

A Co-Development Process of Selecting and Integrating PROM Tools in a Clinical Quality Registry

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Introduction

- The Irish Prostate Cancer Outcomes Research (IPCOR) Project has established a comprehensive nationwide longitudinal prostate cancer (PCa) registry.
- Supported by Movember and the Irish Cancer Society, the first phase of the project, **IPCOR 1.0**, collected high-quality clinical data from newly diagnosed PCa patients across **16 hospitals in Ireland from 2016 to 2020**.
- An important component of the project was the establishment of a patient engagement panel known as the **Lived Experience Advisory Panel (LEAP)**, which was integrated into the project's governance to ensure patient insights directly informed research and its interpretation.
- The next phase of the project, **IPCOR 2.0**, aims to improve PCa management by establishing a prospective, longitudinal, multi-centre clinical quality registry and biorepository in Ireland.
- In addition to aligning with the **ICHOM** patient-reported outcomes (PROMs) set for localised PCa and the **PCOR-ANZ registry**, IPCOR 2.0 seeks to **enhance** these standards by selecting **additional, relevant PROM tools**.
- We describe here a **co-development process** to identify and integrate these new tools, ensuring they are not only scientifically sound but also closely reflect the specific needs of PCa patients in Ireland.

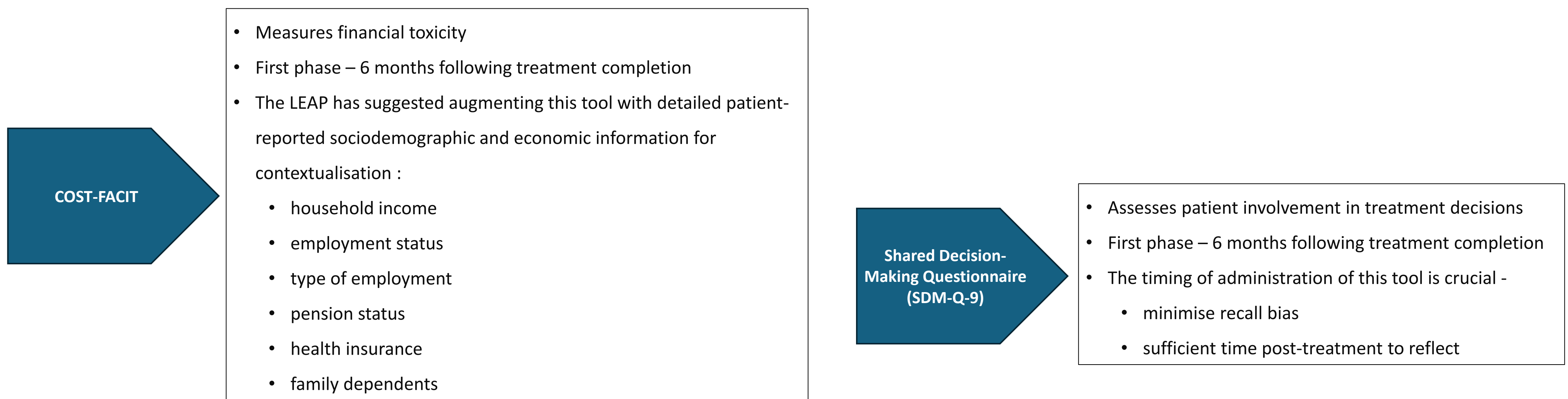
Methods

- **Educational Session on PROMs**
LEAP members participated in a session on PROM development, administration, and evaluation.
- **Review of IPCOR 1.0 PROM Results**
LEAP members reviewed the results from IPCOR 1.0 PROMs for further insights.
- **Identifying additional patient experience aspects not covered**
- **Sourcing and Reviewing of PROM Tools**
Project staff sourced potential validated PROM tools based on LEAP feedback. LEAP members reviewed these tools, assessing their content and timing in the patient journey.
- **Additional information needed**
LEAP members identified additional data needed to interpret PROM tool outputs.



Results

The ongoing process of patient engagement has currently led to the identification of two specific PROM tools incorporated into the IPCOR 2.0 protocol:



Conclusions

- New PROMs have been identified through a **co-development process** and are integrated into the IPCOR 2.0 protocol.
- PROMs are being **integrated into the Movember-funded registry that uses the Electronic Data Capture (EDC) ePROMs Tool—DACIMA by EvidentIQ**.
- The addition of these tools is expected to significantly enhance the **relevance** of the data collected.
- This approach ensures that the research remains **patient-centred**, reflecting **real-world experiences** and needs.

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