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Why cancer patients die in acute hospitals

Mrs Jenny Cardy, Dr Janine Blaney, Dr Graeme Crawford, Dr Anna Gavin, Mrs Roisin Foster, Dr Carolyn Harper, Prof Peter Gregson, Dr Frances Robinson and Dr Yvonne Duff at the report launch in the Great Hall (QUB) on 8 April 2011

Professor Gregson, Vice-Chancellor of Queen’s University Belfast welcomed over 75 people to the launch of the Ulster Cancer Foundation funded report Why Cancer Patients Die in Acute Hospitals. The speakers included Dr Janine Blaney who analysed the data and wrote the report. Dr Graeme Crawford and Dr Yvonne Duff, both members of the project steering group and Dr Frances Robinson presented the GP and clinician viewpoint. Mrs Jenny Cardy shared her personal experiences with us in a very moving talk. Dr Michael McBride concluded the morning after Dr Carolyn Harper outlined steps to address late diagnoses of cancer. The report will soon be available at www.qub.ac.uk/nicr

Recommendations:-

1. All patients nearing end of life should have an advanced care plan in place which incorporates patients preferred place of death.
2. A major initiative to improve earlier recognition of cancer symptoms among both the public and healthcare professionals is required.

(cont’d page 8)
Local progress on the International Cancer Benchmarking Partnership

In December 2009 Northern Ireland joined eleven other jurisdictions to participate in the International Cancer Benchmarking Partnership (ICBP) with Dr Anna Gavin (Director, NICR) representing Northern Ireland on the ICBP Project Board. This is the first international benchmarking initiative to go beyond quantifying cancer survival differences by exploring a wide range of possible reasons for those differences.

Partners were invited on the basis of broadly comparable wealth, universal access to health care and the existence of longstanding, high-quality, population-based cancer registration. The result is a truly international partnership which involves 12 jurisdictions in 6 countries in 3 continents. These are Australia (New South Wales and Victoria), Canada (Alberta, British Columbia, Manitoba, Ontario), Denmark, Norway, Sweden and United Kingdom (England, Northern Ireland, Wales). The scope of the work focuses on four cancers: breast, lung, colorectal and ovarian cancer and involves 5 areas of research. NICR has established a local working group including partners from QUB Centre for Public Health, the Public Health Agency, General Practice and DHSSPSNI. Since the inception of ICBP, significant progress has been made on each research strand.

Module 1 – Epidemiology study

We have already contributed to this module by supplying data on each cancer site for patients diagnosed between 1995 and 2007. The first major results from this study were published at the end of last year in the Lancet. The analysis was carried out by Prof. Michel Coleman and his team at the London School of Hygiene and Tropical Medicine. The major findings were that all countries showed an improvement in cancer survival over the time period studied. However, survival for all four cancers was higher in Australia, Canada and Sweden than those in other countries including the UK and Northern Ireland. This was particularly noticeable in the first year of diagnosis and for patients diagnosed aged 65 and over. The pattern of survival is consistent with patients presenting with a more advanced disease or differences in treatment in those countries with poorer survival. The analysis of treatments received by cancer patients in all the countries is well underway. It is hoped that the results of this will be published in the near future and provide a greater understanding of why differences in survival exist between countries.

Module 2 – Cancer awareness and beliefs

The aim of Module 2 is to explore differences and similarities in awareness and beliefs about cancer between countries. It has been suggested that populations with lower awareness of the signs and symptoms of cancer and/or more negative beliefs about treatment and survival following a cancer diagnosis may present themselves to healthcare later – thereby leading to a worse prognosis. Module 2 which has been funded by the Public Health Agency for Northern Ireland will provide the first robust international comparison of population awareness and beliefs in relation to cancer. This will allow us to explore the role of awareness and beliefs in cancer survival and will identify where interventions to address low cancer awareness and negative beliefs should be targeted. This research will investigate differences in population awareness and beliefs about cancer through a general population telephone survey of over 50 year olds. Northern Ireland local representatives have worked closely with international colleagues in the development of a questionnaire called ‘Awareness & Beliefs about Cancer’ (ABC) with data collection taking place during June 2011 and the project due for completion later in the year.

Reference
Improving Staging Information

The stage of a particular tumour is a measurement of how far a tumour has spread. It is therefore an important measure in planning a patient’s treatment and predicting survival. For current patients, staging information is available electronically to the NICR via the Multidisciplinary Team (MDT) discussions which are recorded on Cancer Patient Pathway System (CaPPS). However, it was clear that staging held by the NICR in years prior to CaPPS introduction was poor for certain sites. To make up for this gap in our data, we looked at other possible sources. The Clinical Oncology Information System (COIS) is an electronic record of patients’ assessments and treatments. Online access to COIS was available and patients with missing staging information were identified and staging information extracted. As a result of this exercise we were able to have accurate staging information for lung cancer patients which previously had only been available by manual note examination. For the years 2004-2008, we now have over 60% of lung cancers staged. We were also able to improve staging for colorectal and breast cancers where there were obvious gaps in our data. Special thanks are to Claire Kirk and Michael O’Rorke who did much of the staging. This level of staging means our data is eligible for further analysis under the International Cancer Benchmarking Partnership (see above).

Module 3: Beliefs, behaviours and systems in primary care

The aim of Module 3 is to explore differences in primary care between countries that might impact on primary investigation and onward referral of patients with possible cancer. This work involves a mapping exercise investigating access to primary care, access to diagnostic tests and other parameters in all jurisdictions and completion of an online survey by approximately 100 GPs in each jurisdiction to assess key issues including their awareness and beliefs about cancer; their usage of tests and perceptions of the adequacy of access to diagnostics; their likelihood of ordering tests (or referring a patient) in defined scenarios. This project is due to commence in late 2011. The local teams are still working to confirm funding for this module.

Module 4: Root causes of delays in diagnosis and treatment

Module 4 aims to quantify and compare the total time spent along the cancer pathway from the onset of first symptoms to the start of treatment. Less time spent along the pathway is linked to earlier diagnosis, which in turn improves clinical outcomes for patients. Module 4 also seeks to assess the proportion of patients entering the cancer pathway through different routes including primary care, specialists, screening and as emergencies, and how this links to time spent along the pathway and stage at diagnosis. The study involves surveys of patients and GPs and a secondary care note review. The local project team are working closely with the UK central team to develop questionnaires and methods of data collection. We are also continuing to seek funding for this important research that will commence in autumn 2011.

Module 5: Treatment, co-morbidities and other factors

The final module of the project is to look at detailed information on the care pathway of cancer patients from presentation to treatments to outcomes. This will require detailed information to be collected from patients’ clinical notes. In the NICR, we are well placed to collect this information, having already collected similar information for our previous cancer pathway reports. Information on ovarian cancer patients is already being collected by our staff with the funding from GAIN. Funding to complete this module for the other cancers is being actively sought.

We will continue to provide progress reports on these exciting projects over the coming months.
Studying the Care of Older Prostate Cancer Patients (CARDI)

This project carried out in the NICR and funded by the Centre of Ageing Research and Development in Ireland (CARDI) aimed to investigate and compare treatment for prostate cancer on the Island of Ireland in older (aged 70 years and over) and younger men. The work was undertaken by Conan Donnelly and Finian Bannon of NICR, and Linda Sharp and Sandra Deady of the National Cancer Registry of Ireland (NCRI).

Prostate cancer is the most commonly diagnosed cancer in men in Ireland. 55% of cases diagnosed with, and 84% of deaths from, prostate cancer occur in men aged 70 years and older. European and US Guidelines for treating prostate cancer recommend that life-expectancy should be taken into consideration when recommending whether a man with prostate cancer should receive curative treatment. Our aim was to investigate and compare treatment of older (70 years or over at diagnosis) and younger (under 70 years) men with prostate cancer on the Island of Ireland. All prostate cancer patients diagnosed in the years 1996, 2001 and 2006 on the Island of Ireland were identified from the national cancer registries (n=7,481). Patient information was collected from hospital medical charts. Missing data was imputed. Logistic and cox regression were used to compare likelihood of receiving curative treatment, being seen by a urologist and survival in older and younger men.

Older men were more likely to present with later stage of disease, and to be treated in a public hospital, and they were twice as likely to die from prostate cancer as younger men. After adjusting for stage and other covariates, older men were less likely to be assessed by a urologist (67% vs 86%), or to have radical prostatectomy (0.8% vs 11%), or radical radiotherapy (6% vs 18%). These differences, in many cases, are likely to be due to factors relating to their general health. Future audit and research would benefit from recording of estimated life-expectancy in medical records.

The Northern Ireland PSA Database

Dr Finian Bannon a Biostatistician from the Registry won “Best Poster Prize” at the All-Ireland Conference on Population-based Cancer Research in Dublin in October 2010 for his poster: “Age-specific PSA relative growth rate as a marker for aggressive prostate cancer—a population-based analysis”. The study investigated men in Northern Ireland with or without prostate cancer to see what summary statistic of Prostate Specific Antigen (PSA) profile would best act as a marker to detect aggressive disease. The relative growth rate in men of PSA prior to diagnosis did not prove a better marker, in terms of test sensitivity or specificity, for prostate cancer than PSA velocity, a commonly proposed marker for aggressive disease.

The study was possible due to the Northern Ireland PSA database (NI PSA database) which is held and maintained by NICR, and which contains all PSA tests that take place in laboratories around Northern Ireland. PSA is a protein produced by the cells of the prostate gland, and is present in small quantities in the blood serum of men with healthy prostates, but is often elevated in the presence of prostate cancer and in other prostate disorders. The PSA level in blood is often used by clinicians, along with other investigations, to diagnose men with prostate cancer.

The NI PSA database has information on all PSA tests that have taken place in Northern Ireland since 1994. Linked-in to the database is any biopsy and cancer diagnosis information on these men. This confidential database is a valuable population-based asset which can monitor the effects of PSA testing on the incidence of prostate cancer and mortality from the disease. It is currently being updated to 2009. A recent publication “Impact of PSA testing and prostatic biopsy on cancer incidence and mortality: comparative study between Republic of Ireland and Northern Ireland” by Anne-Elie Carsin, et al. in 2010 was the fruit of a collaboration between NCRI and NICR using the Northern Ireland PSA database.
Lung Cancer Resection Rates - Increased for women from 1994 - 2007

Surgeons Gwyn Beattie and Jim McGuigan of the Department of Thoracic Surgery, Royal Victoria Hospital (RVH), and Biostatistician Finian Bannon at NICR, have collaborated in a study investigating the resection rates of lung cancer patients in Northern Ireland. From the period 1994 to 2007, NICR supplied information on lung cancer patients diagnosed in Northern Ireland, while the Department of Thoracic Surgery, RVH supplied information on resections from their Regional Thoracic Service Database. Both sources enabled trends in resection rates from 1994-2007 to be estimated using logistic regression.

It was found that resection rates in women have been increasing steadily over the period and are now similar to that of men, while the incidence among men remains higher. The study also used NICR audit data to better understand the trends. In conclusion, the authors felt that the introduction and growing use of multi-disciplinary team meetings, plus better education among medical practitioners and the public, has lead to more patients, and particularly women, being considered for surgery by surgeons. This study was published in the *European Journal of Cardio-thoracic Surgery* in 2010, and was presented by Mr Jim McGuigan at the Cancer Awareness and Early Diagnosis of Cancer Conference organised by the Public Health Agency June 2010.

### All Ireland Cancer Atlas

The first All Ireland Cancer Atlas will be published in Autumn 2011. In this report geographic analysis of cancer will be presented allowing policy makers to focus attention on areas of high cancer incidence. In total 18 different types of cancer will be investigated and will include high resolution maps allowing identification of potential cancer clusters within the Island of Ireland.

In many cases geographic variations in cancer rates are a result of socio-economic and urban/rural inequalities. Thus the atlas will include details of how each of the 18 cancers vary by characteristics of the geographic area within which cancer patients live. The characteristics investigated include population density, unemployment, education and the proportion of elderly people who live alone, giving an added dimension to our understanding of why cancer rates vary depending on where you live.

The All-Ireland Cancer Atlas will be produced in collaboration with the NCRI, and will be freely available online at the NICR web site ([www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)). For further details contact the Registry at nicr@qub.ac.uk.

### CaPPS Update

The N. Ireland Regional Cancer Patient Pathway System (CaPPS) is now in use in all 5 Health and Social Care Trusts. This web-based cancer management system was developed in partnership between NICR, the N. Ireland Cancer Network (NICaN) clinicians and HSC Trust cancer managers. CaPPS development was funded by the Department of Health and system support is provided by the HSC Business Services Organisation (BSO). CaPPS enables the Trusts to manage their weekly multidisciplinary cancer meetings, to collect key clinical data required for regional/national audits of cancer care and for Peer Review of cancer services. It also facilitates regional performance monitoring of the cancer treatment targets.

CaPPS facilitated successful submission from N. Ireland to The National Lung Cancer Audit (LUCADA) and the National Bowel Cancer Audit (NBCA). NICR staff helped with this submission process. CaPPS pathology interface is now live and working well. Further interfaces with other key regional hospital systems (radiology, radiotherapy and chemotherapy prescribing & Theatre Management System (TMS) will follow subject to available funding. Additional clinical modules for children’s and endocrine cancers will soon be available.
Living With and Beyond Prostate Cancer

A study of the impact on men of increased and variable investigation and treatment of prostate cancer in the Island of Ireland

The NICR was successful in securing a grant of £300,000 from the Prostate Cancer Charity and the Research & Development (R&D) Office of the Public Health Agency to examine if increased levels of investigation and treatment improve the physical and psychological quality of life of men diagnosed with prostate cancer. In Ireland, an unusual set of circumstances exist relating to prostate cancer with two similar populations treated in two different healthcare systems reporting significant differences in levels of investigation, incidence rates, treatment and survival. This is an All-Ireland research study and will aim to compare the levels of investigation and treatment of men living in both jurisdictions. The specific research objectives are to quantify long term physical and quality of life effects of prostate cancer treatments and relate these to socio-demographic and health indices, to provide information for men, reports for service providers and peer reviewed publications and ultimately to fulfill the information gap for men diagnosed with prostate cancer.

Dr Heather Kinnear, Research Fellow and Mrs Audrey Craven-Lynn, Project Administrator have been recruited to run the Northern Ireland component of the study and Dr Linda Sharp, Epidemiologist and Dr Frances Drummond, Project Manager will run the Republic of Ireland component. Clerical support will also be provided in the Republic of Ireland. A Project Steering Group with primary care, urologist, patient and research representatives has met three times to advise on the project.

Ethical approval was granted by the Office for Research Ethics Committee for Northern Ireland (ORECNI) on 16 November 2010 and global research governance (Belfast Trust) was granted on 9 May 2011. Local research governance approval across each of the 5 Trusts is currently underway and is almost complete. A draft questionnaire has been devised in consultation with clinicians which encompasses a number of already validated instruments for measuring quality of life such as the EORTC1, EUROQOL2 and the DASS3. We are in communication with urologists to get this finalized as soon as possible so that patient eligibility checks (by the National Cancer Research Nurses who currently operate within each of the 5 Trusts) can proceed and testing can commence.

The cohort for the study will be all men diagnosed with prostate cancer between 1 January 1995 and 31 December 2009 who are deemed eligible to participate in the study. It is envisaged that testing of men will commence September 2011. Men will be posted the questionnaire to be completed in their own homes.

It is envisaged that the outcomes of this study will be to quantify long term (over 15 years) physical and psychological quality of life effects of prostate cancer treatments in Ireland and relate these to socio-demographic and health indices. We will also strive to provide information for men, reports for service providers and peer reviewed publications. This treatment study is the first of a two-part study. The second part will involve a study of men who have undergone a prostate biopsy. The objective of this second part of the research is to document physical and quality of life side effects of prostate cancer biopsy of men on the Island of Ireland and to measure associated regret. It will be measured using the decisional regret scale, decision control scale and a symptom questionnaire. It is envisaged that the biopsy study will commence early in 2012 after data collection has been completed for the treatment study.

1European Organisation for Research and Treatment of Cancer 2European Quality of Life 3Depression Anxiety and Stress Scale

NCIN Update

The National Cancer Intelligence Network (NCIN) produce regular briefings. These include 30 day post-operative mortality after colorectal surgery in England where data on 160,920 patients were analysed. Over time post operative mortality had improved to 5.9% in 2006 from 6.9% in 1998. Post-operative mortality increased with age, co-morbidity, advanced stage, for those living in deprived areas and in those treated as emergencies. There were variations by service provider. It is planned that Northern Ireland would send data for inclusion in the next analysis.

Other briefings were – Routes to diagnosis which showed that 23% of newly diagnosed cancer patients came through emergency presentation and that compared to other patients their one year survival was lower. See http://www.ncin.org.uk/publications/data_briefings/default.aspx for additional briefings.
Unification of English Registry IT Systems

The Eastern Cancer Registration and Information Centre (ECRIC) system OncORE has been chosen as the foundation for the National Cancer Registration System for England (EnCORE). The choice was made by a review team appointed by the UKACR Executive. The Executive had agreed in December 2010 that all the English cancer registries should move to using a single national cancer registration and processing system. When the move to EnCORE is complete, the NICR will be the only registry to use the PRAXIS system, currently operational in five more registries in England.

As a consequence, the IT strategy for the NICR will need to be reviewed. A visit to ECRIC is planned for the future, in order to gain further insight into the EnCORE system. After the visit we will be in a better position to plan our strategy for the NICR information system.

Welcome to our new staff

(I-r)
Dr Patricia McDowell – on temporary secondment from NISRA, Mrs Samantha Jameson - Secretary, Mrs Audrey Craven-Lynn - Clerical Officer - Prostate, Dr Heather Kinnear - Researcher - Prostate

Northern Ireland Barrett’s Register

The Northern Ireland Barrett’s oesophagus register has enjoyed another very successful year with Dr Shivaram Bhat and Dr Helen Coleman continuing research in this area.

Many congratulations to Dr Bhat who has had one of his papers on oesophageal adenocarcinoma incidence in Barrett’s oesophagus accepted by the prestigious Journal of the National Cancer Institute. This showed that risks of progression were lower than previously reported and this has implications for surveillance of Barrett’s. Dr Bhat was also awarded the prize for Best presentation at the Spring 2011 Ulster Society of Gastroenterology conference for his work on prior Barrett’s oesophagus diagnosis in oesophageal adenocarcinoma patients, and has recently presented his results at the British Society of Gastroenterology conference in Liverpool and the Digestive Disease Week conference in Chicago, USA. Dr Coleman has had success on both the national and international stage based on her work coordinating the Barrett’s oesophagus biomarkers study funded by the Medical Research Council. Promising results from this multi centre study were accepted and presented at the British Society of Gastroenterology meeting winning the distinguished abstract award, and at the Digestive Disease Week conference in Chicago (late breaking abstract).

The work from the register will continue to be promoted to an International audience, with Dr Coleman travelling to the World Congress in Epidemiology conference this summer, after being successful in submitting work on trends in Barrett’s oesophagus incidence.

Northern Ireland Colorectal Polyp Register

The Northern Ireland Colorectal Polyp register (funded by the Ulster Cancer Foundation) continues to develop into a useful research tool that promises to follow in the footsteps of its ‘big brother’ Barrett’s register! Dr Coleman is also working in this area and presented findings on factors associated with the risk of a second adenoma diagnosis at the 2nd Population-Based Cancer in Ireland conference in Dublin, October 2010. This register will provide important insight into changes in polyp diagnoses following the recent introduction of Bowel Cancer Screening in Northern Ireland. Lastly, congratulations to Dr Coleman for being nominated for the best postdoctoral researcher award within the School of Medicine, Dentistry and Biomedical Sciences celebration of excellence awards ceremony.
Pancreatic Cancer Audit - Care and Outcomes in Northern Ireland 2007 (with comparisons 2001)

Objectives: 160 patients are diagnosed with pancreatic cancer annually in Northern Ireland, with just over that number dying annually. NICR carried out an audit of pancreatic patients diagnosed in 2001, and recommended service centralisation. A further audit was undertaken of 2007 to determine if care and outcome for pancreatic cancer had changed.

Method: A retrospective clinical note review of patients diagnosed with pancreatic cancer in Northern Ireland 2001 and 2007 was carried out. Data were entered onto an electronic proforma developed with input from clinicians. Information on patient referral, presenting symptoms, comorbidities, investigations, pathology, staging, treatment, aftercare and survival was collected.

Results: Data were collated on 152 patients diagnosed 2001 and 173 in 2007. Patients’ comorbidities were similar in both years. 75% patients were referred to hospital by their GP, with self-referrals almost doubling to 13% by 2007. Over half of GP referrals presented at A&E. Presenting symptoms and duration differed little, with weight-loss (69%) and loss of appetite (68%) being the most frequently recorded. 51% had a histological/cytological confirmation of their diagnosis (42% 2001). Staging improved (28% unstaged 2007, 48% 2001). More patients had an MDT (47% 2007, 13% 2001) and preoperative surgery plan (96% 2007, 22% 2001) recorded. More patients received surgery (26% 2007, 20% 2001), which was carried out in fewer hospitals (7 vs. 11) by fewer surgeons (13 vs. 18). Surgery with curative intent was centralised in one hospital. Patients undergoing curative resection had one year survival of 54%. There was increased referral to dietician (65% vs. 1%), HPB nurse (18% vs. 0%) and palliative care specialists/team (61% vs. 17%).

Conclusions: In 2007 there was better recording of information on stage of disease, with staging possible for almost three quarters of patients. There was evidence of centralisation of services to the HPB unit, with more patients receiving surgery in fewer hospitals and fewer surgeons operating on more patients. More patients were having MDT, but still more than half of patients did not have a record of MDT in their notes. There was increased referral to dieticians and palliative care. This report will soon be available at www.qub.ac.uk/nicr

Why Cancer Patients Die in Acute Hospitals - cont’d from page 1

3. Nursing homes should be specifically targeted for training in early recognition of cancer symptoms and have strategies developed to enable residents with cancer to die in their preferred place of death.

4. For the approximate 20% of patients whose condition would have allowed them to be discharged to die in their place of preference, efforts should be enhanced to ensure facilities and resources in the community are available to support patients and their carers in their choices.

5. The implementation of the Liverpool Care Pathway should be reinforced across all Trusts.

6. Further work is recommended to study what helps to facilitate a home death for cancer patients nearing end of life.

Recent Peer Reviewed Publications (April 2010 – March 2011)


