NCCP PROSTATE CANCER QUALITY AND AUDIT FORUM

6th NOVEMBER 2015

Over 2,571 men were seen in the National Cancer Control Programme (NCCP) Rapid Access Clinics (RAPC) in 2014, with a total of 1,024 men diagnosed with prostate cancer. Speaking at the fourth NCCP Prostate Cancer Quality and Audit Forum on Friday November 6th, Dublin, NCCP Director Dr Jerome Coffey stated:

“Our diagnosis rate is 40% and this illustrates that we are now providing a good service where GPs refer patients into the system.”

This aims to ensure that men are provided with their diagnosis within a three to four week timeframe. For the majority of men who do not have cancer, that timeframe reduces the anxiety that longer waiting involves. And for those men who are diagnosed, their treatment options are discussed and considered by an expert multi disciplinary team who ensure that the patient is given all the options and all the information on the best approach to be taken.”

Dr. Jerome Coffey, confirmed that urological cancers are a priority area for the NCCP in 2016, adding a focus on the further development of services for patients with renal, bladder, penile and testicular cancers.

Over 3,300 men are diagnosed with prostate cancer annually in Ireland and with this number expected to increase over the coming decades as our population ages.

“This event brings together the leading prostate cancer experts from across the country. “

The forum provides them with an opportunity to review the practices of the Rapid Access Prostate Clinics at each of the eight designated cancer centers to date. It also allows for a sharing of the latest information on prostate cancer – diagnosis and treatment options.

With developments in treatment options changing and evolving over time, the NCCP Prostate Cancer Quality and Audit Forum acknowledges that prostate cancer is usually viewed differently to other cancers. According to Mr David Galvin, National Prostate Cancer Clinical Lead, Consultant Urologist, Mater Hospital; “We are exploring ways to provide access to newer robotic prostate cancer surgery. As the prostate cancer service has become established in the last few years, we are now moving to discuss services for other urological cancers such as bladder and kidney cancer, and expert groups are being established to look at these services. Also we are looking at cancer survivorship and optimising outcome for our patients.”

Guest speaker at the Quality and Audit Forum was Mr Ben Challacombe, Consultant Urological Surgeon and Honorary Senior Lecturer Guy’s and St Thomas’ Hospitals NHS Foundation Trust and Kings College London, UK; Mr. Challacombe gave a presentation on robotic prostate cancer surgery.

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In conclusion Dr Jerome Coffey noted that this event takes place annually. “Our Rapid Access Services – for Prostate, Lung and Breast Cancer – have been a significant focus within the development of cancer services nationally. With all of our clinics now open and operating on a standardised basis, our focus is to ensure that they continue to be managed in a quality assured, consistent basis that ensures that regardless of where any of our patients live, they will access the same service delivered in the same manner by our multi disciplinary teams in all eight designated cancer centres.”

NCCP PROSTATE CANCER KEY PERFORMANCE INDICATORS (KPI) UPDATE 2015

2014 is the first year of capture of full suite of KPIs and there is now four year’s data available on the rapid access clinics. 2014 data demonstrates that referral trends to the rapid access clinics continue to stabilise as the overall numbers have remained the same for the last three years. Referral criteria continue to work well with over 40% of new attendances being diagnosed with cancer.

Looking at new to return attendance ratios, there has been a fall in the proportion of new attendances in the cancer centres outside of Dublin. Some of this has been unavoidable as there are no other clinics where the patients can be referred. However, it is worrying as the clinics will no longer function as “rapid access” if the trends continue.

New attendances at the Rapid Access Prostate Clinic (RAPC) clinics by cancer centre, 2011 – 2014 are shown in fig. 1 below:

2014 shows an on-going improvement in time to treatment processes for radiation oncology in all sites, however, timeliness of access to surgery (measured for the first time in 2014) requires significant improvement as less than 60% of all patients were operated on within 30 working days of decision to treat.

Figures two shows the total no. of new attendances at the Rapid Access Prostate Cancer Clinics from 2011 to 2015.

Seventy percent of patients are discussed at a multi-disciplinary meeting prior to their first therapeutic intervention, with wide variation between sites. This should improve over time. The timeliness of histopathology reporting following the first prostate biopsy is in general very good at 88%, with one centre requiring further review. Surgical margins and post-operative prostate specific antigen (PSA) measures following radical prostatectomy are examined for the first time in 2014. It will take a number of years for the true picture to emerge as the number of radical prostatectomies carried out every year is relatively small. Data following radical prostatectomy for patients staged as pT2 appear to be excellent, whereas there appears to be some evidence for room for improvement for patients staged as pT3.
Table 1: Prostate Cancer Key Performance Indicator (KPI) | Total
---|---
Total number of new patients seen in RAPC | 2,580
% of men diagnosed with prostate cancer | 1,066

KPI
1. Referrals to the rapid access prostate clinic shall be offered an appointment within 20 working days of the date of receipt of referral | 49%
2. Access to Therapy (a) For surgical patients, the interval between decision to treat and surgery should not exceed 30 days | 57%
3. All patients with prostate cancer should be discussed at a Multi-disciplinary Meeting (MDM) prior to commencement of therapy | 70%
4. 80% of all men who undergo a prostate biopsy should receive their results within 10 working days. | 88%
5. (A) Radical Retropubic Prostatectomy (RRP) pT2 (a) 85% clear margin rate | 86%
5. (A) RRP pT2 (b) PSA should be undetectable at 3 months in 90%*** | 95%
5. (B) RRP pT3 (a) 60% clear margin rate | 53%
5. (B) RRP pT3 (b) PSA should be undetectable at 3 months in 70% of cases*** | 86%

NCCP HOSTS FOURTH NATIONAL PSA HARMONISATION WORKSHOP

The fourth NCCP PSA Harmonisation Workshop took place at the NCCP offices, Dublin on Wednesday 27th January 2016, which was attended by representatives from national laboratories. This is part of the ongoing project by the NCCP to address the lack of harmonisation of PSA measurements around the country as indicated in a publication in the British Journal Urology International (BJUI).

“This project aims to harmonise PSA assays around the country, leading to better decision-making particularly for PSA results in the narrow 3-7 ug/L range, where a decision to perform prostate biopsy may be taken and where it is thought that lack of standardisation may contribute to unnecessary biopsies.”

The PSA Harmonisation Project Board was set up by the NCCP, and is chaired by Dr. Vivion Crowley, Consultant Chemical Pathologist. IEQAS (Irish External Quality Assessment Scheme) www.ieqas.ie are a key partner in this important quality initiative. The goal is to further elucidate this matter and recommend the best approach to achieving optimal PSA harmonisation.

NCCP ELECTRONIC CANCER REFERRAL PROGRAM

The National Cancer Strategy 2006 recognised that information systems should be developed to manage cancer services. The NCCP in collaboration with a broad range of stakeholders has developed electronic cancer referral for breast, prostate and lung cancer.

The objective was to develop an online system so that patients can be referred by their GP directly to the cancer centre. This ensures rapid referral of patients with suspected cancer in a secure manner. Once the GP sends an electronic cancer referral, an immediate acknowledgment is given. In addition the cancer teams will send a response to the GP, with the date of the patient’s appointment within five working days.

The project builds on using existing technologies already deployed in GP’s surgeries and the wider Health Service. These technologies include the Healthlink infrastructure (www.healthlink.ie) and the accredited GP practice management systems.

This is a multi-agency project involving the following organisations:

1. The National Cancer Control Programme, Parnell Street, D 1 www.hse.ie
2. The National Healthlink Project, Eccles Street, D 7 www.healthlink.ie
3. The ICT Directorate, HSE, Parkgate Street, D 1 www.hse.ie
4. The GPIT group (made up of representatives of the HSE and ICGP)
5. Irish College of General Practitioners, D 2 www.icgp.ie

47% of all breast, prostate and lung cancer referrals were sent electronically in 2015. The target for 2016 is 50%.

Benefits: There are many benefits to electronic GP referral which include:

1. Streamline the cancer referral process
2. Rapid access for patients who are being referred with a suspected cancer
3. Provide automatic confirmation of receipt of GP referral
4. Provision of direct access for GPs to the cancer teams at the eight designated cancer centres
5. Reduce communication difficulties
6. Reduced costs for GP and HSE
7. Introduces a greater degree of safety into the referral process
8. Electronic cancer referral reduces stress for patients as it provides reassurance that the referral has been received by the cancer teams
9. The GP often completes the electronic cancer referral with the help of the patient

Further information is available via the following web link: http://www.ehealthireland.ie/Strategic-Programmes/eReferral/Statistics%20NCCP/

A video demonstrating this NCCP initiative is available at: http://www.hse.ie/eng/services/list/5/cancer/profinfo/resources/gpelectroniCancerReferral.html
Demonstration of effectiveness and success:

There were a total of 1,267 electronic cancer referrals to the prostate cancer service in 2015. University Hospital Waterford takes the lead with 73% of all referrals to their clinic being received electronically. Please see table two for further details.

<table>
<thead>
<tr>
<th>Hospital</th>
<th>No. Attendances</th>
<th>No. E Referrals</th>
<th>% E-Ref</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waterford</td>
<td>215</td>
<td>157</td>
<td>73%</td>
</tr>
<tr>
<td>CUH</td>
<td>197</td>
<td>137</td>
<td>70%</td>
</tr>
<tr>
<td>St. James’s</td>
<td>334</td>
<td>193</td>
<td>58%</td>
</tr>
<tr>
<td>Mater</td>
<td>299</td>
<td>166</td>
<td>56%</td>
</tr>
<tr>
<td>Beaumont</td>
<td>259</td>
<td>132</td>
<td>51%</td>
</tr>
<tr>
<td>St. Vincent</td>
<td>272</td>
<td>110</td>
<td>40%</td>
</tr>
<tr>
<td>GUH</td>
<td>712</td>
<td>278</td>
<td>39%</td>
</tr>
<tr>
<td>Limerick</td>
<td>293</td>
<td>94</td>
<td>32%</td>
</tr>
<tr>
<td>Total</td>
<td>2,581</td>
<td>1,267</td>
<td>49%</td>
</tr>
</tbody>
</table>

There were 20,861 electronic cancer referrals (Breast, Prostate and Lung Cancer and pigmented lesion) in 2015.

Table three provides further details.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of electronic cancer referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>2,070</td>
</tr>
<tr>
<td>2011</td>
<td>4,360</td>
</tr>
<tr>
<td>2012</td>
<td>9,303</td>
</tr>
<tr>
<td>2013</td>
<td>13,381</td>
</tr>
<tr>
<td>2014</td>
<td>16,453</td>
</tr>
<tr>
<td>2015</td>
<td>20,861</td>
</tr>
<tr>
<td>2016</td>
<td>19,232 (1st Jan to 20th Sept 2016)</td>
</tr>
</tbody>
</table>

Data Source: The National Healthlink Project, NCCP

For further details please see below.

Future development includes implementation of the attachment of files. For further information please contact Ms. Eileen Nolan, E-Referral Manager via eileen.nolan@cancercontrol.ie

DEVELOPMENT OF NCCP PATIENT BOOKLET FOR PATIENTS WITH SEXUAL DYSFUNCTION POST TREATMENT OF PELVIC CANCER

The NCCP in conjunction with the national multi-disciplinary prostate and colorectal cancer teams are developing an information booklet for men with sexual dysfunction post treatment of pelvic cancer.

This booklet aims to address the issues that patients may experience post cancer treatment. It will also provide support and information in a clear concise manner. Sexual dysfunction is any problem that prevents a person from desiring or enjoying sexual activity.

All NCCP patient information seeks accreditation by the National Adult Literacy Agency (www.nala.ie) to obtain the “Plain English” certification. Members of the national project board will include representation from urologists, colorectal surgeons, prostate/colorectal cancer nurse specialists, sexual rehabilitation specialists, GPs and most importantly patients.

This patient booklet will include psychological self help tips as well as practical advice for men and their families.
INAUGURAL NCCP MALE UROLOGICAL PELVIC CANCER AND SEXUAL DYSFUNCTION STUDY DAY 2nd OCT 2015

The NCCP hosted their inaugural Male Urological Pelvic Cancer and Sexual Dysfunction Study Day on Friday 2nd October 2015 in St. James’s Hospital.

Over 3,300 men are diagnosed with prostate cancer annually in Ireland and this number is expected to increase over the coming decades as our population ages. Over 2,571 men were seen in the newly established NCCP Rapid Access Clinics in 2014, with a total of 1,024 (40%) men diagnosed with prostate cancer. That figure is expected to increase significantly in 2015.

Speaking at the study day on Friday October 2nd, Dublin, NCCP Director Dr Jerome Coffey stated:

“This inaugural study day was one of the outcomes of last year’s NCCP Prostate Cancer Quality Forum. This demonstrates that we are focusing on quality of life issues and long term survivorship”.

Photograph (Left to Right): Ms. Hilary Murphy, NCCP; Mr. David Galvin, Consultant Urologist, Mater and St. Vincent’s, National Prostate Cancer Clinical Lead; Ms. Anita Cahill, CNS, Cork University Hospital; Mr. Padraig Daly, Consultant Urologist, University Hospital Waterford; Ms. Ger O’Boyle, Radiation ANP, University Hospital Galway; Mr. Ivor Cullen, Consultant Urologist, University Hospital Waterford; Ms. Lynn Casey, ANP Urology, St. James’s Hospital; Dr. Jerome Coffey, Director, NCCP.

Mr David Galvin, National Clinical Lead for Prostate Cancer for the NCCP advised that cure rates and long term survival for prostate cancer are high, and there is growing interest in cancer outcomes nationally and internationally. Here in Ireland, we are very lucky to have a national system of hospital based prostate cancer nurses, upon which we can continue to build a platform for supporting men with sexual dysfunction post treatment of their prostate cancer.

Mr Ivor Cullen, Consultant Urologist/ Andrologist, University Hospital Waterford, provided an update on best practice and treatments available for men with sexual dysfunction post prostate cancer treatment.

The study day brought together prostate cancer experts from across the country. This provided an opportunity to review the management of men who are affected with male sexual dysfunction following treatment for prostate cancer. It also provided a forum to develop a national protocol to standardise the management of sexual dysfunction in this patient group.

The following presented and facilitated at the study day:

NATIONAL CLINICAL GUIDELINE FOR THE DIAGNOSIS, STAGING AND TREATMENT OF PROSTATE CANCER

The NCCP in conjunction with the National Clinical Effectiveness Committee (NCEC) has published evidence-based Clinical Guideline on Prostate Cancer. The guideline is available to download in PDF below.

http://www.hse.ie/eng/services/list/5/cancer/profinfo/guidelines/prostate/

Evidence-based guidelines:

- Aim to improve the quality of clinical care,
- Aim to prevent variation in practice,
- Aim to address areas of clinical care with new and emerging evidence,
- They are based on the best research evidence in conjunction with clinical expertise,
- They are developed using a clear evidence-based internationally used methodology.
LAUNCH OF NCCP PROSTATE CANCER GUIDELINE

Front Row: Ms. Eileen Nolan, NCCP, Dr. Kathleen MacLelland, NCEC, Dr. Anne O’Doherty, Consultant Radiologist, St. Vincent’s, Chair of Breast Cancer Group, Minister for Health Mr. Leo Varadkar; Dr. Susan O’Reilly, CEO, Dublin Mid Leinster Hospital Group;

Second Row: Dr. Niamh O’Rourke, NCCP; Dr. Tony Holohan, Chief Medical Officer, Department of Health; Dr. Eve O’Toole, Guideline Methodologist, NCCP; Dr. Jerome Coffey, Director, NCCP; Mr. David Galvin, Consultant Urologist, Mater and St. Vincent’s, Chair of NCCP Prostate Cancer Guidelines Group.

A Guideline Development Group was responsible for the development of this National Clinical Guideline and included representatives from relevant professional groups. The guideline focuses on the diagnosis, staging and treatment of patients with prostate cancer. It does not include recommendations covering every aspect of diagnosis, staging and treatment. Instead this guideline focuses on areas of clinical practice:

- known to be controversial or uncertain,
- where there is identifiable variation in practice,
- where there is new or emerging evidence,
- where guidelines have the potential to have the most impact.

This evidence-based clinical guideline will ensure standardised multi-disciplinary care for patients, putting evidence into practice to improve patient outcomes.

Comments should be emailed to guidelines@cancercontrol.ie

NCCP PRESENT ON ELECTRONIC CANCER REFERRAL AT EU PARLIAMENT AT EUROPEAN PATIENT RIGHTS DAY 2016

The NCCP were invited to present on the National Electronic Cancer Referral System at the European Patients Rights Day 4th May 2016 at the EU Parliament Brussels. The 2016 European conference of the European Patients Rights Day focused on the fight against waste and inefficiency in healthcare systems in Europe and on the best practices to increase the efficacy and the quality of patient care.

It took place on Wednesday, May 4th in Brussels at the European Parliament co-hosted by MEP David Borrelli, co-Chair of the Europe of Freedom and Direct Democracy (EFDD) Group and MEP Pier Nicola Pedicini, EFDD, Committee on Environment, Public Health and Food Safety, (ENVI) Committee Coordinator. The participants were leaders of civic and patient organizations coming from 25 Countries, some of them outside the European Union, such as Albania, Russia, Macedonia, Switzerland. With them, many representatives and leaders of 18 networks at EU level, professionals and experts, companies and providers, public relation agencies and other relevant stakeholders.

A link to the agenda and presentations can be found via the following link: Link to agenda and presentations: http://www.activecitizenship.net/patients-rights/projects/201-european-patients-rights-day-2016.html

There was a lot of interest in the electronic prostate cancer referral system, and in particular the two way communication between GPs and prostate cancer teams and the ability to integrate a patients recent PSA results within the referral.

Ms. Eileen Nolan represented the NCCP at this event.

IRISH PROSTATE CANCER OUTCOME RESEARCH (IPCOR) UPDATE

The IPCOR study published its first annual public report in August 2015 and is due to publish its second annual report shortly. The reports are available on the IPCOR website www.ipcor.ie.

Phase 1 of the study began with recruitment of the first research officer in May 2015 and her establishment in the hospitals in the South of Ireland, namely, Cork University Hospital, Mercy University Hospital and Bon Secours Cork. During phase 1, the clinical database for the IPCOR study was developed by colleagues in the National Cancer Registry. The IPCOR study has now successfully recruited four research officers and a database support officer.

The research officers are now established in 15 hospitals nationwide which were achieved through the support of clinicians, clinical nurse specialists and working with hospital
CEOs, HR and IT departments. The research officers have a desk space and access to hospital systems such as pathology, radiology, medical records etc. Research officers have successfully accessed Multi-disciplinary Meetings (MDT) meetings and built relationships with the necessary team members to efficiently and effectively identify newly diagnosed prostate cancer patients in a timely manner.

Three of the research officers began collecting the clinical dataset on newly diagnosed prostate cancer patients from February 1st 2016. The fourth research officer is now in place and has begun collecting data in the Dublin South hospitals.

Unfortunately, the IPCOR study does not have enough funding to cover the expenses of the research officers travelling to University Hospital Limerick and University Hospital Waterford from their bases in Galway and Cork respectively.

The IPCOR study successfully secured funding of €45,633 from Astellas Pharma Ireland which has allowed IPCOR to work with Patient Buddy, a health technology software company. Patient Buddy has collaborated with the IPCOR team to develop an electronic patient reported outcomes measurement (PROMs) data collection tool.

Men who wish to take part in the IPCOR study will have the option of logging into the electronic tool through the IPCOR website and consenting to the study and completing the quality of life questionnaires.

The collaboration with Patient Buddy has also led to the development of an IPCOR app which men will be able to download from the IPCOR website. The app allows men to maintain a digital health record. The IPCOR team will also build content for the app which will provide information to men about various treatments, procedures and supports available.

Key Points:
- All key personnel now in place
- Clinical Data Collection commenced 1st Feb 2016
- Patient Reported Data to commence June 2016
- IPCOR website and Patient Buddy App ready to go and will act as a central Portal for all prostate cancer patients in Ireland

### TABLE 4: IPCOR STAFF

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Aine Murphy</td>
<td>Project Manager</td>
<td>Based in Molecular Medicine Ireland (MMI), Dublin</td>
</tr>
<tr>
<td>Dr Leah Bentham</td>
<td>Research Officer</td>
<td>Cork University Hospital (CUH), Bon Secours, Mercy</td>
</tr>
<tr>
<td>Dr Emer McCarthy</td>
<td>Research Officer</td>
<td>Galway University Hospital (GUH), Galway Clinic, Bon Secours</td>
</tr>
<tr>
<td>Ms Hazel Smith</td>
<td>Research Officer</td>
<td>Beaumont, Mater, Beacon</td>
</tr>
<tr>
<td>Ms Lisa McGowan</td>
<td>Research Officer</td>
<td>St. Vincent’s University Hospital (SVUH), St. Vincent’s Private Hospital (SVPH), St James</td>
</tr>
<tr>
<td>Ms Christine Allan</td>
<td>Database Support Officer</td>
<td>Based in National Cancer Registry Ireland (NCRI), Cork</td>
</tr>
</tbody>
</table>

### MEMORIAL

We would like to acknowledge all of the work and commitment of our late colleague Ms. Orla Doogue, Systems Analyst, The National Healthlink Programme brought to the NCCP electronic cancer referral program. (RIP 2015, age 37)
The National Cancer Control Programme would like to thank the multiple agencies whom we have collaborated with over the last number of years.

If you would like to include something in the next issue of this newsletter please submit suggestions to the following:

National Cancer Control Programme
Kings Inns House, 200 Parnell Street, D 1
Phone: 01 8287100
Fax: 01 8287160
E-mail: info@cancercontrol.ie

Abbreviations
ANP- Advanced Nurse Practitioner
EFDD- Europe of Freedom and Direct Democracy
IEQAS- Irish External Quality Assessment Scheme
MDT- Multi-disciplinary Team Meeting
PSA- Prostate Specific Antigen
RRP- Radical Retropubic Prostatectomy
BJUI- British Journal of Urology International
ENVI- Committee on Environment, Public Health and Food Safety
IPCOR- Irish Prostate Cancer Outcome Research
MMI- Molecular Medicine Ireland
NCEC- National Clinical Effectiveness Committee
DNA- Do not attend rate
HSE- Health Service Executive
KPI- Key performance Indicator
NCCP- National Cancer Control Programme
RAPC- Rapid Access Prostate clinic