Data Access Policy

It is the responsibility of the IPCOR Steering Committee to ensure appropriate use of IPCOR data for high quality research projects. The Steering Committee will support the ethical review of a project; it will not replace the need for projects to be reviewed by an ethics committee.

The Steering Committee is comprised of individuals with specific interest and expertise in prostate cancer research. Other expert reviewers may be invited to review a research proposal if it requires specialist skills not held by members of the Steering Committee. This might include basic scientists, psychologists, general practitioners and consumers.

The Steering Committee will be responsible for ensuring that data requests are handled in a responsible and ethical manner. Steering Committee members will have a checklist which will be completed for each data request.

Access to data by researchers must be equal with minimal cost and restraints. Policies on use of data will be transparent. All applications for access to IPCOR data must be reviewed by the Steering Committee. Steering Committee members will review applications lodged on the IPCOR Data Access Form. Steering Committee members will complete a review template to ensure that the research complies with relevant ethical and legal obligations and is scientifically sound and feasible.

Steering Committee members will be asked to comment on:

- Background and rationale for the project
- Scientific importance of the research
- Study design
- Feasibility of the project
- Level of statistical expertise provided and whether this is considered adequate for the research
- Whether the research complies with the ethics and level of consent provided by patients and outlined in the Patient Information Leaflet
- Research will not identify any individual patients, clinicians or hospitals
- A clear plan exists to report results from the research
- Whether additional expertise is required to review the application and potential reviewers, if known.
- Whether authors understand their requirement to acknowledge the registry for any publication arising from the data

All data access research requests and outcomes must be submitted to the project manager and must be accompanied with the relevant ethics committee certification. The Steering Committee will have responsibility for approving or declining a data request. Steering Committee reviewers will be asked to review the application within a four-week period. If disagreement exists among reviewers, a teleconference or face-to-face meeting may be requested to resolve the issue. If the Steering Committee cannot agree after meeting, the decision of the PI and co-investigators will be considered final.

In general, requests from contributing clinicians, prostate cancer clinic staff and academic organisations will be fulfilled without charge. Requests from other bodies will be considered on a case-by-case basis by the Steering Committee and may be subject to a processing fee. All third party requests for access to IPCOR Registry data must take appropriate timelines into account as these requests will need to be scheduled along with routine Registry tasks.

Steering Committee members will be asked to sign a Conflict of Interest Declaration. If there is a Conflict, the reviewer will not be eligible to review the application. Members of the Steering Committee will not reveal any confidential or proprietary information entrusted in the course of their duties. Upon cessation of membership, and thereafter, the member shall not reveal any confidential or proprietary information, which they obtained while a member of the group, and may not use or retain, or attempt to use or retain, any such information, documents or data.

During membership, and thereafter, the member will respect the copyright of any information and resources developed under the auspices of the group as agreed by the full membership.