IPCOR Data Access Information Leaflet

Current Project Sites	Mater Misercordiae University Hospital Mater Private Hospital St Vincent University Hospital St Vincent Private Hospital University Hospital Galway St Luke Radiation Oncology Network
Principal Investigator	Mr David Galvin Consultant Urologist Associate Clinical Professor
Data Controller/Study Organiser	University College Dublin (UCD)
Email	ipcor@ucd.ie support@ipcor.ie
Website	www.ipcor.ie
Data Protection Information	gdpr@ucd.ie

About IPCOR

IPCOR was initiated as a nationwide longitudinal prostate cancer registry which collected high-quality clinical data through the National Cancer Registry Ireland (NCRI), from newly diagnosed prostate cancer patients at 16 hospitals in Ireland from 2015 to 2019. IPCOR identified variability in treatment amongst individuals, its causes and consequences both in clinical outcomes and quality of life, consequently evaluating health system performance.

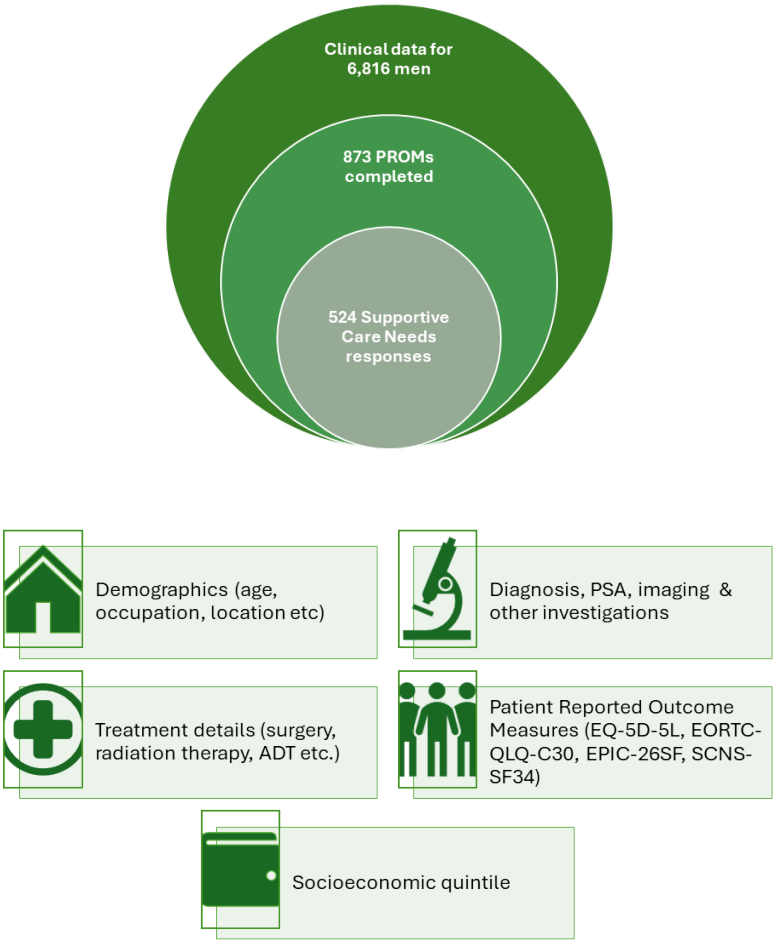
In partnership with Movember, a second rendition of IPCOR was established in 2024 to improve clinical quality and outcomes of prostate cancer in Ireland. IPCOR now contains a biorepository component along with a longitudinal clinical outcomes registry and prospective collection of patient-reported outcome measures (PROMs) at various time points.

IPCOR data collected from 2015 to 2019 is stored, following complete pseudonymisation by the NCRI, on a secure UCD server and utilised by UCD investigators through a HRCDC Consent Declaration. As this data cannot be re-identified by the IPCOR team, follow-up and additional data collection on past participants is not possible. Annual survival updates are performed by the NCRI.

Current IPCOR data is actively being collected since March 2025. Explicit consent is taken from participants and their data is abstracted into a digital registry software under the sole control of IPCOR at UCD. The consent obtained from patients includes sharing of data and biosamples with external companies and researchers for improving diagnosis, treatment and quality of life of men suffering from prostate cancer as well as approaching them for future purposes. The IPCOR registry and biorepository is governed by a Data Oversights & Access Committee (DOAC) and Steering Committee, who must approve all data access requests.

A. What data can you request?

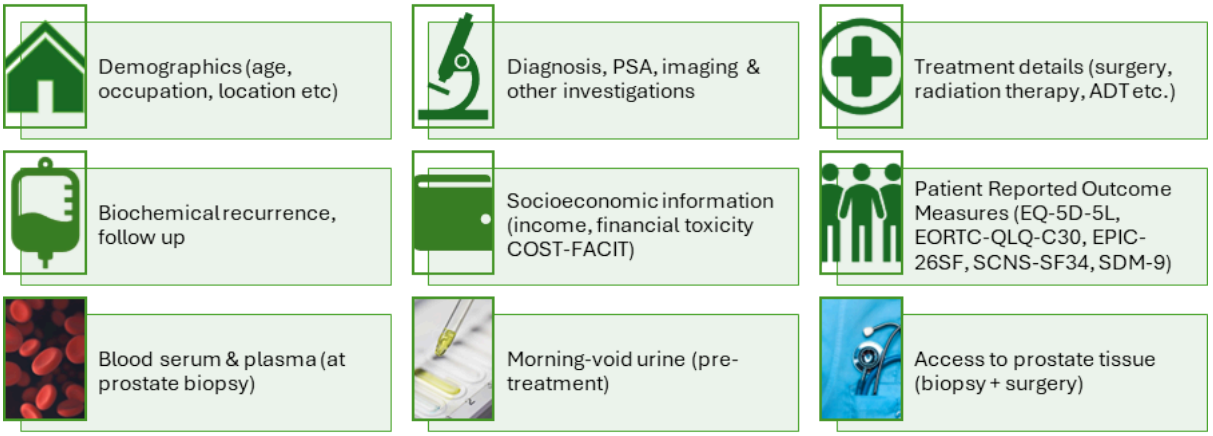
IPCOR 1.0 - 2015 to 2019



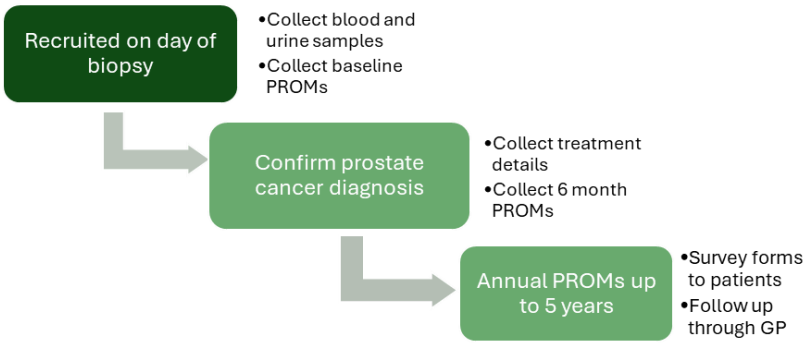
A detailed data dictionary, describing all clinical variables included in this dataset is available on the IPCOR website (www.ipcor.ie).

IPCOR 2.0 - 2025 onwards

As the current IPCOR registry is recruiting participants across active sites on a daily basis, information on the available data and bio-specimens can be followed on the IPCOR website or an email request can be sent to the project team. The detailed data dictionary listing all available variables can also be accessed here (www.ipcor.ie).



Data Collection Timeline



B. What is the data request process?

Researchers and organisations interested in IPCOR data for clinical or translational research and clinical trials must submit a written request outlining their project and requirements. This request can be submitted via the IPCOR website (https://forms.gle/EeeUU4ajA5yEEFuVA) or by email (ipcor@ucd.ie). The research must be for purposes aligning with IPCOR, i.e. for improvement in prostate cancer diagnosis, management or patient experience. All requests must be approved by relevant IPCOR governing bodies, a process that can take from 2 to 4 weeks and is conditional to appropriate ethical approval. Successful parties will be offered two pathways to access data:

1. Federated Approach
    - ❖ The IPCOR data dictionary will be provided, outlining available data variables and their descriptions.
    - ❖ A dummy dataset will be provided with the data variables selected by the researcher.

- ❖ Statistical code for analysis, preferably based on the R programming language or other common statistical software or languages, will be provided to the IPCOR team after testing on the sample dataset.
- ❖ Code will be applied to the raw dataset by an IPCOR representative, and the output will be returned to the researcher.
- ❖ Queries, changes and corrections will be entertained to ensure that the research question has been answered to the researcher's satisfaction.
- ❖ Timelines for completing analysis on the dataset will vary according to the requirements of the requesting researcher. The average processing time is 2 weeks.

This approach only requires IPCOR and ethics committee approval, as the individual-level dataset is not provided directly to the requesting researcher. This is the only pathway available for IPCOR 1.0 data (2015 to 2019) as approved under the HRCDC consent waiver.

2. Direct Access
   - ❖ The IPCOR 2.0 data dictionary will be provided, outlining available data variables and their descriptions. The requesting researcher will specify the variables required for their project.
   - ❖ UCD legal will be engaged to create and/or review a data-sharing agreement between IPCOR and the requesting party. The timeline for this process cannot be provided and may take several weeks, depending on the availability of the legal representative.
   - ❖ Once the legal agreement is finalised and signed by both parties, a ready-for-analysis dataset will be shared.
   - ❖ Support from IPCOR personnel for analysis will not be available after the data file is shared.

Legal agreements are not required for researchers employed by UCD. However, they may be asked to sign confidentiality statements.

Charges for processing data requests may be applied depending on the nature of the request, the support required and the resources available within IPCOR. Details on charges will be shared individually at the time of request approval.

How will data sharing work?

The ready-for-analysis (de-identified) dataset will be shared through HEANet File Sender or a similar secure platform. The file will be password-protected and locked with a unique key. This key will be shared separately to the data through a different medium of communication.

The data will be shared with one single point of contact, the Principal Investigator or an appointed representative who is responsible for conducting the approved research.
The recipient will be responsible for ensuring all confidentiality and data security measures are abided by and the data is used solely for the purpose that was specified.

Researchers based in UCD will receive their dataset through a secure UCD workspace link.

Are there any publication/presentation considerations?

Researchers and organisations utilising IPCOR data are required to acknowledge the role of IPCOR in their project, particularly in scientific publications, posters and presentations.

A sample acknowledgement is given below. This can be adapted according to word allowance or space considerations.

"The [research/result] is [based on or derived from] the dataset/samples collected by the Irish Prostate Cancer Outcomes Research (IPCOR), a University College Dublin (UCD) project supported by Movember. Any opinions, findings, conclusions or recommendations are those of the author(s) and not necessarily those of IPCOR, UCD or Movember."

Additional information for biological specimens

The updated volume of available biological specimens can be checked on the IPCOR website or a request sent directly to the IPCOR team (ipcor@ucd.ie). Following required ethics and institutional approvals, the timeline and cost of processing and transporting requested samples will be shared with the requesting party directly.

All associated clinical data required will be shared from the registry via the mechanisms described above. No clinical data is stored locally in the biobanks and is accessed through sample IDs from the IPCOR registry itself.

C. Requesting Participant Access

If you are interested in accessing the IPCOR participant pool for enrolment in prospective or retrospective studies, please provide details in the data request form (add link).

Studies that require additional data collection, will need to attach the questionnaires to be disseminated. On approval of the request, available participants that fulfill the inclusion criteria of the study or trial will be provided by an IPCOR representative. Identifiable information for contact will not be shared with any researchers, contact for consent to participate in any external studies will be coordinated by the IPCOR team themselves. Charges may be applied according to the requirements of the research and resources within IPCOR.

Data for retrospective trials and studies will follow the same process outlined above in 'Direct Access' in Section B.

For further queries please contact ipcor@ucd.ie. Please note that the request process cannot be sped up and researchers should plan well in advance of any deadlines.