

UNDERSTANDING PRAGMATIC OUTCOME MEASURES IN ONCOLOGY

Building the roadmap to outcomes-based cancer care

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Outcomes Measurement (OM) is increasingly important in the complex oncology landscape

- Increasing age of population and incidence of cancer
- Rising sophistication and complexity of care
- New oncology therapies, including immunotherapy and precision medicines
- This, coupled with the increased rates of prevalence and longer treatment periods are driving up the costs of cancer care
- Variation exists in cancer treatment access, usage and outcomes

Systematic OM at scale is yet to occur in routine practice

- Lack of time for data entry, resources and expertise for implementation
- Differences in data recording e.g. structured or unstructured
- Variation in use of health information systems and lack of interoperability, creates challenges in comparability
- Limited standards and guidelines on the target outcomes to measure which creates variation in the definition of outcomes and in data collection
- Variation in care pathways, treatment choices and the use of outcomes in budget systems

Research goal: to identify outcome measures with a high level of insight which can be measured at scale

Interviews were conducted using quantitative and qualitative questions. Each interview explored::

- The impact routine outcomes measurement will have on interviewees' organisations or professions
- The accelerators and barriers to widespread outcomes measurement within cancer care in Europe
- Specific parameters, value and complexity, of a list of outcomes measurements in cancer care
 - › The value of each measure in regards to clinical level of insight and meaningfulness to patients
 - › The complexity and cost to capturing these outcome measures
- Recommendations to policy makers to encourage the systematic and widespread measurement of outcomes

26 interviews with stakeholders from organisations across the European cancer community were conducted

Oncology Healthcare Professionals

- Radiation Oncologist
- Oncology Pharmacist
- Paediatric Oncologist
- Neuro-Oncologist
- Oncology Nurses
- Surgeons
- Medical Oncologists

Patient Representatives for different malignancy types, including:

- Lung
- Neuroendocrine
- Colon
- Chronic Myeloid Leukaemia
- Thyroid

Based on how they are commonly collected, we identified 6 groups of outcome-related measures

Group	Outcome description
1. Patient Reported Data (PRD)	Outcome measures made through direct patient observations captured in questionnaires
2. Measures of Survival	Outcome measures based on duration of survival (with or without aspects of survival)
3. Clinical Evaluation Scales	Outcome measurement using simple grading scales that capture information about the patient's status or their response to a therapy
4. Direct Measure of Disease	Outcome measures related to disease characteristics collected through imaging or pathology
5. Measures Derived from Treatment Delivery	Outcome measures derived from treatment delivery and reported by Physician or Pharmacist and/or from transactional data
6. Measures Derived from Healthcare Encounters	Outcome measures based on events/encounters in the end-to-end care of a cancer patient (proxy for outcomes impacted by health system)

The gap between what is valuable to patients and what is valuable to clinicians is closing, yet patients perceive the gap to be larger

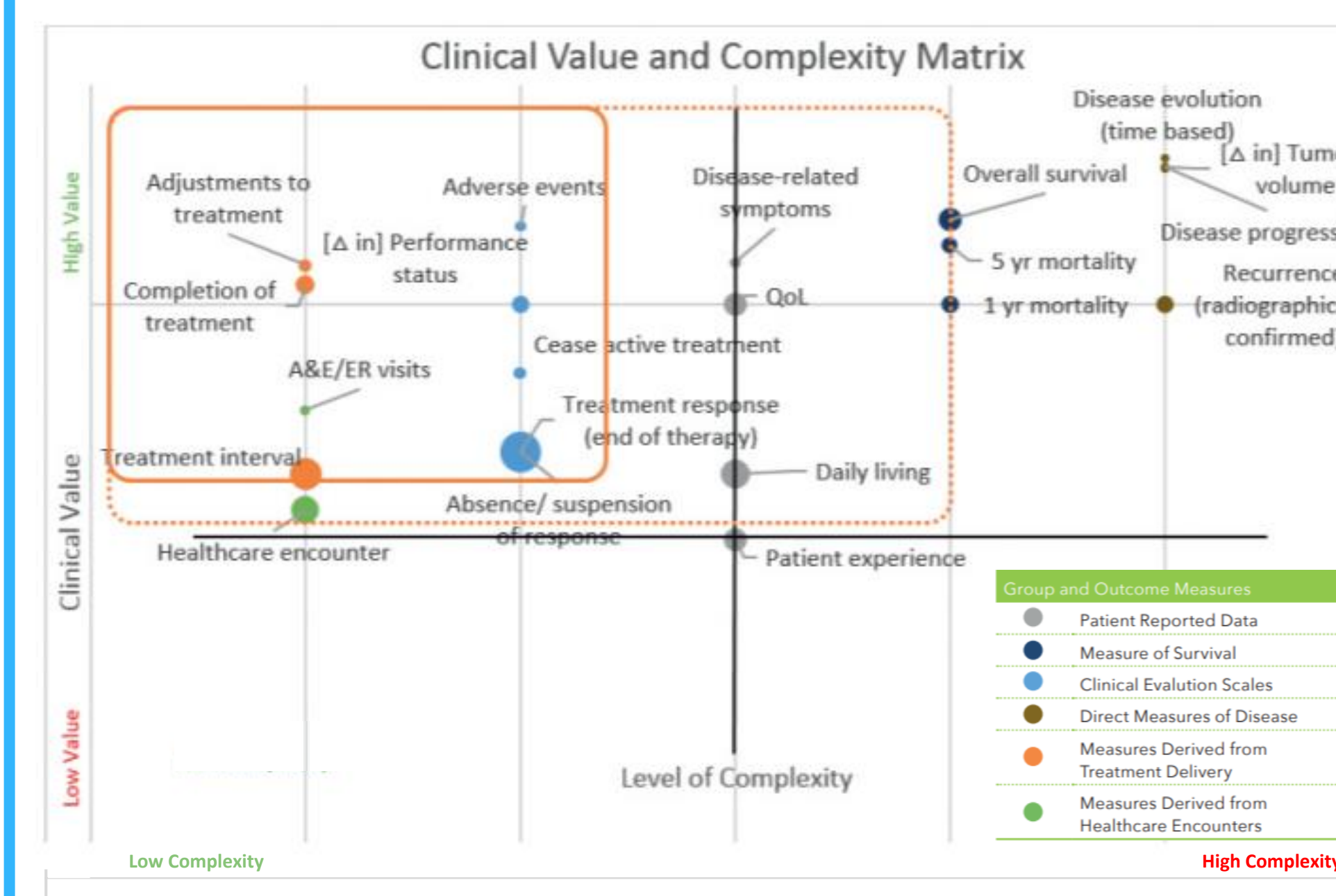
- On average, interviewees found change in tumour volume, disease progression and time-based measure of disease evolution (e.g. progression-free survival) to have the highest level of clinical value
- The measures with a higher level of variation include physician evaluation of treatment response, physician confirmation of absence/suspension of response, treatment interval, and activities of daily living
- Patients rated the clinical value (value to clinicians) of patient reported data lower than the clinicians, specifically daily living and patient experience
- Patient reported data were seen as more valuable to patients than clinicians, specifically, activities of daily living and standardised measures of patient experience

Interviewees generally agreed with the complexity of capturing and interpreting the outcome measures

Just over half of the interviewees agreed with all of the proposed rankings whilst the remaining interviewees generally cited only one or two points of difference around:

- Measures derived from healthcare encounters and patient reported data were deemed more complex to capture/analyse
- Measures of survival were deemed simpler to capture/analyse

A set of "pragmatic outcome measures" were identified which can be captured today at scale



Pragmatic Outcome Measures were defined by the interviewees as "measures of the outcomes of cancer care which can be efficiently generated, recorded and accessed at-scale in a real world setting and provide meaning to patients, providers and the wider healthcare community."

The figure on the left highlights the identified pragmatic outcomes:

- The smaller rectangle highlights metrics of low complexity to capture but of high clinical value
- The larger rectangle highlights metrics of medium complexity to capture but of high clinical value. These could be an expanded set of metrics accessible in the mid-term
- Other measures which currently support individual decision making can be harnessed to inform broader patient care in the longer term once complexity issues have been addressed

There was consensus around the value that systematic OM at scale can provide to all involved in cancer care

- Direct measures of disease (e.g. measurement of tumour volume and evolution) are valuable in the individual clinical decision making but are more complex to measure and difficult to collate, particularly in near real time and at scale
- Measures using clinical evaluation scales (e.g. change in patient performance status) and measures derived from treatment delivery are less complex to measure and to capture at scale. These provide insight into treatment efficacy across populations
- Patients rated PRD, change in performance status and absence/suspension of response, and overall survival as more relevant to informing decisions than clinicians did, which may be linked to importance of PRD to the individual patient experience
- Patients perceived the clinical value of PRD lower than clinicians, specifically daily living and patient experience
- Further research is needed to understand these differences in perspectives between patients and clinicians regarding the value of specific outcome measures

A 3 step road map towards comprehensive outcome measurement in oncology & recommendations

1. Harness POMs	2. Overcome near-term barriers	3. Work towards comprehensive OM
Today	Mid-term: Collective Action	Longer Term
<ol style="list-style-type: none"> 1. Increase knowledge of, and buy-in to, the value of outcome measures across oncology stakeholder types 2. Develop and embed European-level 'essential requirements' and/or guidelines for outcome measurement to make data capture 'business as usual' and move away from a need to do 'studies' 	<ol style="list-style-type: none"> 3. Identify a systematic approach to incorporating PRD into routine clinical practice 4. Investigate ways of combining use of date-of-death with treatment data to calculate survival and draw conclusions on treatment efficacy 5. Better utilise existing systems to capture outcome measures 	<ol style="list-style-type: none"> 6. Provide additional resources (or re-allocate existing ones) to support outcome measurement 7. Increase uptake of innovative technologies to support the capture and analysis of outcome measures

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