

Oncology Data Registry: Real World Evidence from Dead-end to Highway

Background	<p>State Oncology patients' registry existant, but:</p> <ul style="list-style-type: none"> • Due to congestion, health care professionals do not fully and with delays comply with filling registry data; • Two university hospitals have their own internal information systems and they are not interconnected with the National registry; • In 2018 State registries handed over to the NHS and integrated in the govermental electronic system E-health. <p>Inaccessibility of real-world data complicates decision-making and analysis of outcomes for both, healthcare professionals and healthcare institutions - in service planning and in analyzing the effectiveness of spending.</p>
Proposal	<p>Purpose of the Pilot Project is with the involvement of all stakeholders to define the necessary data set extensions and functional enhancements to the Oncology Registry, enabling the collection and analysis of the real-world efficacy and outcome results of the applied medical technologies.</p> <ul style="list-style-type: none"> • Focusing on one oncological indication (e.g. lung cancer) through co-defining improvement objectives, scope and of best improvement options. • Implementation of the selected solution would facilitate assesment of its benefits and identification of the weaknesses to be prevented before potential scaling of the approach to other indications within Oncology Registry and outside oncology disease area.
Project Stage I	<p>Design Thinking Workshop</p> <p>One day workshop with all involved stakeholders based on design thinking methodology with a target to discuss:</p> <ul style="list-style-type: none"> • Existing data collection process, differences between health care institutions; solutions to improve data entry speed and data quality; , add new data sets, solutions to improve data entry speed and improve data quality, capabilities to automate data entry, interconnectivity of the ICT systems; • what support would be necessary to drive change. <p>The expected outcome is to reach agreement on a specific action plan to improve real world evidence collection in the Oncology Registry and analysis for the previously selected indication..</p>
Project Stage II	<p>Implementing solutions identified during the Stage I</p> <p>Action plan identified during the Stage I, which might be, but not limited to:</p> <ul style="list-style-type: none"> • Data digging and research; • Creating an alpha prototype of the improved data registry; • Draft procurement documentation package etc. <p>Stage II could be financed by the Latvian Investment and Development Agency through the innovation voucher scheme.</p>
Potential stakeholders	<p>State institutions Health care professionals – delegated representatives of relevant doctors' societies Patient advocacy groups University hospitals Research institutes Pharma industry representatives Healthtech companies, ICT solution providers Social anthropologists, design planning experts</p>