ECCO-CODE ROUNDTABLE

Building the Roadmap to Outcomes-Based Cancer Care

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code collaboration for oncology data in europe

ECCO EUROPEAN CANCER ORGANISATION

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EXECUTIVE SUMMARY

The ECCO-CODE November 2018 Roundtable "Building the Roadmap to Outcomes-Based Cancer Care" was jointly organised by the European CanCer Organisation (ECCO) and the Collaboration for Oncology Data in Europe (CODE). Its aim was to chart a path forward for policy makers in respect to achieving the promise of outcomes-based healthcare, building on the findings of the ECCO-CODE joint research project on pragmatic outcomes measurement (POM). The research identified metrics of high value and low complexity to measure and this event was held to move forward with these metrics in the context of the value-based healthcare debate and provide guidance to policy makers.

Representatives from key stakeholder groups attended the event, including patient organisations, clinicians, biopharmaceutical and medical devices industry representatives, associations, and policy makers. Participants included representatives from ECCO and its Member Societies (SIOPE - the European Society for Paediatric Oncology , ESR - European Society of Radiology), ECCO Patient Advisory Committee (ECPC -European Cancer Patients Coalition ECPC, European Oncology Nursing Society (EONS), MPNE - Melanoma Patients Network Europe, Digestive Cancers Europe), UseMyData, European Federation of Pharmaceutical Industries and Associations (EFPIA), the International Consortium for Outcomes Measurement (ICHOM), Belgium Cancer Registry and the UCLH Cancer Collaborative.

The report of the POM research includes a roadmap outlining key recommendations which will help move European oncology practice towards comprehensive outcomes measurement. Julia Levy, CODE External Engagement Lead, presented the findings and recommendations and facilitated a discussion focused on three of the recommendations:

RECOMMENDATIONS	Today	Mid-term: Collective Action	Longer Term
	Increase knowledge of, and buy-in to, the value of outcome measures across oncology stakeholder types ◉	Identify a systematic approach to incorporating patient reported data into routine clinical practice ◎	Provide additional resources (or reallocate existing ones) to support outcomes measurement
	Develop and embed European-level 'essential requirements' and/or guidelines for outcomes measurement to make data capture 'business as usual' and move away from a need to do 'studies' ◎	Investigate ways of combining use of date-of-death with treatment data to calculate survival and draw conclusions on treatment efficacy ◎ Better utilise existing systems to capture outcome measures	Increase uptake of innovative technologies to support the capture and analysis of outcome measures ◎

◉ Completed ◎ In progress

To progress towards value-based healthcare through the adoption of pragmatic outcome measurement, the participants made the following recommendations:

Drive

- Encouragement for further dialogue, debate and exchange between stakeholders on the matters raised at the meeting and in the ECCO-CODE report *'Understanding Pragmatic Outcome Measures in Oncology'*

Engage

- A call for coordination of innovation across oncology stakeholders to build a focused approach to achieving systematic outcomes measurement
- A call for a co-ordinated approach to the capture of patient reported data to allow inter-centre and inter-national comparability
- A recommendation for direct engagement with payers on pragmatic outcome acceptability

Connect

- A call for data infrastructures to support near-real time delivery of information back to healthcare systems

Deliver

- Encouragement for an Essential Requirements, or other exercise, examining how to achieve routine capture of pragmatic outcomes measures

FULL REPORT

Overview

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1 INTRODUCTION TO THE ECCO-CODE PROJECT ON UNDERSTANDING PRAGMATIC OUTCOMES IN ONCOLOGY

Ms. Birgit Beger, ECCO CEO, opened the event saying, "We are all here today to discuss the importance of outcome measurement in oncology."

She then introduced ECCO, "The mission of ECCO is to bring all members of the oncology community together to have a breadth of people who will contribute and strive together to achieve outcomes through multidisciplinarity in cancer care."

Ms Beger highlighted that outcomes measurement was an important topic for ECCO, which is why ECCO had conducted the research on Pragmatic Outcomes Measurement (POM) with CODE. "Structured pathways connect the nurses with the physicians and these pathways need to be streamlined as time is of the essence in oncology. Therefore, having access to information in a timely way helps to improve outcomes. Today, there is data that sits in registries, but it is difficult to connect and share between registries given a lack of interoperability and trust." Ms. Beger explained that with outcomes measurement being such a powerful tool, there is a need to improve outcomes measurement and bring data together to help understand each patient and the patient's perspective.

She acknowledged that to achieve outcomes measurement and use it to improve cancer care, data is needed. "Data is a crucial tool, we need to have data connected to be knowledgeable and make crucial decisions in cancer care." Ms. Beger explained that this is where the synergies between CODE and ECCO exist, as CODE is creating a platform which enables data collection and transforms the data into useful insights to the cancer community. Dr Ian Banks, chairman of ECCO's Patient Advisory Committee (ECCO PAC), added that through this joint research project, "What CODE is doing is finding out what patients want and find most useful and reporting back to the healthcare system."

Dr Banks shared the purpose of the ECCO PAC and the need to understand the needs and wants of patients in making care decisions. "If you ask any patient with cancer, or carer, a successful outcome is normality. They want back as much of their life as they can before cancer touched them. For many years, the medical profession assumed what patients need, but now, patients are saying what they want: normality in everyday life is crucial."

Ms. Julia Levy, CODE External Engagement Lead, introduced CODE, "CODE is bringing together cancer centres to share information to help inform cancer care and better understand the value of anti-cancer medicines." She explained that CODE is building a cooperative and collaborative network aiming to bring information back to the healthcare system in near real-time and enable comparability, scalability and avoid administrative burden on data entry by using an automated extraction method.

Ms. Levy gave an overview of the ECCO-CODE project and explained that the research explored:

- The value and insights which various outcome metrics could provide;
- The feasibility, complexity and challenges of capturing the required data;
- And, the drivers and challenges of outcomes measurement.

This resulted in a proposed roadmap starting with what can be achieved today and understanding what is needed to achieve comprehensive outcomes measurement.

Ms. Levy explained that the research consisted of 26 interviews conducted with representatives across the oncology community. A definition of POMs was confirmed/tested/agreed as a result of these interviews, POMS are measures of the outcomes of cancer care that provide meaning to patients, providers and the wider healthcare community and can be efficiently generated, recorded and accessed at-scale in a real world setting. The research also considered the patient and clinical perspectives in the identification of a specific set of outcome measures metrics that could be collated at scale today and also identified an expanded set which can be collected in the near to medium term, but with additional focussed effort. Lastly, it focused on metrics which can captured in the longer term. These are dependent on increased resourcing and focus from the community in order to enable their capture.

Ms. Levy presented the roadmap from the Report outlining key recommendations that will help move European oncology practice towards comprehensive outcomes measurement. Ms. Levy underlined the importance of the Roundtable meeting, saying, "Having all of you together in this room, allows us to start achieving the goal of these recommendations." Discussions focused on three of the recommendations made in the Report:

	1. HARNESS POMS	2. OVERCOME NEAR-TERM BARRIERS	3. WORK TOWARDS COMPREHENSIVE OM
	Today	Mid-term: Collective Action	Longer Term
RECOMMENDATIONS	Increase knowledge of, and buy-in to, the value of outcome measures across oncology stakeholder types ◯	Identify a systematic approach to incorporating patient reported data into routine clinical practice ◯	Provide additional resources (or reallocate existing ones) to support outcomes measurement
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◯ Completed ◯ In progress

Professor Klaus Meier, Chair of the ECCO OncoPolicy Committee, ESOP President and an author of the Report, stated "It is important to come nearer to the point where our work has results, and we need to ensure healthcare stakeholders are a part of the outcome. From an oncology pharmacist perspective, we see the decisions and the drugs, but we don't always see the outcomes."

Dr. Lydia Makaroff, ECPC Director, added, "It is great to see so many stakeholders take part in this discussion. The recommendations [of the POMs report] are very practical, by focusing on the outcome measures which most useful to patients and clinicians and quantifying the metrics which are of low complexity to measure."

Ms. Aline Topouchian, Siemens Healthineers Policy and Reimbursement Strategy Director discussed the potential for payers to use POMs. "For us, it is a no brainer to capture outcome measures. But we need to include the payers to such discussions to understand the acceptability of POMs in HTA assessments and payment models. It is important to consider how outcomes data can be factored in payment models. Are these points brought up during the discussion with the payers?"

Mr. Thomas Allvin, EFPIA Executive Director Strategy and Healthcare Systems, discussed EFPIA's work in this area, "Acceptability of data is important for all of us. EFPIA is working on projects to support real world data at scale. Already today, pharma companies are going into agreements with payers to measure the results of individual drugs, but this is not being done at scale partially because of the administrative burden and lacking availability of data."

Dr. Patrick Crombez, Cancer Institute Bordet Head Nurse in the Department of Haematology and EONS Executive Board Member, discussed the value of connected data. "Outcomes measurement helps the multidisciplinary team connect with patients. Connecting the data across patients has value to nurses. Nurses play an important role in data collection and use the data for symptom management and tracking oral drug adherence."

Participants agreed that, to inform quality feedback loops and build learning systems to help deliver quality cancer care, information needs to be provided back to the healthcare systems quickly and efficiently.

2 INTEGRATING PATIENT REPORTED DATA INTO ROUTINE CLINICAL PRACTICE

Ms. Linda Wiinberg, CODE Analyst, shared the Report findings related to integrating Patient Reported Data (PRDs) into routine clinical practice and highlighted that a key theme was the need to consider patient views in care decisions. She explained that targeting the outcomes that matter the most to patients can help to improve the quality of care provided, ensure a high quality of life, and improve the outcomes and experiences of patients.

Ms. Wiinberg presented the challenges of incorporating PRD into routine care at scale identified in the research including:

- Time required and administrative burden
- Variability in the tools and measures used to capture
- A lack of integration into Electronic Medical Records
- Difficulty in making information available to clinicians in near-real time
- A lack of a system to track the outcomes at scale to inform larger scale changes

Roundtable participants agreed with these findings and discussed the process of integrating PRD into routine care at scale. Two principle themes emerged from the discussion – firstly, the importance of having a starting point to capture these endpoints and, secondly, a call for innovation to identify a pragmatic and scalable approach.

Professor Marc Peeters, University of Antwerp Professor and Antwerp University Hospital Coordinator MOCA and Department Head of Oncology, shared experiences from his cancer centre, where PRD is routinely collected. “Integrating Patient Reported Outcomes (PROs) into daily practice will allow you to get more information from your patients and this can be considered in your clinical decision tree... From integrating this in our daily routine, centres in Belgium and their oncologists are already feeling that they are able to make more informed decisions.” Professor Peeters explained that a challenge that they often faced was the lack of interoperability between health information systems at different cancer centres.

Mr. Lee Baker, Interel European Affairs (Health) Director, a global public affairs and association management consultancy, commented, "Perfection is the enemy of the good, if we want to aim for perfect interoperability and alignment [of PRD] it will never happen. In terms of best practices, you have to ask hospitals to embed it into their systems. You have to make PROs a part of the consultation and assessment process, including prospective care planning with patients. Then you can build PROs into the digital health systems.”

Mr. Geoffrey Hennings, Digestive Cancers Europe, and Dr Banks discussed the importance of creating a data collection process where clear roles and responsibilities are defined within the multidisciplinary team and patients become accustomed to contributing.

Participants discussed that there are many existing initiatives and hospitals working on trying to capture patient reported data, but there is a need to ensure that data capture is not burdensome on the centre, that the data captured is comparable with data from other centres, and that patients have the right support and education to want to share their information. These discussions led to a call to innovators to share their work and connect with other to allow a systematic and widespread approach to be taken to capture the outcomes that matter most to patients.

3 CONNECTING THE DOTS BETWEEN INITIATIVES WORKING ON OUTCOMES MEASUREMENT IN CANCER

Mr. Allvin presented EFPIA’s work with ICHOM to produce comprehensive data sets for different cancers. He explained that ICHOM is working to capture a 360 degree view of how a treatment works to enable the data to be used in outcomes and Value-Based Healthcare (VBHC). They are developing the standard outcome measures to be used in specific disease areas and help implement their measurement.

Mr. Vincent Clay, Pfizer Senior Manager of EU Government Affairs and EFPIA member, shared the findings of EFPIA’s oncology data landscaping report. He explained this project aimed to understand oncology data sources, what is currently available today, distinguish between the sources, and identify how they can be improved. He invited participants to attend the 2109 EFPIA Oncology Data Summit where the findings of the research would be further shared and discussed.

Ms. Elizabeth Maclean, ICHOM, spoke about ICHOM’s work to achieve comprehensive data sets for cancer. “There are a number of different cancers data sets being developed by ICHOM. One of the most positive things we have seen is the high level of engagement across Europe on outcomes measurement. Obviously, there are a number of challenges but there is a high level of energy to overcome these and capture the data." She also discussed VBHC as a major driver for outcomes measurement, and shared that various cancer clinics in Belgium are working on implementing VBHC.

Mr. Allvin and Mr. Clay highlighted that there is a need to understand the work of other initiatives and connect the dots so that collectively, initiatives can achieve scalable outcomes measurement more effectively. Participants agreed with the “connect the dots” approach and encouraged initiatives to share their findings and results of projects like those of EFPIA and ICHOM to make the information accessible.

4 DEVELOPING AN ESSENTIAL REQUIREMENTS FOR QUALITY CANCER CARE FOR OUTCOMES MEASUREMENT

Mr. Richard Price, ECCO EU Affairs Policy Manager, gave an overview of the Essential Requirements for Quality Cancer Care (ERQCC) and presented the idea of developing a new ERQCC focused on integrating outcomes measurement into daily practice, a key recommendation made in the report on POM.

Roundtable attendees showed support for developing an ERQCC on outcomes measurement and provided suggestions on process and stakeholder types to involve including clinicians, patients, representatives from European oncology organisations, payers, and data scientists.

Ms. Kacie King, Melanoma Patient Network Europe, stated "it will be important to involve patient advocates, as professionalising patient advocacy is important to ensure patients have access to this information and to education."

Mr. Pete Wheatstone, UseMyData, suggested to write the ERQCC in a simpler and more accessible way for patients. Ms. Beger added that simplifying the document to a 1-pager make it more accessible to patients and policy makers.

Ms. Donna Chung, UCLH Cancer Collaborative, noted that "there are difference in how we define a health system, some systems have better patient advocacy than others. For pragmatic outcomes measurement, we need to address that variation."

5 BUILDING THE ROADMAP TO OUTCOMES-BASED CANCER CARE

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Professor Klaus Meier, President ECCO OncoPolicy Committee and ESOP President, "The discussion today has been very fruitful. When we think about data collection today, it is necessary is to have communication that reflects these issues and not just issues around the doctors but those around the whole team. The take home message from this discussion about pragmatic outcomes measurement is not at the end, it is in the middle. We need to bring in all relevant stakeholders, to ensure the full picture of cancer is painted."

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