efpia | ONCOLOGY DATA SUMMIT

Unleashing the potential of data to improve cancer care

18/06/19
BRUSSELS

ONCOLOGY DATA SUMMIT REPORT

I. INTRODUCTION

Over 180 participants came together at the Oncology Data Summit organised by EFPIA, building greater understanding of the current oncology data landscape in Europe, and identifying actions that can help deliver better cancer outcomes.

The Summit built on a programme of activity developed by the EFPIA Oncology Platform through recent years, which has been engaging with a variety of stakeholders to identify key determinants that would improve cancer care in Europe. From these exchanges, the more effective use of oncology data emerged as a key horizontal enabler for many different aspects of prevention and treatment[1]. In 2017, EFPIA initiated the Oncology Data Landscape in Europe project, which identified the need for a clearer shared understanding of the fragmented, rapidly evolving landscape of oncology data.

Using the information coming from new sources is a key challenge today, as the potential of data remains to a large degree untapped in a broad societal sense. The Oncology Data Summit in 2019 was developed as a catalyst to build a common understanding of the challenges and opportunities we collectively face.

The Oncology Data Summit therefore brought together thought leaders on data, oncology stakeholders, patients' representatives and decision-makers, in order to foster new ideas and build partnerships on the access and use of oncology data. Participants included Roberto Viola, Director General of DG CONNECT, European Commission and Dr. Vera Katalinić-Janković, Assistant Minister of Health of Croatia. The Summit also followed the Romanian Presidency-endorsed conference "Value of Data" in Bucharest on 5 June 2019.[2]

II. CONFERENCE OUTCOMES

Based on the day's discussions, participants suggested 'recommended actions' in five areas, before voting for three in each area as the outcomes from the conference.

AREAS FOR ACTION

1. DATA GOVERNANCE, PROTECTION & PRIVACY

1. Create a Pan-European Data Commons or Cancer Knowledge Network to overcome the siloes around the availability of data for research, including restrictions on data access, particularly those funded from the public sector.
2. Invest in health literacy and help overcome negative perceptions and misconceptions around personal health data for patients and healthcare professionals around personal health data use.
3. Establish a process that can lead to harmonisation of divergent national GDPR requirements affecting health research.

2. STANDARDS & INFRASTRUCTURE

1. Identify the steps needed to create a connected data system in Europe by adopting harmonised quality and content standards and linking electronic health record systems and other sources of data across Europe.
2. Bring together a health data community to share best practices, apply common principles and recommendations on responsible use of health data to create real life impact for cancer patients and shared learning across different disease areas.
3. Encourage European projects aimed at ensuring consistency and uniformity in data conventions including dataset structures, standards, definitions and terminology.

3. ACCEPTANCE OF REAL-WORLD DATA BY REGULATORS & HTA

1. Develop a roadmap to integrate Real-World Evidence into reimbursement decisions in each national health system.
2. Use Real-World Evidence to support and accelerate regulatory assessments through a fit for purpose regulatory framework that recognises new digital health technologies.
3. Increase awareness on the value of health data to enable innovative pricing models and improve financial sustainability and coverage decisions.

1. This is described in the 'Taking action on cancer together' discussion paper, under Priority 1: Improving the sustainability and integration of cancer care, Idea C: Map initiatives to improve data collection and usage, share experiences of successes and blockages and consider what action can be taken to accelerate progress
2. Conference website available at this link: https://data-oncology.eu/

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4. DATA FOR EFFECTIVE, SUSTAINABLE HEALTH SYSTEMS

1. Optimise the secondary use of data to support the development of personalised healthcare.
2. Promote the uptake of data by payers to ensure efficient spending and to select appropriate treatment for patients to avoid waste in the system and negative patient outcomes.
3. Integrate new data sets, including the secondary use of health data, to enable more effective R&D through innovative research methods.

5. OTHER ACTIONS

1. Invest more in improving data skills for health care practitioners.
2. Create an EU dashboard of metrics on cancer including screening, outcomes and access to measure Member State implementation of best practices.
3. Facilitate the transparency of publicly funded data sets across Member States to improve decision making.

THE VOTING PROCESS

Throughout the Oncology Data Summit, EFPIA encouraged members of the audience to identify and table concrete yet ambitious proposals for actions which they could insert in the five thematic areas above. EFPIA in fact believes that every stakeholder has a role to play in enabling the collection and use of data to transform cancer care. The room was full of ideas as **more than 40 proposals were tabled.** Participants then voted on the proposals they wished to prioritise. The top three proposals in each area now form the 'recommended actions' from the Summit, in which every stakeholder can play a role in unleashing the potential of oncology data. These should be priorities at the start of the next EU political mandate, as well as for Member States and oncology stakeholders.

III. DISCUSSIONS AT THE CONFERENCE

Setting the Scene

The Oncology Data Landscape in Europe report from AT Kearney and IQVIA, provided a foundational understanding of the current situation of oncology data in Europe. This was followed by a presentation of the Data Saves Lives project, coordinated by the European Patients Forum, which will launch in autumn 2019. The project aims to enhance public awareness, understanding and acceptance of how health data is used, and provide a forum for relevant stakeholders to collaborate. Finally, Nathalie Moll, the Director General of EFPIA, emphasised the need to bridge the technological with the human aspects of data to accelerate the digital transformation – and the need for a European mandate to achieve this.

Value of Health Data for Cancer Care

This session highlights the benefits that better use of oncology data can bring to patients and to health systems through a series of case studies. For instance, it was shown how meaningful health data at scale (collected and analysed from several sources, such as electronic health records, genomic data, imaging data and digital health tools) can lead to better and more personalised healthcare. Technology can facilitate this process, with biobanks facilitating collection and access to data, while artificial intelligence has the potential to support decision-making and lead to more improved diagnosis and treatment.

ROBERTO VIOLA, DIRECTOR GENERAL OF DG CNECT, EUROPEAN COMMISSION, highlighted that in 2018 the Commission announced a data-driven strategy to develop standardised electronic medical records for every European citizen, and take steps towards pooling of genetic data across Member States. Patient empowerment is imperative to deliver on the promise of this initiative, which will help deliver more personalised medical advice. Mr. Viola strongly believes that if we can better understand the data, we can make many advancements in cancer care.

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Access to data

Enhanced access to data depends on the confidence of patients to securely share their sensitive data, but also on increased interoperability, which needs appropriate infrastructure and data standardisation. On the former issue, presenters see patient empowerment, improving health literacy and transparency as essential means to increase people's trust in this new system. Many questions were raised: Should patients have access to their own data? Should they own their data? Why should they consent to access by third parties? Patient representatives also discussed the 'right to be forgotten', i.e. the need to protect cancer patients from discrimination, for example when trying to access life insurances and mortgages. Discussions also noted the potential to enhance access to data held by private companies.

Regarding infrastructure and standardisation, the current situation is fragmented. Standardising and harmonising cancer data types are important for providing timely, comparable data on cancer epidemiology and care. In turn, establishing database partnerships or federated networks can ensure we have the necessary infrastructure to access necessary health data.

Use of data

High-quality Real-World Data (RWD) can be used to inform regulatory, reimbursement and health policy decisions. A first panel discussion addressed the current acceptability of RWD by regulators and health technology assessment (HTA) bodies. Food and Drug Administration (FDA) and European Medicines Agency (EMA) representatives recognise the potential of RWD and are developing frameworks for its use in regulatory assessments. The National Institute for Health and Care Excellence (NICE) is using RWD to enable timely patient access to innovative cancer medicines through Data Collection Agreements. However, quality and reliability remain a challenge. Technology-enabled abstraction of unstructured data from electronic health records combined with rigorous quality control was raised as a possible way to obtain high-quality data.

A second panel discussed the enhanced use of data which can lead to improved sustainability of health systems. Today, data can help assess and compare the performance of health systems, but it is not being used to its full potential. Cancer registries play an important role in collecting relevant and comparable data, and European countries should adopt the best practices available. An oncology dashboard has been proposed to evaluate yearly progress, including screening percentages, outcomes by type of cancer, impact of innovative treatments, etc. The collected data can be used to measure performance at national and EU level.

DR. VERA KATALINIĆ-JANKOVIĆ, ASSISTANT MINISTER OF HEALTH OF CROATIA, highlighted the upcoming Croatian presidency of the Council of the European Union starting January 2020 and shed light on their priority areas. The specific healthcare priorities the presidency will focus on are 'transplantation and organ donation' and 'life-long care with a focus on challenges of ageing and oncology'. Knowledge and sharing best practice will contribute to continuing improvement of treatment. Dr. Katalinić-Janković quoted the popular phrase "what gets measured gets done" and reiterated the Croatian Presidency's commitment to enhancing the collection and structuring of data throughout Europe. "Together, we can and will achieve greater results", she concluded.

Looking ahead

Presenters noted the need for policy action to deliver on the potential of health data – and a European Cancer Plan could help provide this. Following the current change in European leadership, the next five years represent an opportunity for progress like never before. The recommended actions emerging from this Summit should help guide policymakers on how data could be addressed in such a plan, and provide a starting point for further action. These will also be discussed during the ECCO 2019 European Cancer Summit in September, and the European Health Forum Gastein in October 2019. Stakeholders will have to move from a silo mentality to a more collaborative approach, as none of the suggested proposals for action can be accomplished alone. All involved stakeholders need to set the vision, the agenda, set benchmarks, and make it happen.

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ANNEX – SUMMIT AGENDA

MODERATED BY
TAMSIN ROSE, SENIOR FELLOW, FRIENDS OF EUROPE

08:30 TO 09:30
REGISTRATION & NETWORKING

09:30 TO 10:50
SETTING THE SCENE

Welcome
Alexander Roediger, Chair of the EFPIA Oncology Platform and Tamsin Rose, Senior Fellow, Friends of Europe

Oncology Data Landscape Report
Calypso Montouchet, Manager, AT Kearney

James Anderson, Principal in Real-World & Analytics Solution, IQVIA

Keynote speech
Roberto Viola, Director General, DG CONNECT, European Commission

Data Saves Lives Project
Nicola Bedlington, Former Secretary General, European Patients' Forum

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

Conclusion
Nathalie Moll, Director General, European Federation of Pharmaceutical Industries and Associations (EFPIA)

10:50 TO 11:10
NETWORKING COFFEE BREAK & POSTERS

11:10 TO 12:00
VALUE OF HEALTH DATA FOR CANCER CARE

Case studies
Maurits-Jan Prinz, Personalised Healthcare Policy Strategy Leader, Roche

Loubna Bouarfa, CEO and Founder, OKRA Technologies

Piers Mahon, Senior Principal, European Data and Evidence Networks, IQVIA

Francesco Florindi, Strategy & Partnership Manager at BBMRI-ERIC

12:00 TO 13:00
NETWORKING LUNCH & POSTERS

13:00 TO 14:20
SPOTLIGHT ON ACCESS TO DATA

Panel: data governance, protection & privacy
Martijn ten Bloemendaal, European Regional Privacy Counsel, AbbVie

Šarūnas Narbutas, Co-founder and Chairman, Youth Cancer Europe

John Butler, VP External Innovation & Alliances at Bayer Pharmaceuticals Division, Responsible for the IMI Harmony project at External Innovation & Alliances, Bayer

Tapani Piha, Special Adviser, Fipra International & Former Head of Unit, Cross-border Healthcare & eHealth, European Commission

Q&A

Panel: standards and infrastructure
Otto Visser, Director, Netherlands Cancer Registry & Chair, European Network of Cancer Registries (ENCR)

Dr. Melinda J Daumont, Director, Worldwide Health Economics and Outcomes Research, Oncology, Bristol-Myers Squibb

Prof. Fabien Calvo, Chief Scientific Officer, Cancer Core Europe

Nigel Hughes – European Health Data & Evidence Network (EHDEN Initiative)

Q&A

14:20 TO 15:05
SPOTLIGHT ON THE USE OF DATA - PART I

Panel: acceptance of real world data by regulators & HTA
Ritu Nalubola, Director, Food and Drug Administration (FDA) Europe Office

Nicole Mahoney, Senior regulatory policy Director, Flatiron Health

Filipa Alves da Costa, Research Consultant, Portuguese Cancer Registry

Flora Musuamba Tshinanu, Vice Chair Person, European Medicine Agency (EMA) Scientific Advice Working Party & Pharmacometrics Expert, Federal Agency for Medicines and Health Products (Belgium)

Thomas Strong, HTA Adviser – Managed Access (Cancer Drugs Fund), National Institute for Health and Care Excellence (NICE)

Q&A

15:05 TO 15:20
NETWORKING COFFEE BREAK & POSTERS

15:20 TO 16:10
KEYNOTE SPEECH
Dr. Vera Katalinić-Janković, Assistant Minister of Health of Croatia

SPOTLIGHT ON THE USE OF DATA - PART II

Panel: use of data for effective and sustainable health systems
Stefan Gijssels, Executive Director, Digestive Cancers Europe

Nils Wilking, PhD Associate Professor Swedish Institute for Health Economics (IHE)

Dr. Marius Geantă, President, Centre for Innovation in Medicine

Q&A

16:10 TO 16:15
VOTING ON POLICY RECOMMENDATIONS

16:15 TO 17:00
LOOKING AHEAD

Addressing Europe's Cancer Challenges through a data enabled lens
Mark Lawler, PhD, Queen's University Belfast

Panel: European Masterplan for Cancer
Antonella Cardone, Director, European Cancer Patient Coalition (ECPC)

Frederico Calado, Head of Real World Evidence Innovation & Partnerships at Novartis Oncology

Presentation of voting results and conclusion
Alexander Roediger, Chair of the EFPIA Oncology Platform and Tamsin Rose, Senior Fellow, Friends of Europe

17:00 TO 18:00
NETWORKING RECEPTION