All.Can Global Summit

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

27 May 2021, 15:00 - 17:15 (CEST)

EVENT REPORT

On 27 May 2021, during the European Week Against Cancer, All.Can held its virtual Global Summit entitled 'Improving efficiency in cancer care through multi-stakeholder collaboration'.

The Summit gathered over 200 stakeholders from 37 countries across the globe, including patients and patient associations, healthcare professionals, policymakers and public authorities, industry representatives, academics and other experts.

Keynote presentations and panel discussions focused on how efficiency can be improved across the cancer care continuum, and how data can best be used to transform cancer care. The Summit also saw the launch of All.Can's new policy report, 'Harnessing data for better cancer care'.

Welcome and introduction

Alex Filicevas
President and National Initiatives WG Co-Chair,
All.Can International

Alex Filicevas welcomed the attendees and presented All.Can, its membership, mission, and objectives. Founded in 2016, All.Can International is a not-for-profit organisation with a global, multi-stakeholder membership.

With at least 20% of healthcare spending wasted on ineffective or inefficient practices, All.Can seeks to raise awareness of the need to improve efficiency in cancer care, generate evidence to drive policy change, and facilitate the exchange of best practices.

The presentation included a new video illustrating what efficient cancer care means for All.Can, why it matters, and how it can be achieved across the entire care continuum and at different system levels.

"For All.Can, efficient cancer care delivers the best possible health outcomes using the human, financial, infrastructural and technological resources available, with a focus on what really matters to patients and society."

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SESSION ONE:

Efficiency across the cancer care continuum

Driving transformational change in health systems:
the case for efficiency

Gregory Katz
Professor, Chair of Innovation & Value in Health, University of Paris School of Medicine and President of PromTime

In his keynote speech, Prof. Gregory Katz made a case for efficiency, taking the substantial differences in hospital outcomes as a starting point. Such differences are known to be widespread but are not well documented owing to the lack of bench-marking and transparency in outcomes data. Accordingly, inefficiencies resulting in reoperations and other procedures are 'rewarded', as payments are driven by the volume of care provided, while patients remain in the dark as to where they can get high-quality care. Moreover, significant divergence exists between the views of patient and practitioner on the importance of outcomes.

For patients, efficiency means value, which is defined according to outcomes that matter most to patients divided by the costs for the full cycle of care. Moreover, efficiency does not denote lean management or cost-containment. Outcomes that matter the most to patients should take precedence over others.

It is important to make a distinction between Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcome Measures (PROMs). PREMs concern hospitality indicators, including comfort during treatment, whereas PROMs involve quality of life and functional recovery, i.e. the end-result of care. On the other hand, Clinician Reported Output Measures (CROMs) such as 'visual acuity' are different to PROMs, such as 'reading a newspaper'. Hence, it is essentially

PROMs that measure success in healthcare, according to what patients consider most important. Beyond survival and physical well-being, PROMs include indicators such as mental and social well-being. Therefore, maintaining a broad perspective is crucial. In quantifying value, the difference between PROM scores before and after treatment can be an important indicator.

Promoting transparency is vital to drive high-quality care. Unlike siloed evaluations of hospital performance that do not measure outcomes, open benchmarking of health gains according to defined standards, shared with real-life data registries and audited by third parties, enable comparisons and foster the exchange of good practices between peers. This in turn can lead to remarkable improvements in patient outcomes. It also allows providers and payers to shift to outcome-based payments and value-based procurement, and benefits practitioners and manufacturers by driving patient referrals, research and innovation. Neutral auditing of patient health gains is fundamental to the operation of outcome-based registries, which in turn are key to improving efficiency.

PANEL DISCUSSION

Towards improved efficiency across the cancer care continuum – time for a paradigm shift in policies and practice?

Facilitated by

Vivek Muthu
Managing Director, Marivek Healthcare Consulting

Kathy Oliver
Chair and Founding Co-Director, International Brain Tumour Alliance

Based on her personal experience with cancer in her family, Kathy Oliver explained what efficiency means from the patients' point of view.

Many patients around the world do not receive efficient cancer care, as revealed in 2018 by the All.Can patient survey. Involving nearly 4000 patients and caregivers in over 10 countries, this survey revealed large gaps in cancer care efficiency and identified four key areas for improvement:

1. Swift, accurate and appropriately delivered diagnosis

2. Information-sharing, support and shared decision-making

3. Integrated, multi-disciplinary care

4. The financial impact of cancer.

To help address this, All.Can established the Efficiency Hub, aiming to create a learning community where best practices in improving cancer care efficiency are shared to help others find potential solutions to common issues. The COVID-19 pandemic has prompted us to look at more efficient ways of supporting cancer patients. In this context, it is important to remember that innovative solutions need not be expensive. Affordable and powerful equipment can make a big difference, especially in low-resource settings. A good example is the 'Paperfuge', a 20-cent hand-powered centrifuge made of paper, string, and plastic that can separate plasma from a blood sample, developed by Stanford bioengineers.

Patient insights on cancer care: opportunities for improving efficiency
Findings from the international All.Can patient survey

All.Can Changing cancer care together

Christobel Saunders
Research and Evidence WG Co-Chair and Board member, All.Can International and
Professor of Surgical Oncology, University of Western Australia

Prof. Christobel Saunders said that although healthcare professionals and providers do think about efficiency when designing and delivering services, the disparate and siloed systems in which they work hamper collaborative work. To co-design efficient cancer services with patients, clinicians need to rely on data and accountability. A holistic approach spanning the entire patient journey – from general practice through diagnosis, acute treatment, supportive care and follow-up care – is needed to understand what is important to patients and to help them not only to survive, but to thrive. It is only through high-quality data and transparency that we can achieve better outcomes and improve efficiencies.

Niek Klazinga
Head of the Health Care Quality Indicator Programme, Organisation for Economic
Co-Operation and Development (OECD)

Healthcare spending accounts for around 10% of the gross national product of many OECD member states. However, better information on quality and outcomes is needed to capture the extent to which this spending actually contributes to the health of the population. The OECD Health Care Quality Indicator Programme was established in 2003 for this purpose. In the field of cancer, Dr Niek Klazinga highlighted three key considerations:

1. The cancer care continuum is taken in its entirety, starting with risk factors, then the existence of (and participation in) evidence-based screening programmes, and diagnosis and treatment trajectories. One of the few internationally comparable indicators is the 5-year survival rate, though readmission and complication rates can also be considered.

2. The OECD is involved in many discussions to improve the data infrastructure in member states, to create knowledge to advance the effectiveness of care and to streamline the efficiency of care trajectories. A key concern remains how to link different types of data, including registry data, administrative data, electronic health records, and patients' own data.

3. Since 2017, the OECD has been mandated by health ministers to work on person-centred outcomes. In particular, the Patient-Reported Indicator Surveys (PaRIS) initiative promotes the use of PREMs and PROMs. Countries are encouraged to collect these data to better inform measures of cancer care value, beyond mortality and survival. It is essential that these measures become routine within cancer care and in the dialogue between healthcare professionals and patients.

The alignment between the work of All.Can and the OECD to support the harnessing of data to improve cancer care is encouraging. All.Can's work can enrich the high-level, aggregate information that the OECD collects, and help and profile the situation and progress made in individual countries. All.Can can also help better communicate the importance of collecting and sharing data within the broader stakeholder community. Data are crucial for improved cancer care efficiency and learning, but in some cases a resistance to share data curtails their availability.

Amadou Diarra
Senior Vice President Global Policy & Government Affairs, BMS

Amadou Diarra underscored that the industry does not operate in a silo and that all stake-holders need to 'row in the same direction'. The All.Can patient survey has uncovered many inefficiencies and it is important for BMS to partner in this global effort to improve the efficiency of care along the entire cancer pathway by joining forces with patients, healthcare professionals, experts and policy-makers. As efficient care not only delivers the best possible outcomes for patients but also underpins the sustainability of healthcare systems at large, all of these actors have a stake in promoting this virtuous cycle.

Industry has a responsibility to listen to patients, healthcare professionals, policy-makers and others, to understand their evolving needs. After listening, the industry should provide solutions to address unmet needs and bridge the gap between the expectations of patients and healthcare professionals – which can differ – while contributing to the overall sustainability of healthcare systems.

In the Q&A that followed, the following points were raised:

» Beyond mortality and survival, patients value quality of life, experiencing fewer and more tolerable side effects, and innovative care. They also appreciate being listened to and the efficient handling of their time. Importantly, what is meaningful and valuable for a patient is not static but can change throughout their journey.

» Improving care according to the aforementioned aspects does not necessarily decrease the cost-effectiveness of care for the healthcare system, since it leads to fewer missed appointments, better adherence to treatments, better engagement with the system, and ultimately to improved outcomes. Efficiency is not about cost containment, but efficient use of resources. The call to improve efficiency is hence not at odds with trying to raise more resources for health, as long as these are used efficiently.

» Whether the indicators we have are fit for purpose depends on our perspective: at the global level, where there are sizeable gaps between countries, comparing 5-year mortality rates can still yield important insights. However, when looking at countries where 5-year mortality rates are converging at uniformly high levels for major cancer types, other indicators are needed. Standardised outcomes that are comparable within countries, such as hospital readmission and complication rates, would be beneficial to allow benchmarking and mutual improvement.

» Equity of care remains a fundamental concern, as wide gaps prevail both between and within countries. Even in countries where outcome measures are collected, disadvantaged population groups may not be considered owing to language barriers or other reasons. Efficient cancer care should be championed not only in high-income countries but also in low- and middle-income countries.

» In a post-COVID-19 context, a follow-up All.Can patient survey could reveal important insights as to where patients find inefficiencies in their care.

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SESSION TWO

Harnessing data for better cancer care

Matthew Hickey
Research & Evidence WG co-chair, All.Can International and Founding Director and CEO, The Health Value Alliance

Matthew Hickey presented the new All.Can policy report 'Harnessing data for better cancer care' in his keynote speech. The digitalisation agenda emerges as an integral part of post-pandemic recovery and provides an opportunity to address long-standing hurdles to optimising the role of data in driving high-quality and efficient cancer care. The COVID-19 crisis caused a substantial backlog of cases that will require a greater effort to build sustainable cancer care systems, and putting data to use will be integral to achieve this transformation.

Against this backdrop, the new All.Can report offers policymakers, patients, care providers and decision-makers a forward-looking view on how to ensure that high-quality health data are systematically collected and used to improve cancer care and patient outcomes. Accordingly, the recommendations address the main barriers to unlocking the potential of data in cancer care, including:

1. **Challenges inherent in data**, such as poor quality, data not being representative of entire populations (inequity and bias), lack of data on the patient perspective

2. **Challenges with data systems**, such as limited interoperability of data sets, inconsistent use of data governance frameworks, and low patient trust

3. **Challenges embedding data into clinical practice**, such as limited actionability of data, poor integration of data insights into clinical decision-making, and high burden of data collection on care teams

4. **Challenges in drawing insights from data**, such as poorly validated algorithms and inadequate analytical methodologies, and lack of trust in artificial intelligence.

Harnessing data for better cancer care

A policy report by All.Can International

With this report, All.Can calls on policymakers to drive optimal use of data across the cancer care continuum, in all settings and for all cancer patients. Data should be considered both an investment and an innovation – having the right data systems in place that enable the analysis and extraction of meaningful insights to guide decision-making is as important to the future of cancer care as new medicines and other advances.

PANEL DISCUSSION

Data for optimising efficiency in cancer care – what needs to be done?

Facilitated by

Suzanne Wait
Managing Director, Health Policy Partnership

Dipak Kalra
President, European Institute for Innovation Through Health Data

Prof. Dipak Kalra highlighted five areas where investments should be prioritised to use data as an empowering resource driving better quality care for all:

1. **Better data quality and systems that enable quality data capture**: Data quality remains poor and haphazard. People need enough time to enter data, which requires training and treating record-keeping seriously. Clinician- and patient-centred systems should be put in place.

2. **Wider adoption of interoperability standards**: The standards landscape is mature enough and much could already be done if we could just use everything that is already available. However, implementation and adoption lag behind. People with cancer can live a long time and have multiple diseases, therefore care teams need joined-up, holistic views of individuals – requiring long-term perspectives and life-time records.

3. **Tools and apps for patients**: Patients have every right to understand what is going on and to be part of joint, informed decision-making. Outcomes should not merely be collected by healthcare professionals in paper form at the hospital bedside – they need to be continuously tracked and for this, people need digital tools to capture and use their own outcomes.

4. **Infrastructures and good governance models developed with active patient involvement in decision-making**: There are still many stumbling blocks in scaling up data use for research, for learning health systems and quality improvement. Hesitancy to share data remains an important barrier to using data more widely. The General Data Protection Regulation (GDPR) must be respected, but there are plenty of ways we can use privacy enhancing methods to share insights and learn much more from the good, interoperable data that are available.

5. **Data literacy**: A data ecosystem reflecting All.Can's vision will need patients, caregivers, healthcare professionals and researchers to be data literate. We need an empowered, educated workforce that better understands the limitations of interpreting data of variable quality, what interoperability standards are, and good data protection practices.

Antonella Cardone
Board Member, All.Can International and Director, European Cancer Patient Coalition

For Antonella Cardone, the data revolution is already transforming healthcare services worldwide and so must be tackled now. Digital health has an enormous potential that can greatly accelerate the shift towards patient-centred healthcare in Europe. Experiences during COVID-19 have shown the importance of data exchange between countries and healthcare systems, and telemedicine has come to play a fundamental role in improving outcomes and tailoring treatments sustainably. Innovative ways of using and collecting data, as well as the ability to draw insights from it, are key means to improve efficiency at each stage of the care pathway. To create awareness of this fact and enhance patient trust, there is a need to develop educational tools that showcase the value and power of data in improving cancer care. Patients need to know how their data is being used and be a part of the debate on the use of their data. Patient-driven governance of data is what empowers patients and builds trust in data sharing and management.

Abdullahi Sheriff
Associate Vice President, Global Leader, Affordability and Sustainable Access Solutions, MSD

To build robust and appropriate regulatory frameworks that empower all stakeholders interested in data, Dr Abdullahi Sheriff suggested that policymakers should focus efforts around transparent and inclusive standards. Nuanced, objective and hyper-localised conversations are vital to help people see the relevance and benefits of data. Since no single actor has the solution, it is key to foster frameworks that are conducive to advancing collaboration and the convergence of interests among diverse stakeholders.

Roberta Ortiz
Global Initiative for Childhood Cancer Medical Officer, World Health Organization

Dr Roberta Ortiz said that robust information systems are essential for cancer control planning, monitoring and transforming data into health-related decision-making. Incentives can be seen as a tool for policymakers and managers to retain healthcare professionals, particularly in the case of data managers who have the know-how and training to improve health information systems. Incentive schemes for healthcare professionals can involve a variety of measures. According to WHO guidelines, successful incentive packages are tailored to the specific needs and preferences of healthcare professionals on the one hand, and are realistic, context-appropriate, equitable and transparent on the other.

Incentives can include both financial interventions like additional payment or bonuses, and non-financial interventions such as flexible working schedules, training and education. Non-financial incentives are particularly relevant for low- and middle-income settings.

Regional networks supported by international partners can contribute remarkably to the development of health information systems, such as the Asociación de Hemato-Oncología Pediátrica de Centro América (AHOPCA) network in central America, in collaboration with St Jude's Children's Research Hospital (Memphis, USA).

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In the Q&A that followed, speakers re-emphasised the importance of gathering all stakeholders around the table.

>> Examples included multistakeholder EU-funded projects using big data to support cancer care as part of Horizon 2020 or under the Innovative Medicines Initiative (IMI). The Industrial Strategy Challenge Fund in the UK also serves as an example of policymakers, clinicians, patient associations, academics and industry partners coming together to tackle key challenges and define the future of care delivery. The Global Initiative for Childhood Cancer to advance the quality of care for children with cancer worldwide was also cited as a good example, based on effective partnerships and networks both at regional and global levels.

Wrap-up and conclusion

Matti Aapro
Board Member, All.Can International, President, European Cancer Organisation and Board Member, Clinique de Genolier

Closing the meeting, Dr Matti Aapro thanked all the participants for a fruitful meeting and highlighted some of the key messages from the discussion:

>> Improving efficiency is not about cost-cutting, but allocating available resources smartly, and adopting new, evidence-based methods to deliver the best possible outcomes for patients.

>> There is clear consensus that PROMs are crucial, but there are difficulties in collecting and analysing them.

>> To make progress in driving efficiency in cancer care, countries should work together, move beyond siloed thinking and learn from other areas of healthcare.

>> The role of primary care providers and the importance of high-quality data collection must not be neglected.

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Changing cancer care together