

Annual Report **2018 Executive Summary**



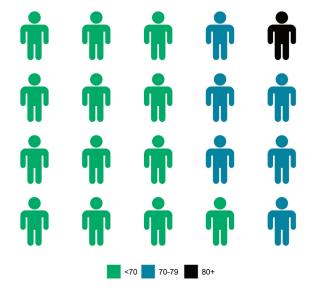


www.ipcor.ie

IPCOR was funded in 2014 by the Irish Cancer Society and the Movember Foundation with the aim of establishing a national prostate cancer registry to follow men diagnosed with prostate cancer through their cancer journey. In collaboration with the National Cancer Registry Ireland (NCRI) and the Clinical Research Facility in Galway (HRB-CRFG), IPCOR allows us to systematically track the most important outcomes of Irish men diagnosed with prostate cancer. The IPCOR investigators include a Urologist, a Medical Oncologist, a Radiation Oncologist, a Cancer Epidemiologist and the Research Manager at the NCRI. Data collected involves both detailed clinical information and patient reported outcome measures (PROMs). Starting this year, IPCOR will publish annual reports containing data for patients, the public and stakeholders, in addition to contributing hospitals and doctors. Based on the accumulated data, the IPCOR investigators will then make recommendations to health care providers aimed at improving the quality of care of Irish men with prostate cancer.

Patients have been involved with IPCOR from the start, and a Patient Panel will shortly be formed to better guide the IPCOR research, PROMs collection and dissemination strategy. IPCOR also works with the Movember Foundation and TrueNTH Global Registry to share data so that patient outcomes in Ireland can be compared with those achieved in other countries. Men will also benefit from the TrueNTH patient portal and decision support tools which will be introduced in 2019. This portal will provide men with a suite of tools which aim to help them make the best treatment choice for their lifestyle based on research and the experiences of other men and will also include a place for men to track their symptoms. The data published in this report shows:

• Over 4,800 patients were registered in IPCOR in 2016 and 2017, equating to approximately 250 men newly diagnosed with prostate cancer every month.



For every 20 men in IPCOR

Figure 1. The age profile of men registered in 15 IPCOR hospitals from February 2016 to December 2017.

- The average age at diagnosis was 66 years (Figure 1)
 - one-fifth of men diagnosed were < 60 years of age.
 - two-thirds of men diagnosed were < 70 years of age.
- Men under the age of 70 are more likely to be diagnosed via the NCCP Rapid Access Prostate Clinics in the public hospital system, than in the private hospital system. (Figure 2)
- A typical man had a diagnostic biopsy 49 days after an elevated prostate specific antigen (PSA) blood test, and was informed of their prostate cancer diagnosis at 79 days following the PSA test.

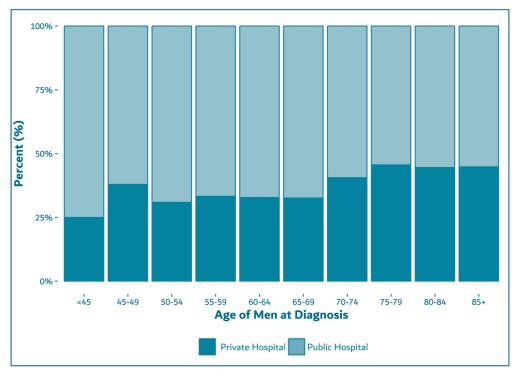


Figure 2. The age of men at diagnosis in public and private hospitals (n = 4830).

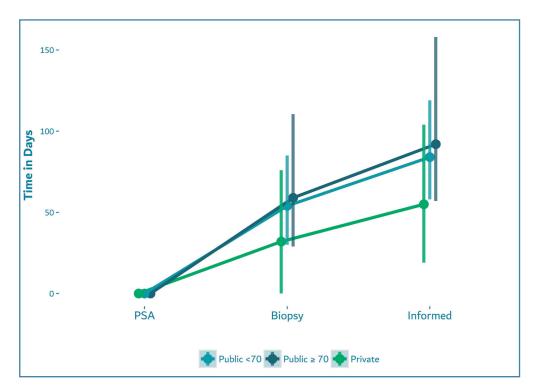


Figure 3. Timing the man's average journey from last PSA test before biopsy, to his biopsy and to being informed of his cancer diagnosis in public and private hospitals. The vertical lines show the inter-quartile range.

 When these milestones are examined broken down by the public and private hospital systems, the time from PSA blood test to biopsy was shorter for patients who had their biopsy in a private hospital (32 days v 56 days) as was the time from PSA test to being informed of a prostate cancer diagnosis (55 days v 85 days). However, this is unlikely to be clinically significant (Figure 3).

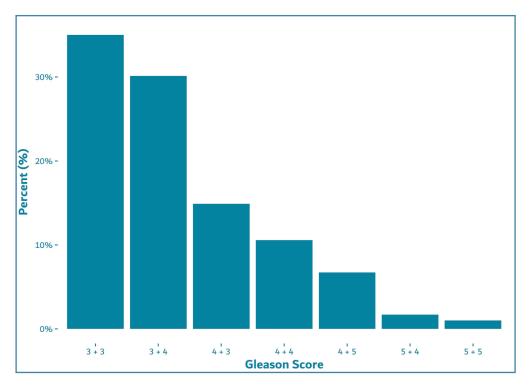


Figure 4. Gleason score at diagnosis (n=4702).

- Approximately two-thirds of men were diagnosed with Gleason 3+3 (ISUP group 1) or Gleason 3+4 (ISUP group 2) prostate cancer, and one third with more aggressive disease (Gleason 4+3 - 5+5, or ISUP group 3 - 5). (Figure 4)
- Younger patients were more often diagnosed with less aggressive disease, and older patients with more aggressive disease. There may be factors other than age that contribute to this e.g. patient co-morbidities or physician discretion.
- Four out of five men diagnosed with prostate cancer had no symptoms. However, older men were more likely to present with potentially cancer-related symptoms e.g. bone pain.
- MRI imaging has been rapidly adopted internationally for the identification and staging of
 prostate cancer. The benefits are that the subsequent biopsy is targeted and this improves
 the cancer detection rate. In addition, fewer repeat biopsies are needed (Kasivisvanathan et
 al. 2018, Ahmed et al. 2017). However, in Ireland the access to MRI scanners is limited leading
 to long waiting times.

- Four out of every five men had a prostate MRI.
- Of the men who underwent an MRI scan, 43% had their MRI before their biopsy.
- Patients in the private service are three times more likely to access a pre-biopsy MRI.
- In relation to the use of CT scans, as men's CAPRA risk score increased they received more staging CT scans, in line with expectation. The occasional use (<20% of patients) of CT imaging in low and intermediate risk disease requires further evaluation (Department of Health 2015).

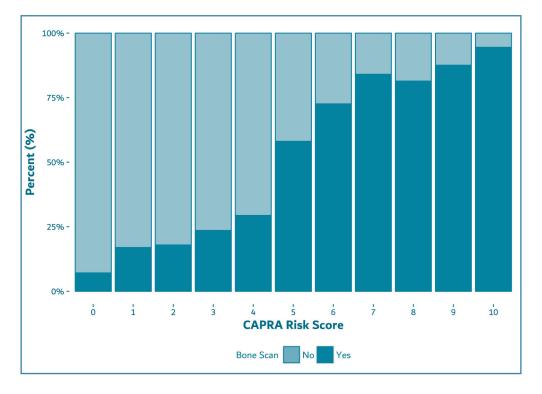


Figure 5. Percentage of men who had a bone scan categorised by CAPRA risk score (n = 3269).

• In a similar fashion, there is an association between the use of bone scans and a man's CAPRA score. Again the occasional use of bone scans in low and intermediate grade disease is generally unnecessary (Department of Health 2015)(Figure 5).

Future Plans:

- In 2019, IPCOR will also publish its first hospital level and doctor level reports.
- IPCOR will continue to grow and will form research partnerships with the National Cancer Control Programme and Cancer Trials Ireland so that IPCOR can support clinical trials in Ireland.
- A Patient Panel will be convened to maximise patient engagement in IPCOR.
- The PROMs collection will recommence.

- The IPCOR website and IPCOR App will be further developed.
- IPCOR will further develop its relationship with Movember and the TrueNTH Global Registry, engaging in global research through the TrueNTH platform.
- IPCOR will offer the TrueNTH platform to men with prostate cancer in Ireland during 2019.
- The next IPCOR annual report will be published in November 2019.

For more results and discussion please see the full report on ipcor.ie

References

Department of Health. 2015. "Diagnosis, Staging and Treatment of Patients with Prostate Cancer." National Clinical Guideline No. 8. June 2015. Updated March 2016. ISSN 2009-6259.

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