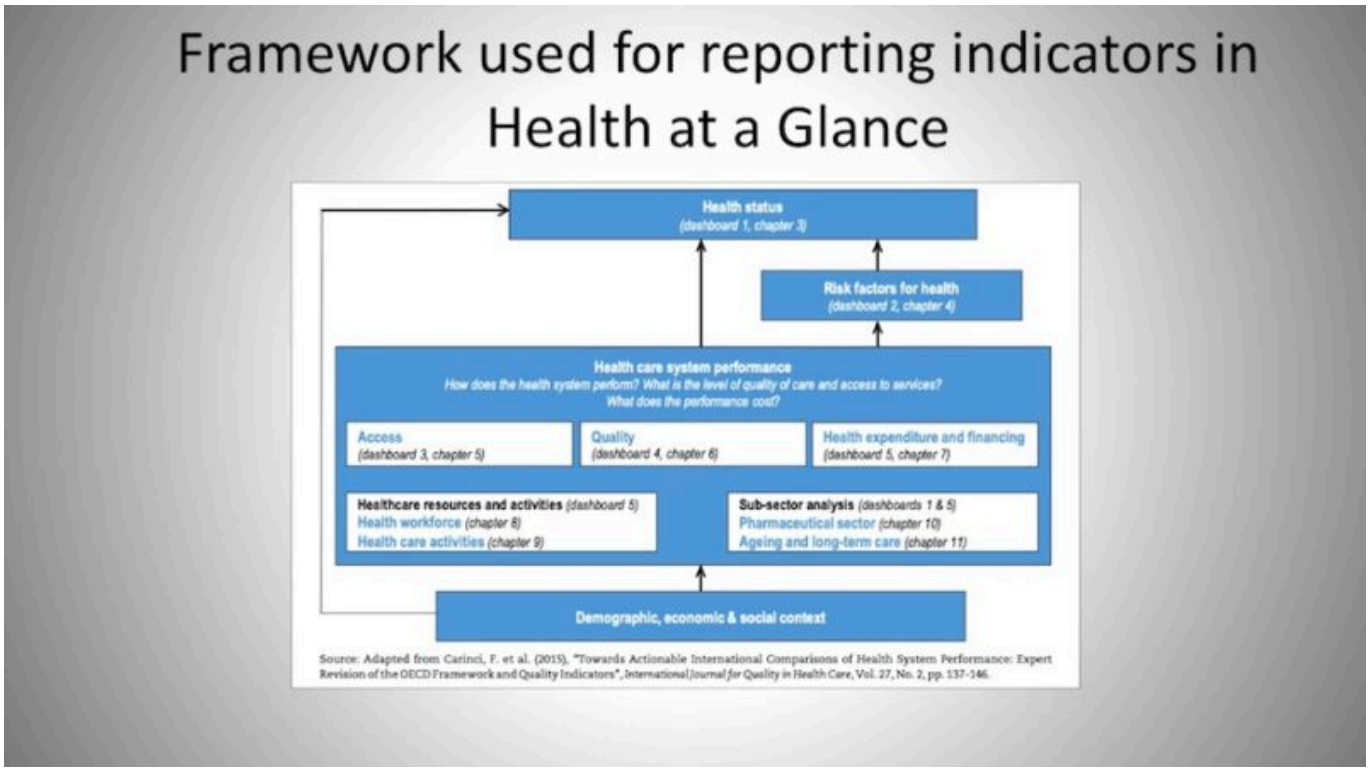
Transparency and inclusivity underpinned by clear standards are fundamental for driving and sustaining innovation in cancer care. They build trust, strengthen decision making, stimulate innovation and enable advancements in its delivery, in a sustainable way. To obtain them we need to drive deeper collaboration between the various actors – industry, healthcare system, patient groups, academia – to stimulate innovation, and establish common frameworks. We must get patient groups actively involved in the design, the delivery, and the implementation of all these innovations, and we need to globally coordinate the design and implementation of standards.

The final speaker was **Dr. Niek Klazinga**, Head of the Health Care Quality Indicator Programme, Organisation for Economic Co-Operation and Development (OECD).

Capturing quality and outcomes through OECD programmes

Data challenges, of course, are not unique to cancer care. Similar discussions about the optimization of data usage arise in the healthcare system as a whole and, more broadly, in economic developments. OECD's Health Division provides comparative data and analyses on the health care systems of its 38 member states. Cancer care data are an integral part of this work and are viewed within the context of the overall performance of the heath care systems. A large amount of data on this is already in the public domain on the OECD website. The report *Health at a Glance* is released every two years. The next edition will be out in November this year and will contain a wealth of statistical information on the performance of healthcare systems, structure, process, outcomes, number of professionals, number of healthcare services, waiting times, throughput, quality of outcomes, and so on. 'Quality of outcomes' is the program for which Dr Klazinga is strategic lead. Information on health data governance is fundamental. The quality of the data infrastructure in a country is essential for monitoring its health system performance. The *Health Data Governance* edition from 2017 includes council recommendations on standards for member states, how to set-up their health data infrastructure to maximize the use. *Cancer Care – Assuring Quality to Improve Survival*, published back in 2013, shows the same philosophy found in the All.Can report: it looks at what a country is doing with respect to the entire pathway, from prevention, screening, diagnosis, treatment, to follow-up care. *Health at a Glance* indicators are reported within the broader view of the determinants of health, such as health status, risk factors, performance of the systems, in order to identify excess quality and expenditure, and set them within the context of the demographic and even of the economic and social situation of a country. At a macro level, we can look at equity and efficiency, but we can also zoom in and look at specific disease areas, which is what it is being done with cancer care. OECD often works with the European Union and was asked to draft out the potential building blocks of a cancer framework for its Beating Cancer Plan. The framework starts with the foundation, such as prevalence, incidence, and burden of different types of cancer in a given country. Then it looks at the beating cancer pillars identified in the official EU document: prevention, early detection, diagnosis, treatment, quality of life. It then proceeds to look at the

cluster of policies addressing these pillars: access and quality of cancer care (workforce, technologies such as IT, pharma, radiation therapy), organization of cancer services, financing/re-imbursement and so on. This is then linked to the overall outcomes, which are not just expressed in terms of survival, but also of quality of life, the results of PROMS, and the overall costs allocated to cancer care.

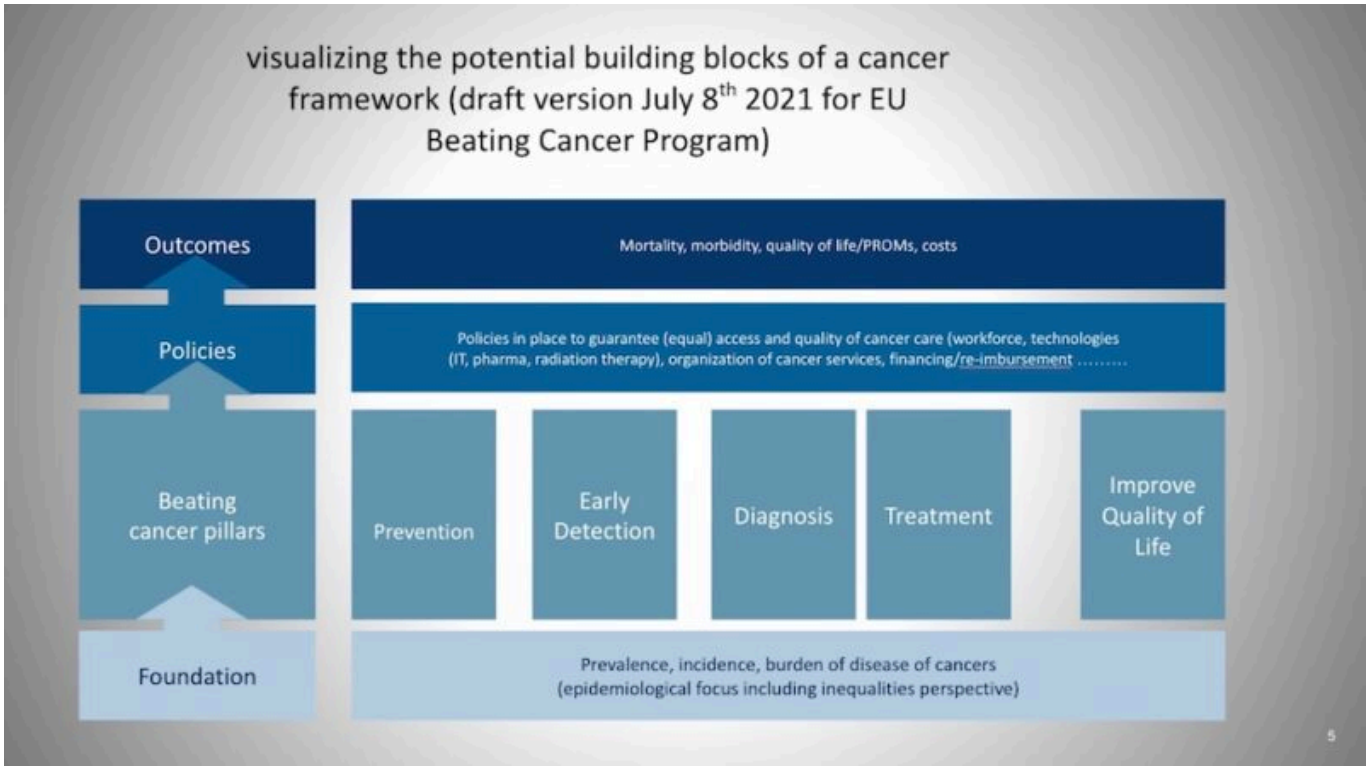


One example of the information which OECD has been working on for the past 15 years is the 5-year cancer survival. This project is done in close collaboration with the CONCORD programme for global surveillance in cancer survival, led by the London School of Hygiene & Tropical Medicine. It is based on 250 registries and monitors the five-year survival rate for a variety of cancers in different countries. A second type of data collected at OECD is on stage distribution, which, of course, depends on whether the cancer registries in the various countries have sufficient types of cancer staging information available. But comparing at what stage patients entered the system, for instance early detected breast cancer or advanced stage, can be an indicator of how good the system is in capturing cancer at an early stage. Right now, discussions are taking place with cancer registries to ensure we see the potential changes during the 15 months of the pandemic. In some cancer types we can see already that there is a shift in severity, but we also need to know where the delays are happening. Is the delay in the screening or further along the pathway? The third example of data collected is patient-reported data. Ministers of health have asked OECD since 2017 to promote work on PROMs and PREMs. One of the areas that has been particularly covered is breast cancer. Although this is still pilot work, the samples are not representative for countries, it still helps us ensure that we are not just looking at mortality but also on what the added value is as reported by the patients themselves.

What are the data challenges?

Cancer registries, and what they cover: mortality data? Do they have staging data? Reporting frequency – what is the time lag between cancer diagnosis and information captured by the registry? In some countries, for instance in South America, cancer registries are still being set up. **Claims data** and administrative data are another important source: number of operations, how long patients stay in hospital, readmissions. Standardisation is important but so is depth of coding, especially in

analysis of cancer care, to know, for instance, whether the cancer patient also had diabetes or COPD. **Electronic health records** should be the primary source of the data but still many systems lack an automatic uptake of data from electronic health records into administrative data or even registries. We want to have the whole pathway, how is the electronic health record of the primary care physician, the hospital, and the follow-up care? Is there home care, how are they linked? **Personal Health Data/Portals**, i.e., the patients keeping their own data. Portals are loaded differently in different countries and in some areas, especially with chronic diseases, the patients become the owners of their own data, and it is interesting to see how it gets embedded in the data infrastructure of the country. Lastly, we have the overall **population surveys** and, in some countries, where, for instance, there are no standard screening programs, we are totally dependent on the reporting in the population surveys. In short, the challenges are in the interoperability between the different data carriers and in the linkage capability. Already in a lot of countries it is possible to link administrative data with data registries, but a broader linkage, for example between pharmaceutical data, administrative data, and statistics, is still quite complex at national level. A lot has to do with governance. Does a country really want to have a national health data strategy and is it steering the various components in that direction? The OECD has provided advice on how best to organize governance on health data, and a very big component here is how **privacy and data security** are dealt with and implemented because, again in the EU, although there is a common legislation, its implementation and interpretation differ from country to country.



To move forward it is necessary to build public trust in data-sharing: in many countries, governance and technical capabilities are in place, but a common understanding is still needed about the importance of data sharing. There are places, like Finland, where data sharing is even embedded in legislation and secondary data use is a common goal. But in other countries trust is not there and progress is hindered by arguments on privacy and a lack of understanding that this kind of data should be a public good. A coherent plan is needed to strengthen national health data infrastructures. Like other industry sectors, the health care systems should be data driven. We need a good strategy to put all the elements in place, and countries should use opportunities when they arise, such as the European Health Data Space. Of course, there are two reactions. A country can see it as dangerous and in need of containment, or understand what thinking is behind it and how it can be used and optimised. The combination of a European Data Space on the one hand and a

European Cancer Plan on the other potentially opens the doors to a better future. To reiterate, though, we must align work on cancer with the broader approaches towards standardisation, digitalisation, and better use of data in the healthcare systems.

Next event