

PIONEER WP2

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PIONEER is part of the Innovative Medicine Initiative's (IMI's - *IMI is by default a collaboration between the EU Commission and the industry, both contribute half of the needed financial support*) "Big Data for Better Outcomes" (BD4BO) umbrella program. The BD4BO mission is to improve health outcomes and healthcare systems in Europe by maximizing the potential of Big Data

PIONEER aims to transform the field of prostate cancer care with particular focus on improving prostate-cancer related outcomes, health system efficiency and the quality of health and social care across Europe.

Consortium partners

PIONEER is a "big" project with a large number of partners, EAU is one of the coordinators of the projects. In EAU the guidelines committee is involved and through this Europa Uomo. We are not a partner, from the patient organizations we find ECPC (European Cancer Patient Coalition) as a partner, but they are an umbrella organization where Europa Uomo is a member.

Work Package 2 disease understanding & outcome definitions

WP2 will develop standardized definitions of prioritized prostate cancer outcomes and diagnostic and prognostic factors across the different stages of prostate care, whilst considering existing heterogeneity in data collection and the disease itself. WP2 aims to directly inform guideline development and clinical practice by standardizing definitions and terminology regarding diagnosis, prognosis, and outcomes for prostate cancer. The most important outcomes for different stakeholders will be prioritised and defined and a core outcome set will be developed for different stages of the disease. For each of the outcomes identified as core, the most appropriate and feasible outcome measurement instrument will be recommended. Consensus will also be sought for diagnostic tests and parameters, and prognostic factors. WP2 will feed into WP3, 4 and 5, whilst the results from WP4/WP5 will feedback into WP2.

Objectives:

1. Identify core outcome sets and diagnostic and prognostic factors for localised, locally advanced, and advanced-metastatic prostate cancer in the context of the patient's treatment pathway, including quality of life, patient-reported outcomes and economic endpoints.
2. Assess how these outcomes and diagnostic and prognostic factors should be prioritised and recommend a valid and feasible outcome measurement instrument for each of the outcomes.
3. Disseminate findings and guidelines to health practitioners and patients to improve management and care of men with prostate cancer in close collaboration with WP7.

Key achievements to date:

1. Four systematic reviews completed for the core outcome sets for the four different prostate cancer stages.

2. Four expert group meetings, combination of face-to-face and virtual, were conducted in support of the core outcome set work and the systematic review on diagnostic and prognostic factors.
3. Ethical approval for qualitative interviews granted in the UK and applied for in Germany and the Netherlands.
4. Five abstract presentations presented.

Partners: European Association of Urology, King's College London, Università Vita-Salute San Raffaele, International Consortium for Health Outcomes Measurement, University of Aberdeen, EORTC (European Organisation for Research and Treatment of Cancer), Bayer, Sanofi, Janssen Pharmaceutical, Orion Corporation and Astellas Pharma.

Our involvement

Europa Uomo was and is not a partner but some of our members participated in ZOOM meetings, we had no particular task to complete and had no responsibility

Request

PIONEER WP2 are conducting a survey to better understand the communication between patients diagnosed with prostate cancer and their treating physician. The survey is based off the EORTC OLQ-COMU26 and should not take patients any more than 5-10 mins to complete. The results of the survey will contribute towards answering part of one of PIONEER's prioritised research questions. As you have requested, we have translated the survey into Spanish, German, French, Italian and Dutch.