

# Lessons Learned from IPCOR: A Multi-Institute Prostate Cancer Registry in Ireland

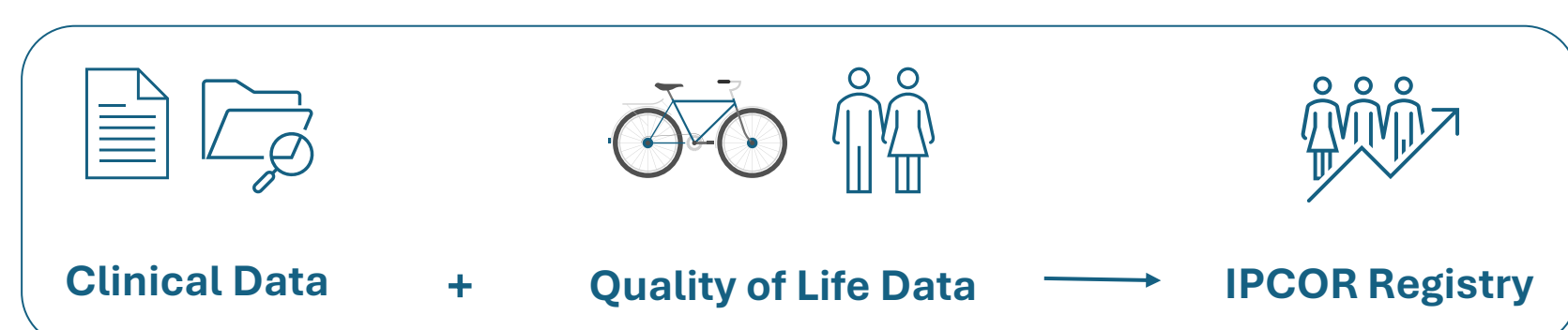


Wasfa Farooq<sup>1</sup>, Noa Gordon<sup>1</sup>, Cara Dooley<sup>1</sup>, Aine Murphy<sup>1</sup>, William Watson<sup>1</sup>, David Galvin<sup>1,2,3</sup>

<sup>1</sup>University College Dublin, Dublin, Ireland; <sup>2</sup>St Vincent's University Hospital, Dublin, Ireland; <sup>3</sup>Mater Misericordiae University Hospital, Dublin, Ireland.

## Introduction

Health registries are a powerful tool in improving population health and creating a bridge between healthcare and scientific advancement through research. Registries can provide insight into utilisation of resources; help save costs in patient care and assist in clinical decision-making and shaping guidelines. To better understand national trends of the most common male malignancy diagnosed in Ireland, the Irish Prostate Cancer Outcomes Research (IPCOR) initiative created a unique longitudinal clinical registry integrating comprehensive prostate cancer (PCa) data of 6816 newly diagnosed men with their patient reported outcome measures (PROMs) collected between 2016 and 2020. The novel experiences of the IPCOR team within the Irish healthcare landscape are now being incorporated in a second rendition of IPCOR, to be initiated in 2024.



## Methods

IPCOR, through funding from Movember Foundation and the Irish Cancer Society, collected data from 16 public and private institutes around Ireland, including rapid access clinics at 6 NCCP-designated cancer centres, 2 additional public hospitals, 7 private hospitals and a radiation oncology network facility. IPCOR expanded the dataset collected by the National Cancer Registry Ireland (NCRI) in partnership with Health Research Board Clinical Research Facility Galway (HRB-CRFG) and Clinical Research Development Ireland (CRDI). This initiative was led by a team of urologists, medical oncologists, radiation oncologists and epidemiologists. Following ethical approvals at each institute, a research team recruited through the NCRI engaged in data abstraction from hospital medical records. Diagnosis of PCa was confirmed through pathology reports of men receiving prostate biopsies, tracked in liaison with relevant department staff. Data was collected throughout treatment and beyond for long-term outcomes. PROMs questionnaires were dispatched annually according to ICHOM guidelines.

## Results

### Data Ownership & Management

- A detailed data management plan must be in place, prioritising granular patient consent considering implementation of GDPR. Explicit informed consent from participants is crucial, as direct data access, regular analysis and feedback is necessary to improve project processes and facilitate changes.
- In data dictionaries, prioritise variables related to clinical indicators that are also relatively simple to abstract from medical records. Maximising completeness, data quality and alignment with international standards, such as the ICHOM set, over volume of data variables reduces abstraction time and leads to greater evidence generation for comparison with other registries.

### Stakeholder Management

- Onboarding of sites, in a multi-institutional project, should be done phase-wise, allowing learning from one institute to be transferred. This is also beneficial while approaching individual hospital research ethics committees that may have varying requirements.
- Smooth integration of project staff must be given attention, particularly in private hospitals where systems may work uniquely. Having local champions, preferably senior clinicians, willing to assist with inter-departmental cooperation streamlines connection with sources of data and key individuals.

### Effective Use of Resources & Technology

- Data abstraction from medical records can be quite labour intensive, a process that can be streamlined with an appropriate use of technology. When following long treatments and follow up periods, automated systems should be prioritised over attempts at manual monitoring.
- During data collection, the primary focus of research officers should be on time-sensitive datasets. Follow-up data abstraction can be postponed to a time when maximum information is available instead of regularly investing time in collecting partial and incomplete information.
- Digitising communication methods is necessary to improve efficiency and maximise response rates from participants, particularly if needed by a fixed time point.

For queries: [ipcor@ucd.ie](mailto:ipcor@ucd.ie) ([www.ipcor.ie](http://www.ipcor.ie))

## Conclusion

Local lessons from IPCOR can greatly benefit discussions on establishing multi-institutional health registries. These include informing National Cancer Control Programme (NCCP) and international bodies on clinical guideline implementation, quality improvement of care on an institutional level, cross-site comparisons of outcomes and international benchmarking.

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