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IPCOR: First results from Ireland's only prostate cancer specific registry

Áine Murphy, Cara Dooley, Frank Sullivan, Ray McDermott, Conan Donnelly, Linda Sharp, David Galvin

PROSTATE CANCER is the most commonly diagnosed cancer in Ireland and accounts for almost 30% of the total number of cancers diagnosed in men (excluding the common but rarely fatal non-melanoma skin cancer). The National Cancer Registry Ireland estimate annual average incidence to be over 3,500 patients in the period 2016 to 2018.[1] In terms of mortality, from 2013 to 2015, prostate cancer accounted for 522 deaths annually making it the third most common cause of cancer death (just over 11% of the total cancer mortality). With improving treatment, a changing disease profile and a changing patient demographic, five-year survival has increased significantly from 66% for patients diagnosed from 1994-1998 to 92% for those diagnosed from 2010-2014.[1]

Due to improving survival and increasing incidence, the number of men living with prostate cancer has increased year on year with an estimated 35,125 men with a history of prostate cancer at the end of 2016. As prostate cancer incidence is projected to increase to in excess of 6,000 by 2045 based on population ageing alone, prevalence is expected to continue to increase. These changing patterns in prostate cancer burden present significant challenges for service planning and patient care.

IPCOR

The longitudinal clinical and patient reported outcomes data, compiled by the Irish Prostate Cancer Outcomes Research (IPCOR), will provide the information necessary to inform and improve care for men living with the disease and the consequences of its treatments. The IPCOR study aims to provide evidence-based data on men with prostate cancer and to make recommendations to clinicians, hospitals, decision-makers and the National Cancer Control Programme that promote improvements in care *(see Table 1)*.

To do this, IPCOR is collecting detailed clinical and patient-reported data on men's prostate cancer journeys from the time of diagnosis, throughout treatment and beyond. This will improve our understanding of how prostate cancer impacts men over their lifetime and provide the evidence on how best to improve care and use limited healthcare resources.

PiCTuRE study

IPCOR also wants to share its findings with the public, particularly men with prostate cancer and their families. The recent, large, population-based PiCTuRE study investigated the treatment decision-making, treatment side-effects, wellbeing and health-related quality of life in men living with prostate cancer on the island of Ireland (data published[2,3,4]).

However, there is little long-term data, in Ireland or internationally, tracking men's experiences from diagnosis and throughout their treatments and beyond. This lack of information means that doctors are unable to inform men of their expected outcomes with any confidence. IPCOR's ambition is that men who are diagnosed with prostate cancer in the future, and their doctors, will be able to use the IPCOR data so that together they can make informed decisions about treatments and understand the outcomes men can expect.

To find out more about the establishment of the IPCOR registry, its governance structure and data collection procedures, please

Table 1: IPCOR goals

1	Create national standards for prostate cancer care in Irish hospitals
2	Collect data and produce reports that will influence decision makers to improve prostate cancer care
3	Ensure decisions about prostate cancer care are transparent and based on high quality data
4	Carry out research studies which investigate issues that impact men with prostate cancer e.g. dietary and lifestyle issues
5	Compare Irish prostate cancer care with care around the world and ensure men in Ireland receive the highest standards of care

Figure 1: Number of men registered with the IPCOR database from Feb 2016 to Dec 2017 categorised by month and year (n = 4,814)

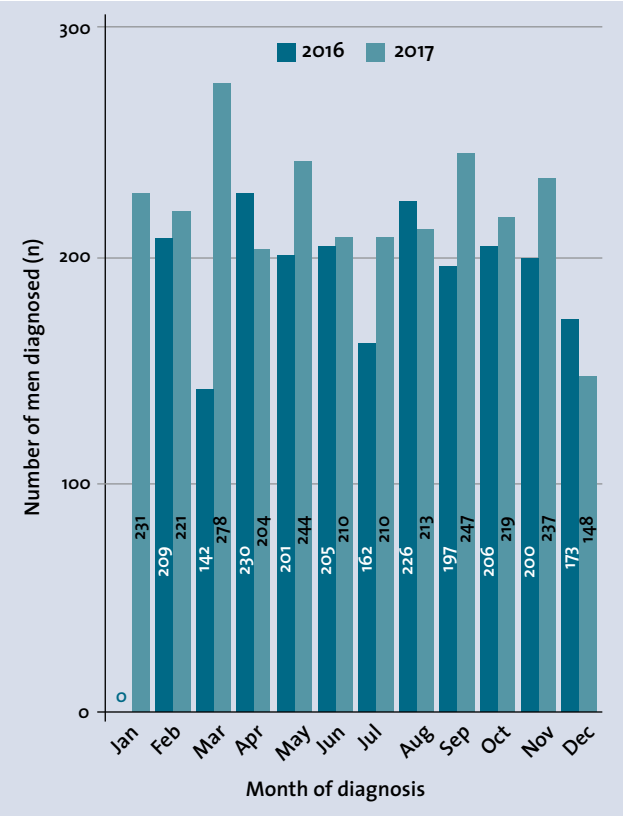

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Figure 2: The age profile of men registered in 15 IPCOR hospitals from February 2016 to December 2017

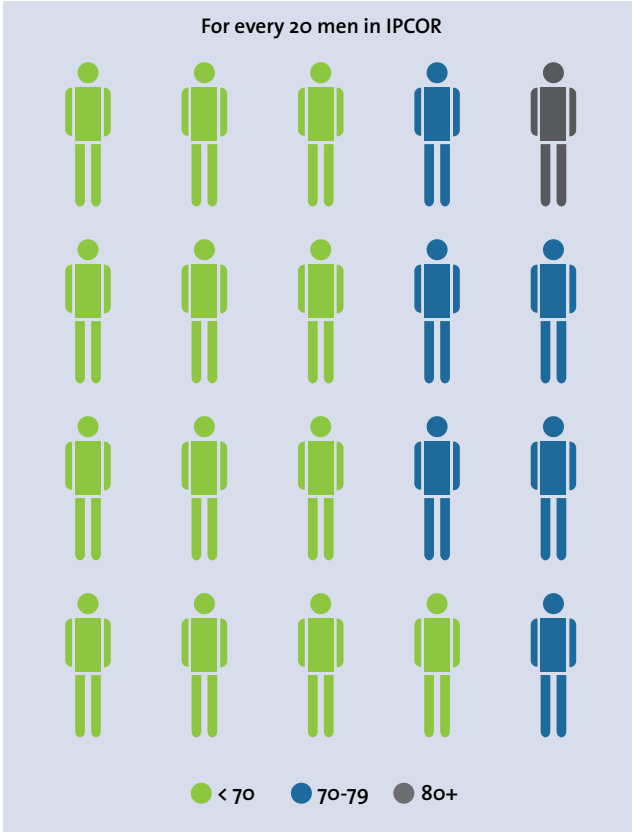
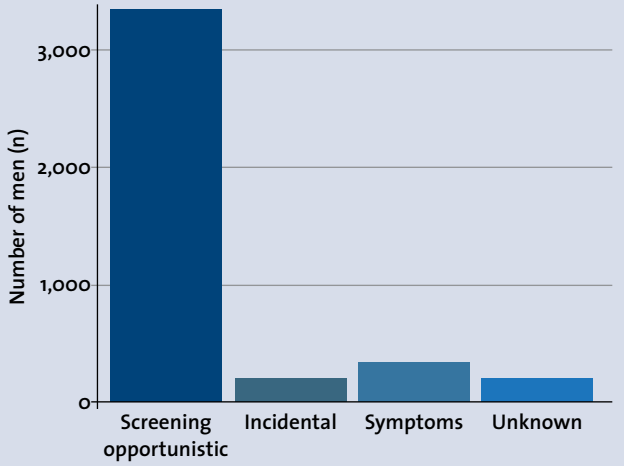


Table 2: Number and percentage of men by method of presentation

	Number (n)	Percent (%)
Screening – opportunistic	w3340	81.7
Incidental	197	4.8
Symptoms	351	8.6
Unknown	201	4.9
Total	**4,089**	**100.0**

Figure 3: Number of men by method of presentation (n = 4,089)



refer to the article entitled *Bridging the data gap* published in *Cancer Professional*, spring edition, 2016.[5]

Latest Irish data

IPCOR published its 2018 annual report in November 2018 and it describes demographic and diagnostic information on 4,868 men diagnosed with prostate cancer in 15 hospitals across Ireland, from February 2016 to December 2017.[6]

Below are examples of the data that is outlined in the report.

Figure 1 shows the month and year of diagnosis for the men registered in IPCOR. The number of men registered per month has increased slightly from 2016 to 2017, as the project expanded, with on average 222 men diagnosed with prostate cancer each month in 2017.

Figure 2 shows that prostate cancer is a diagnosis made commonly in men during their working life. The average age at which men were diagnosed was 66 years old. Despite perceptions, this is not only a disease of old men. Approximately two-in-five men (41%) are diagnosed under the age of 65 and two thirds of men diagnosed are under 70; as retirement age continues to increase, more men will be diagnosed during their working life.

Their diagnosis could have an impact on their occupation or career, financial position, and their relationship with their partner and children. This can create anxiety, stress and depression in men at a busy time in their lives. Older men may also suffer psychosocial symptoms,[7] often with less social support structures and additional comorbidities. As men's working lives are increasingly prolonged with increasing life expectancy, the impact of a prostate cancer diagnosis is likely to increase over time.[8,9]

The IPCOR annual report also examines the method of how men are presenting to their GP and urologist. By reviewing the medical records, men are categorised as either presenting with symptoms due to their underlying prostate cancer or not. There has been much publicity against routine prostate-specific antigen (PSA) testing recently and the US Preventative Services Task Force recommended against routine screening in men 70 and older.[10] GPs in Ireland are advised by the NCCP to discuss the pros and cons of testing with men beforehand. PSA testing in primary care is not well characterised.

Figure 3 and *Table 2* show that prostate cancer is detected in four out of five men by screening (using a PSA blood test), these men did not have symptoms of prostate cancer. Men are commonly told to talk to their GP if they are experiencing symptoms such as urinary problems or bone pain. However, the majority of men have no symptoms and their prostate cancer is first detected by an abnormal PSA level.

Figure 4 demonstrates that men over 80 are more likely to experience symptoms of prostate cancer prior to their diagnosis. The opportunity to detect these cancers earlier in a man's life may have been possible with earlier PSA testing.

Screening for prostate cancer remains highly controversial. The evidence from randomised trials suggests that screening for prostate cancer may result in a small absolute benefit in prostate cancer specific mortality over 10 years but does not improve overall mortality.[11] PSA testing seems to increase the detection of

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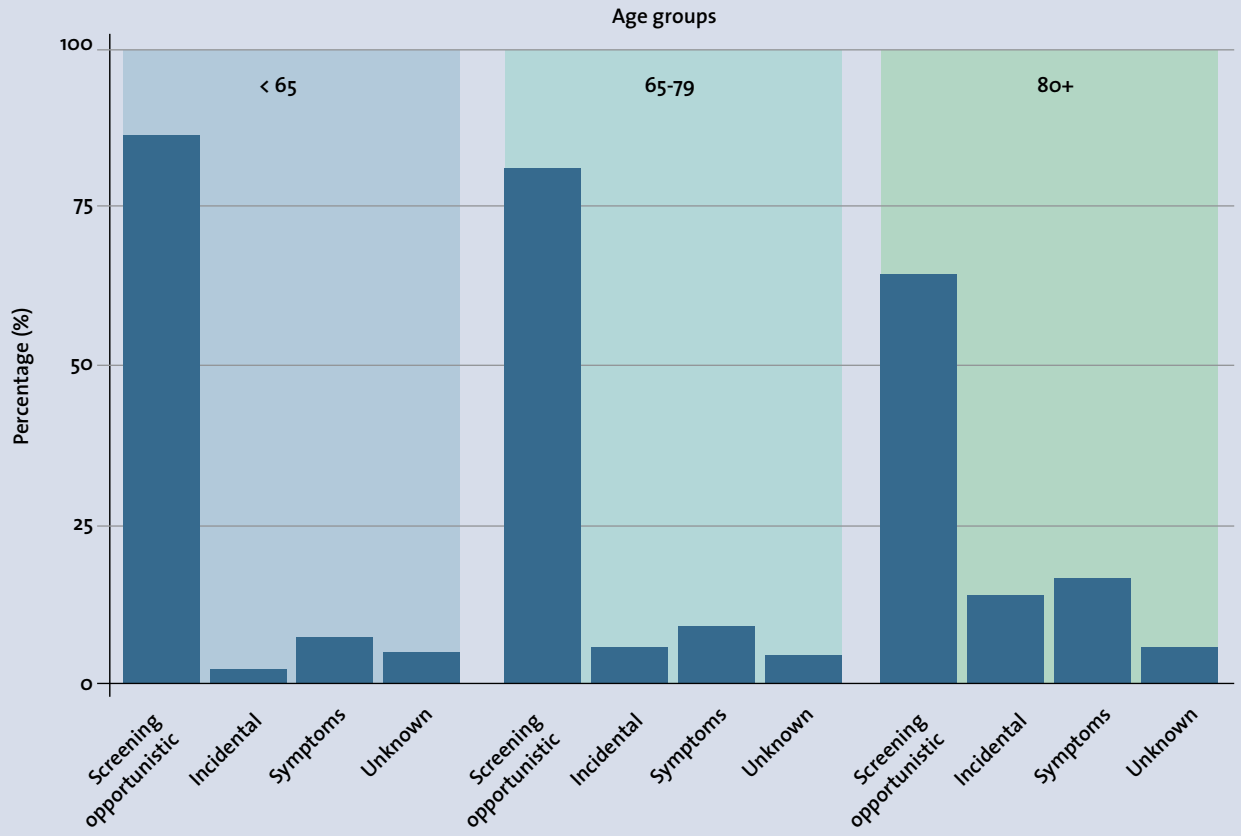
Figure 4: Percentage of men by method of presentation by age



localised prostate cancer and may slightly decrease the incidence of advanced cancer.[12,13] Any benefit of prostate cancer screening should be weighed against the potential complications of false positive and false negative findings. Approximately two thirds of men with an elevated PSA will not be diagnosed with prostate cancer[14] while 15% of men with a PSA < 4ng/mL will be diagnosed with prostate cancer.[15]

Other complications to be considered include those as a result of biopsy or subsequent treatment such as urinary or sexual dysfunction. The United States Preventative Services Task Force advocate for an individualised approach to screening for men aged 55-69.[10]

Conclusion

The data presented in the IPCOR report provides evidence for the importance of men discussing their prostate health with their GP and for the GP to outline the pros and cons of PSA testing.

To view the full IPCOR annual report, please go to **www.ipcor.ie/Research-and-Publications**

Áine Murphy is IPCOR project manager, Clinical Research Development Ireland (CRDI); **Cara Dooley** is an IPCOR statistician, CRDI; **Frank Sullivan** is a consultant radiation oncologist, adjunct professor of medicine, National University of Ireland, Galway and the Galway Clinic, and IPCOR co-investigator; **Ray McDermott** is a consultant medical oncologist, Tallaght and St Vincent's University Hospitals, and IPCOR co-investigator; **Conan Donnelly**, is research manager, National Cancer Registry Ireland, and IPCOR co-investigator; **Linda Sharp**, is professor of cancer epidemiology at Newcastle University, UK, and IPCOR co-investigator; and **David Galvin** is a consultant urologist, Dublin Academic and Medical Centre, St Vincent's and Mater Misericordiae University Hospitals, and IPCOR principal investigator

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