

N. Ireland Cancer Registry

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PROVIDING INFORMATION ON CANCERS FOR RESEARCH, PLANNING AND EDUCATION
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Launch of Audit Reports



Mr Stephen Kirk, Dr Dermot Hughes, Mrs Deirdre Fitzpatrick, Dr Anna Gavin, Dr Tracy Owen, Dr David Donnelly, Dr Finian Bannon, Mr T Nambi Rajan, Mr Roy Maxwell and Ms Elvira Lowe, speakers at the launch of three cancer audit reports on 2 June 2010

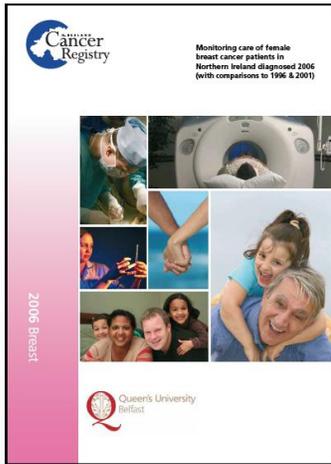
The Registry team have collaborated with clinicians and the Northern Ireland Cancer Network (NICaN), to measure the changes in the process of care and outcomes for patients diagnosed with breast, colorectal or prostate cancers in 1996, 2001 and 2006. The reports document improvements in care in line with the recommendations of the 1997 Campbell Report. More detail of the findings and recommendations can be found later in this newsletter.

The full reports are available from our website www.qub.ac.uk/nicr or on request from the registry. The Registry is currently working with clinicians to audit pancreatic cancer and leukaemia & lymphoma patient care, while regional audits of care and outcomes from bladder cancer and ovarian cancer are planned.

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Breast Audit Report

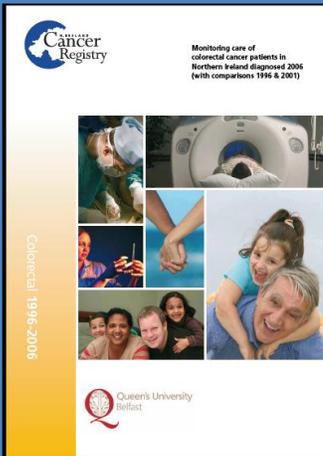
Breast cancer is the leading cancer among women in Northern Ireland with survival rates approximately 83% after five-years, a considerable improvement compared to 10 years ago. Changes in breast cancer services and treatments in Northern Ireland have largely been responsible for these improvements and a new report launched by the Cancer Registry in June 2010 auditing these changes highlights the service improvements.

The report "*Monitoring care of patients with breast cancer in Northern Ireland diagnosed 2006*" was produced in cooperation with local clinicians and documents the process of care experienced by cancer patients in Northern Ireland including their symptoms, referral to hospital, diagnosis, treatment and survival.

However while it illustrates the improved service provided to patients with these diseases it also demonstrates the need for continued work to prevent breast cancer by addressing general health issues such as diet, exercise, obesity and alcohol consumption.

According to Dr David Donnelly, the report's main author, some of the key findings in the report were:

- 1,079 women are diagnosed with breast cancer in Northern Ireland each year, with rates of the disease increasing by 1% per year.
- Survival is very good and improving. In 1996 84% of patients were alive two years after diagnosis. By 2006 this had improved to 91%.
- In 2006, 76% of patients had noticeable symptoms such as a lump in the breast, breast pain, nipple discharge or skin changes. While most patients present quickly for investigation of symptoms, unfortunately some patients delay. 23% of patients were diagnosed in 2006 with late stage disease, pointing to the need to further promote earlier diagnosis through symptom awareness and attendance at breast screening sessions.
- In 2006, 39% of breast cancer patients aged 50-65 were referred to a hospital by the breast cancer screening programme.
- Survival is highly dependent upon the stage at which diagnosis occurs, ranging from 97% after two years for patients diagnosed at a very early stage to 31% after two years for those diagnosed at a very late stage.
- 91% of patients diagnosed in 2006 received surgery, with 58% of all surgery patients receiving a full mastectomy.
- In 2006 almost half of patients received chemotherapy, two thirds of patients received radiotherapy and 80% of patients received hormone therapy. Less than 2% of patients received no form of treatment.
- Specific improvements in service provision over the last decade include:
 - Centralization of breast cancer services in each Trust area;
 - Increased use of investigative techniques;
 - Increased use of multidisciplinary team meetings attended by a range of healthcare staff who deal with patients.
- However there is room for further improvements to address
 - Geographic inequalities in the use of multidisciplinary team meetings, sentinel node biopsies and breast reconstruction after a mastectomy;
 - Low participation in clinical trials.



Colorectal Audit Report

Monitoring care of colorectal cancer patients in Northern Ireland diagnosed in 2006.

In Northern Ireland on average 501 men and 451 women are diagnosed with colorectal cancer each year, with 222 men and 207 women dying from this cancer annually. After non-melanoma skin cancer it is the second most common cancer in men and the third most common cancer diagnosed in women. The report "Monitoring care of colorectal cancer patients in Northern Ireland diagnosed in 2006" details the pathway of care for patients in the years 1996, 2001 and 2006, documenting change in service provision over the 10 years.

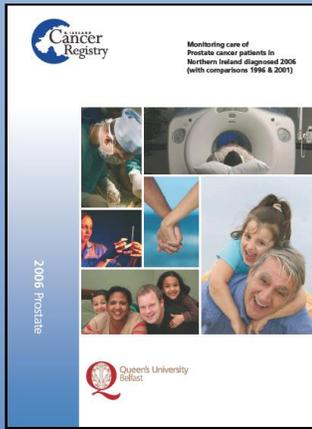
The report's main author, Mrs Deirdre Fitzpatrick, summarised the improvements in service provision:

- The increased use of MRI scans, CT abdomen and colonoscopy.
- More patients had at least 11 nodes examined, enabling more accurate staging.
- More patients were discussed at multidisciplinary team meetings (MDT).
- There were no open and closed operations in 2006, indicating better preoperative diagnosis using scans.
- Fewer patients had a resection as their only form of treatment.
- Increased use of Total Mesorectal Excision for rectal cancers.
- A doubling in the use of radiotherapy for rectal cancers.
- Most patients with a stoma formation were referred to a stoma therapist.
- Recording of treatment plan in patient notes improved.
- More information given to the patient, family and GP.
- Marked improvement in survival for patients with cancer of the rectum, in particular those patients with Dukes C disease and those who had surgery.

However in 2006,

- Difficulties for services persist as 43% of patients with colon & RS junction cancer and 21% of rectal cancer patients present via Accident & Emergency.
- There is geographical variation in the use of diagnostic tests with higher use of sigmoidoscopy and lower use of colonoscopy in the Southern Board.
- Discussion of patients at MDT varies with low participation in the Northern Board.
- There are still a high number of operators carrying out a low volume of procedures. 25 surgeons did only one procedure in the audit year 2006.
- There were greater delays in diagnosis to surgery from 1996 to 2006.
- Few patients were entered into clinical trials in 2006 compared with earlier years.
- There was no significant improvement in survival for patients with cancer of the colon and recto-sigmoid junction.

Recommendations include the need for further service specialization and the need to have all patients discussed at MDTs.



Prostate Audit Report

The report *Monitoring care of prostate cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 & 2001)* documents the care pathway of 782 men diagnosed with prostate cancer in 2006 (95.5% of all prostate cancer patients of that year) and compares this to the care and outcome for patients diagnosed 1996 and 2001. In recent years, numbers of men diagnosed with prostate cancer have almost doubled, increasing 78% between 1996 and 2006. This is associated with a parallel increase in Prostate Specific Antigen (PSA) testing.

More men were shown to have been assessed by a urologist (98% of audited patients) and had their management discussed with an oncologist (64%) or their care facilitated by a specialist urology nurse (34%).

According to Dr Finian Bannon, the report's main author, by 2006 there was:

- Increased and improved equity of access to diagnostic tests including MRI (60%).
- Over 90% of patients had a pathological diagnosis in 2006 with an increase in patients staged to 72%, while 92% had a Gleason score recorded.
- Almost 60% of patients had a record of MDT discussion.
- Increased number of patients had radical prostatectomy and curative radiotherapy and there was improved communications with the patient.

However

- 5 out of 9 urologists were recorded as performing less than 5 radical prostatectomies while only 2% of patients were entered into clinical trials.
- Patients in the Southern Board were less likely to be discussed at MDT than other Boards, while patients in the Southern and Western Boards had lower levels of staging recorded compared to the average.
- While the services saw more patients within defined times, the proportion of those diagnosed and treated within timescales fell. This reflects the increased patient burden and indicates a need for further resources in this area.

Recommendations include that

- All patients should be discussed at an MDT.
- Consideration should be given to defining workloads for radical prostatectomies.
- The increased volume of patients should be recognized in the allocation of resources.
- A specific prospective study of side effects of treatment should be undertaken.

The latter recommendation will be achieved as part of the output of a Prostate Cancer Charity funded proposal (see later in the newsletter).



Left - Dr Anna Gavin, Director, N. Ireland Cancer Registry, Dr Dermot Hughes, Medical Director, N. Ireland Cancer Network and Dr Tracy Owen, Consultant in Public Health Medicine, Public Health Agency at the launch of three audit reports at Queen's University Belfast on Wednesday 2 June 2010
Right - Mrs Deirdre Fitzpatrick, Dr Finian Bannon and Dr David Donnelly, authors of audit reports on colorectal, prostate and breast cancer respectively



Research Update

Northern Ireland Barrett's register

Appointed in Summer 2009, Dr Helen Mulholland and Dr Shivaram Bhat are analysing information from the Northern Ireland Barrett's oesophagus register and have recently presented their findings at the British Society of Gastroenterology conference in Liverpool (March 2010) and the prestigious Digestive Disease Week in New Orleans, USA (May 2010).

Dr Mulholland is working on Trends of Barrett's oesophagus in Northern Ireland from 1993-2005 and Dr Bhat is analysing the risk of progression to oesophageal cancer and the cost-effectiveness of surveillance in these patients, which will contribute to his PhD thesis. Their work will also include analysis of risk factors for cancer progression in 3000 Barrett's patients, thanks to a successful case note review by Tumour Verification Officers Rosemary Ward, Kate Donnelly and Olwyn Dawson which was completed in March 2010. This work is building on the original work on the Barrett's Register funded by the Ulster Cancer Foundation and is currently funded by R&D Office Northern Ireland and Medical Research Council.

Northern Ireland Colorectal polyp register

Dr Helen Mulholland is also working on the Northern Ireland colorectal polyp register data, continuing the work initiated by Dr Khaled Kasim. This data will provide a valuable insight into colorectal polyp trends prior to and after the introduction of the Northern Ireland bowel cancer screening programme in April 2010.

This work is funded by the Ulster Cancer Foundation.



Dr Helen Mulholland, Dr Shivaram Bhat and Ms Janine Blaney

Why do cancer patients die in hospital?

The study, Why do cancer patients die in hospital? is well underway. Since the last update, a new member of staff – Janine Blaney has been appointed to the post of data analyst (1st December 2009). Tumour Verification Officers, Jackie Kelly and Julie McConnell have done an excellent job on collecting the data for this study, which was completed in February of this year. Data cleaning has also been completed and analysis of the data is in the final stages. It is planned that a report of this work will be ready by November 2010 and it is hoped that findings will inform future policy and services for palliative care patients and act as a benchmark for future studies in this area.

The Registry would like to thank the Ulster Cancer Foundation for funding this study, and members of the project steering group for their valuable input to date.

Leukaemia Lymphoma Audit

This project funded by Guidelines & Audit Implementation Network (GAIN) aims to document on a regional basis, the care received by leukaemia and lymphoma patients diagnosed over a 12 month period. Data collection has commenced and it is planned that the audit will be complete by March 2011.

Pancreatic Audit

This project funded by Guidelines & Audit Implementation Network (GAIN) aims to document on a regional basis, the care received by each pancreatic cancer patient diagnosed over a 12 month period in 2007 and compares this with data collected for patients diagnosed 2001. Data Collection is now complete and data cleaning and analysis are underway. The final report is expected December 2010.

International Cancer Benchmarking

The International EUROCARE and CONCORD studies have indicated significant international differences in cancer survival for patients diagnosed during the 1990s. To investigate these differences further the International Cancer Benchmarking Partnership (ICBP) was established. It aims to update cancer survival comparisons for colorectal, breast, lung and ovarian cancers and to explore the underlying causes of differences. Countries taking part are Australia, Canada, Denmark, Norway, Sweden, England, Wales and Northern Ireland. Detailed cancer registration data has been collected from population based cancer registries in those countries.

The project has 5 modules

Module 1 – is basic cancer survival using registry data – N. Ireland link Dr Richard Middleton

Module 2 – relates to population level awareness of cancers – N. Ireland link Dr Michael Donnelly

Module 3 – will investigate primary cares role in early cancer diagnosis – N. Ireland link Dr Nigel Hart, GP

Module 4 – patient experience of cancer diagnosis and delays – N. Ireland link Mr Conan Donnelly

Module 5 – detailed study of patient pathways and treatment – N. Ireland link Dr Richard Middleton

Management Board member is Dr Anna Gavin.

Relative survival at 1 and 5 years and conditional 5-year survival will be estimated for patients diagnosed during 2000-2007. The impact on survival differences of stage at diagnosis and access to treatment by surgery, radiotherapy and chemotherapy will be modelled. Data from Northern Ireland has been submitted for Module 1 and the analysis is being carried out by Professor Michel Coleman's team at the London School of Hygiene and Tropical Medicine. Initial results from their analysis are expected in the summer of 2010. Staff from NICR are working to achieve funding for the other modules.

'Greater gains from smoke-free legislation for non-smoking bar staff in Belfast'

This is the title and key finding of an article published in *The European Journal of Public Health* by Dr. Finian Bannon (NICR), Dr. Anna Gavin (NICR), and Anne Devlin and Gerry McElwee of the Ulster Cancer Foundation (UCF). The article is based on a survey designed and conducted by the UCF one month before and three months after the smoking ban was introduced in April 2007, the data was analysed in the NICR. Bar staff were asked about the following symptoms: wheeze, cough, shortness of breath, red eyes, runny nose, and sore throat. The survey also asked bar staff about their attitudes to the smoking ban and their concerns regarding health and business.

All self-reported symptoms among bar staff declined after the ban, however, for non-smoking bar staff sharp falls occurred in self-reported wheeze, cough, and sore throats. On the whole, staff reported fewer hours of exposure to second-hand smoke after the ban at home, in social settings, and in the workplace. After the legislation, 74% of bar staff that smoked were glad of the smoking ban, while 91% of non-smoking staff supported it. Ninety-eight percent of bar staff believed the bar was a healthier place because of the legislation. Before the legislation, 44% of bar staff that smoked were concerned about the effect of the ban on business; after the ban this had fallen to 31%, and non-smokers to 17%.

In summary, in the immediate wake of the smoking ban, there was a perceived improvement in health among bar staff, and their attitude to the legislation was generally very positive. *EJPH* 2009 19(6) 638-643.

Grants Achieved

Over the last year the Registry has been working hard to develop its research function and build on existing research projects. In the field of Prostate Cancer, we have been awarded almost £300,000 from the Prostate Cancer Charity to complete research into the impact of increased and variable investigation and treatment of prostate cancer in the Island of Ireland to determine if more investigation results in better health. This important study will begin in September this year and will involve collaboration with the Centre for Public Health with the Department of General Practice and the National Cancer Registry of Ireland.

We have also secured a further £20,295 from the Centre for Aging Research and Development in Ireland (CARDI) to use Registry data to explore treatment variations in prostate cancer in Northern Ireland and the Republic of Ireland to determine if age a determining factor in the treatment of men with prostate cancer. Results of this study will be presented later this year.

The Registry is also planning studies in the area of cancer awareness and early diagnosis. A research proposal has been submitted to CRUK/NAEDI to investigate use of a GP urgent referral system to improve early detection of cancer in a region of the UK. This application was successful at the preliminary stage and the outcome will be known in September 2010.

Cancer awareness and early diagnosis Conference Monday 21 June 2010

The need to improve patient awareness of cancer symptoms and ensure patients with symptoms suggestive of cancer are quickly investigated and treated was highlighted at a recent conference in Belfast. The conference organised by the Public Health Agency was attended by over 120 people. Professor Mike Richards explained the gains in survival and quality of life for patients if their cancers were diagnosed earlier. The findings of a population survey of awareness were explored by Dr Alice Simon, Research Associate, University College London. The role of GPs in promoting earlier diagnosis and mechanisms to improve this were delivered by Dr Paul Baughan, Forth Valley Lead Cancer GP and West of Scotland Cancer Network Primary Care Clinical Lead. Improvements in investigation of local lung cancer patients were explored by Dr Tim Warke, Consultant Respiratory Physician, Belfast HSC Trust. Other speakers included Dr Carolyn Harper, Executive Medical Director/Director of Public Health, Public Health Agency (PHA), Dr Tracy Owen, Consultant in Public Health Medicine, PHA, Ms Mary Black CBE, Assistant Director of Public Health, Health and Social Wellbeing Improvement, PHA, Mr Dean Sullivan, Director of Commissioning, Health and Social Care Board, Dr Anna Gavin, Director, Northern Ireland Cancer Registry, Mr Jim McGuigan, Clinical Director of Cancer Services, Belfast HSCT, Consultant Thoracic Surgeon, Dr Beverley Adams, Consultant in Obstetrics and Gynaecology, Southern HSC Trust and Mr Chris Hagan, Consultant Urologist, Belfast HSC Trust.



Prof Sir Mike Richards with speakers and chairperson at the recent conference on Cancer awareness and early diagnosis

NCIN Update

The National Cancer Intelligence Network (NCIN) is a UK body which brings together cancer registries, clinical champions, health service researchers and a range of other interested parties under the auspices of the National Cancer Research Institute (NCRI).

Partners in the NCRI including the Research & Development (R&D) function of the Public Health Agency Northern Ireland, links with NCIN and Northern Ireland are being strengthened.

Review of cancer mortality

The N. Ireland Cancer Registry gathers its information electronically from several organizations, including the General Register Office (GRO) of Northern Ireland which provides information on all deaths from cancer occurring within Northern Ireland. The GRO is part of the Northern Ireland Statistics and Research Agency, which regularly publishes statistics using GRO data, most of which are gathered in the Registrar General Annual report.

Due to the links with GRO, NICR were invited to contribute a chapter to the annual report of the Registrar General focusing on deaths from cancer. Entitled "A review of cancer mortality in Northern Ireland" the chapter encompassed a wide range of topics including trends, geographic variations, socio-economic factors and cancer survival. The report was launched in November 2009 and was later followed by a presentation from Dr David Donnelly, the chapter author of the results in April 2010 to the Statistical and Social Inquiry Society of Ireland. A modified version of the original article, including additional information on cancer incidence in Northern Ireland, will be included in the next issue of the society's journal.

The original chapter is available at www.nisra.gov.uk while the SSISI article is available at www.ssisie.ie.

IT Update

The NICR has been upgrading its computing facilities, including the implementation of 2 new servers and a refresh of a number of PCs. We have also expanded our accessibility to the HSCNI network by adding more PCs. In addition, a number of enhanced security measures have been implemented. The first of these happened recently and involved a significant upgrade of the biometric authentication software. Secondly, all laptops and PCs which connect to the NICR network employ whole disk encryption to secure sensitive data. Finally, the registry has purchased a number of secure FIPS 140-2 level2 certified USB flash drivers with hardware-based 256-bit AES encryption to provide secure transfer of data and backup of data on mobile devices.

The registry has also been granted access to CaPPS – the system used by Trusts to record MDT and cancer waiting times data. This and access to the CaPPS Business Objects universe will allow the registry to produce regular extracts of MDT/cancer waits data to enhance cancer data timeliness and accuracy.

The registry now has a lookup facility to facilitate the capture of Health and Care numbers – HCN Webview. Finally, NICR have been collaborating with all UK registries on the new UK Cancer Information System – a UK-wide system which provides incidence, mortality and survival statistics for each of the countries. The statistics are highly configurable by the user, e.g. in term of geography, time intervals and tumour types. The UKCIS is now live on the NHS network and potential user need to apply for access, please contact us for further information. Plans are being discussed, however, to make the system available to the wider Internet.

Cancer Patient Pathway System (CaPPS) Update

The N. Ireland Regional Cancer Patient Pathway System (CaPPS) is now in use in all 5 HSC Trusts. This web-based cancer management system was developed in partnership between NICR, the N. Ireland Cancer network clinicians (NICaN) 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.

Phase II saw the development and implementation of the additional clinical modules for Urology, Head & Neck, Skin, Upper & Lower GI, Haematology & Neuro-oncology. Trust-wide training of clinicians, clinical nurse specialists, secretarial/admin staff and other allied health professionals (radiographers, dieticians, social workers) continues. The availability and use of CaPPS by our multidisciplinary cancer teams was encouraged in recent feedback from the London Zonal Peer Review team visits.

The interface with the regional pathology reporting system "Labcentre" has been developed and is currently in test phase. 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.

Marathon Team

The NICR had a relay team take part in the Belfast City Marathon on 3rd May 2010 raising money from among NICR staff for the two official charities—Concern Worldwide and Marie Curie Cancer Care. The team had been training for the previous month, and even organised a Twitter to aid communications on the day. All the effort proved worthwhile as the team came in at 4:04 h:m, and 651st out of 1969 participating teams. The achievement was celebrated with coffee and muffins in a not-far-from-the-finish-line café. Congratulations to our athletes Colin Fox, Conan Donnelly, Finian Bannon, Giulio Napolitano and Helen Mulholland.



Staff Success

Giulio Napolitano has been awarded by Manchester University an MSc with Distinction in Bioinformatics, with a dissertation titled *An Evidence-Based Integrated Clinical-Assessment and Decision-Support Tool for Oncologists*.

The project produced an easily configurable web site for cancer statistics and a prototype tool for clinical decision support system. The tool provides a selection of peer-reviewed publications filtered on the basis of a patient's profile, in addition to epidemiological data.

Congratulations also go to Janine Blaney for successful completion of her PhD thesis titled '*Exercise in the management of cancer-related fatigue: Feasibility, barriers and facilitators.*'

Welcome

Welcome to our new staff:

Dr Helen Mulholland
Miss Janine Blaney
Dr Shivaram Bhat

On Temporary secondment from NISRA:-

Mr Conan Donnelly
Dr Arlene Connolly

Farewell

Mrs Helen Wilson

Thanks to Dr Erin Montgomery who returned to NISRA after a short secondment to the Registry.

Recent Peer Reviewed Publications

- **Bannon F, Devlin A, McElwee G, Gavin A.** Greater gains from smoke-free legislation for non-smoking bar staff in Belfast. *Eur J Public Health*. 2009; 19(6) 638-643.
- **Montella A, Gavin A, Middleton R, Autier P, Boniol M.** Cutaneous melanoma mortality starting to change: a study of trends in Northern Ireland. *Eur J Cancer* 2009 45(13): 2360-66.
- **Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M and Moller H.** Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer* 2009 101(3): 541-47.
- **Jeganathan R, Kinnear H, Campbell J, Jordan S, Graham A, Gavin A, McManus K and McGuigan J.** A surgeon's case volume of oesophagectomy for cancer does not influence patient outcome in a high volume hospital. *Interact Cardiovasc Thorac Surg (ICVTS)* 2009 9(1): 66-9.
- **Van Leeuwen PJ, Connolly D, Gavin A, Roobol MJ, Black A, Bangma CH, Schroder FH.** Prostate cancer mortality in screen and clinically detected prostate cancer: Estimating the screening benefit. *European Journal of Cancer* 2010; 46(2), pp377-383.
- **Gavin A, Donnelly C, Devlin A, Devereux C, O'Callaghan G, McElwee G, Gordon S, Crossan T, McMahon N, Loan P, Martin S, McPeak L, Caughley J and O'Hagan AH.** Public at risk: a survey of sunbed parlour operating practices in Northern Ireland. *British Journal of Dermatology* 2010; 162, pp627-632.