

OECD Health at a glance report 2019

MULTI-ACT project in line with OECD analysis calling on healthcare systems to place more attention on patient reported outcomes and experiences

The OECD Health at a Glance report 2019 includes a dedicated chapter on “measuring what matters for people-centred health systems” calling on healthcare systems to place more attention on patient reported outcomes and experiences.

The article underlines the essential dimension of the patient perspective on the outcomes and experience of their care in driving continuous quality improvement of health services. It is also increasingly relevant in overcoming the broader demographic, epidemiological and economic challenges faced by all health systems. The rise of chronic conditions as the main source of disease burden, coupled with better but also more expensive technologies to manage them and prolong life, heightens the need for a more people-centred approach to both policy and practice. But people-centred health systems remain an empty promise without more information on how health care and health policy actually affect the lives of individual patients explains the article.

The OECD argues that it makes sense to capture this knowledge in a way that is systematic and useful for decision-making. Forward thinking provider organisations, disease registries and some health systems have been collecting this information for some conditions or procedures. However, coherent and systematic patient reporting across the entire range of health system activities and interventions is not yet in place. Traditional outcome measures like survival or mortality will remain useful but cannot capture more subtle yet important effects. Outcomes valued by patients should be a key indicator of success of significant interest to patients but also providers as well as policymakers.

Data generated by patients can also contribute towards assessing the performance of medical products, combination therapies, care pathways, health services and the health system as a whole. Combined with other data, these can furnish researchers, regulators, health technology agencies, payers, researchers and policy makers with the knowledge to make more informed decisions to maximise health system performance, and meet the expectations of patients, citizens and communities (Calvert, O’Connor and Basch, 2019[16]).

The ability to elicit information from individuals on their health status, quality of life and care experience is now decades old. The available instruments and surveys have undergone rigorous psychometric testing and statistical validation, with results published in the peer-reviewed literature. The field is mature and evidence supports that these instruments reliably measure what is intended (Black, 2013[17]).

The chapter concludes that in the end, no single data source can provide information for a complete assessment of how a highly complex, adaptive health system performs. Patient-reported data need to be interpreted in the context of other metrics on health system activity and performance. They are not meant to supplant but to complement existing data that are collected in an effort to avoid tunnel vision and generate a more complete picture of performance for all involved: patients, providers, regulators and policy makers. In order for patient-reported measures to fulfil their promise in service provision, research and policy, standardisation of methods for data collection, analysis and reporting

are essential. This relies heavily on international collaboration (Calvert, O'Connor and Basch, 2019[16]).

In line with the Responsible Research and Innovation (RRI) approach which is demanding for more effort towards public engagement in science, the mapping of existing patient engagement (PE) initiatives as part of the MULTI-ACT project confirmed that PE still deserves attention and innovative guidelines.

The MULTI-ACT project which places strong emphasis on integrating patients' experiential knowledge in health research fits well with the OECD analysis and recommendations.

Preliminary guidelines for patient engagement have been developed by the project consortium following a detailed landscape analysis which reported a lack of clarity about when and how to engage patients in R&I, as well as standardized best practices and metrics, demanding for clear and evidence-based methods, including minimum quality criteria, for the development, content, and governance of patient engagement.

The focus of the MULTI-ACT Patient Engagement (PE) strategy is to ensure that patients are engaged in R&I as co-researcher to empower, recognize, maximize, and value their 'experiential knowledge', a perspective that escapes researchers and that provides different and complementary insights than those provided through scientific education (Smith et al. 2019).

The value and effectiveness of PE relies on impacting on outcomes that matter to patients while being sustainable in achieving this goal. PE strategies directed to engage patients through the 7-steps R&I path, both in the governance of R&I (*with*) and in its impact assessment (*of*), are instrumental to meet transformational mission's health R&I.

To enable the involvement of patients throughout the entire research processes, the future adopters of MULTI-ACT Framework are prompted to implement governance structures taking two main actions:

- 1) Appointing an Engagement Coordination Team (hereinafter also referred to as "ECT"), that will be in charge of coordinating the involvement of stakeholders, including patients, their families and caregivers, in all the operations;
- 2) Creating a Patient Advisory Board (hereinafter also referred to as "PAB"), a specific group of patients, their families and caregivers within the Stakeholders Advisory Board, to be involved and engaged throughout the entire development of the initiative, providing advices, insights and perspectives on the activities of the initiative.

The proposed MULTI-ACT Engagement Coordination Team (ECT) intends to be a neutral team dedicated to enable the R&I paradigm shift by enabling the transition from the individual to the collective patients' experiential knowledge. Patient Organizations will play a pivotal role in enabling the empowering of 'collective patients' experiential knowledge'

The ECT should be in charge of mitigating challenges such as ethical conflicts in protocol design, tokenism, power struggles, difficulties in recruiting different patients, additional time or cost.

A strong partnership has more potential to produce results that reflect patients' expected outcomes and, thus, to have a positive impact on society.

MULTI-ACT has defined specific governance criteria in relation to patient engagement (e.g. mechanisms in place to recognize the value of patients' experiential knowledge) as well as indicators (e.g. appropriate mechanism for recognition of patient's contribution).

The preliminary guidelines define a 13-steps process to design the patient engagement plan and includes specific recommendations for effective patient engagement (at operational, empowerment and ethical levels).

Final guidelines will be produced after a public consultation which will gather perspectives from patients and stakeholders on a global scale with the aim to consolidate the guidelines with more insights and comprehensive recommendations.

They will be tested on a case study to collect feedback on their usability.

The innovation of the MULTI-ACT PE guidelines relies mainly on three key aspects:

- i) the potential for innovation of the Engagement Coordination Team (ECT, see D5.4 “MULTI-ACT Model for collaborative initiatives”);
- ii) training focused on how to empower patients to bring their experiential knowledge into the R&I continuum, complementing existing training to make patients “experts”;
- iii) the importance to understand and measure the impact of R&I on outcomes that matter to patients.