Northern Ireland Cancer Registry

NICR Newsletter

New Interim Director for NICR

December 2022 Volume 28



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Farewell gathering for Professor Gavin, pictured with current and past members of NICR Staff

In July 2022 the Registry said a sad farewell to our Director of 28 years, Professor Anna Gavin. Prof Gavin established the Registry in 1994 and it lead to developing it into what it is today. Dr Damien Bennett is the newly appointed Interim Director and we are excited to see what the future holds for the NICR. A full tribute to Anna can be found on page 2.

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Farewell to Professor Gavin

As the founding director, Professor Anna Gavin, established the N. Ireland Cancer Registry (NICR) in 1994, as a confidential, safe and reliable registry, and the first electronic one of its kind in the world, which is respected and trusted locally and internationally. NICR is recognised internationally for its high data quality and unique population datasets on premalignant diseases such as Barrett's oesophagus and colorectal polyps.

Anna has carried wide ranging valuable research using NICR data and premalignant registries, as evidenced by her extensive publication record of over 200 publications. She developed a productive collaboration with the National Cancer Registry Ireland and is co-author of numerous All-Ireland cancer reports including an All-Ireland atlas identifying geographical cancer variations.



Pictured above is Mr. Michael Wood, Director of the Ulster Cancer Foundation, presenting the Cancer Registry staff with a photocopier.

Professor Gavin built international links with organisations such as the International Association for Research on Cancer (IARC), International Association of Cancer Registries (IACR), Rarecare, Eurocare, the US National Cancer Institute (NCI), the International Cancer Benchmarking Partnership (ICBP) and through her current chairmanship of European Network of Cancer Registries (ENCR).

Professor Gavin's work established a world class cancer intelligence service and developed the Registry as a bridge between the University and the Health Service in Northern Ireland. This was recognised when QUB won the coveted **Queen's Anniversary Prize** for higher and further education in 2012.

Professor Gavin recognised the need for local audit of cancer services and over the years secured funding to support more than 20 audits of cancer services across various cancer types, providing detailed baseline audit data from 1996 and key information to improve outcomes for patients. She continues with this work and recently was awarded a grant of £229k from Breast Cancer Now to undertake an audit of the impact of Covid on breast cancer services.



The maintenance of secure clinical datasets and NICR's vibrant and supportive culture have enabled expansion of collaborative cancer research within QUB and internationally. For example, NICR data and related supports were significant contributing factors to successful awards of several prestigious Cancer Research UK Population Research Postdoctoral Fellowships and provide the foundation for three QUB Vice Chancellor's Fellowship awardees. Professor Gavin's expertise in cancer registra-

tion has helped establish registers on suicide, cerebral palsy and out-of-hospital cardiac arrests. She was the IARC nominated expert advisor for the International Atomic Energy Agency providing expert advice to the Sultanate of Oman 2013 and the Department of Health, Qatar 2012-2013 regarding establishment of cancer registries.

Farewell to Professor Gavin

Other highlights include:

- Working with researchers from IARC to establish epidemiological evidence regarding breast screening impact. The results of this international research programme and other work led the UK Department of Health to conduct a major review of breast screening evidence which changed communication of screening information to women.
- Leading a European Network of Cancer Registries (ENCR) program developing new guidance for haematological malignancies registration, now used in cancer registries internationally.
- Production of <u>official annual cancer statistics for N. Ireland</u> as directed under legislation by the Minister of Health.
- Leading the Registry's development of the award-winning Cancer Patient Pathway MDT system (CaPPs) used throughout NI Health service which helped transorm the organisation of patient treatment and increasing availability of clinical and research relevant cancer information.
- Leading an international group on cancer staging tool and development of a CanStaging by NICR. This was adopted by CaPPs and can be accessed by 50 countries to increase consistency and reliability of cancer staging which is essential for judging survival.
- Working to lobby Stormont's health committee for **specific legislation** on secondary use of Health and Social Care data which received Royal Assent in 2016.
- Chaired Action on Smoking and Health (ASH NI) for over 20 years which had a leading role in successful campaigns on smoke free workplaces, plain packaging and graphic tobacco harm advertisements.
- Founding and chairing the multiagency **Care in the Sun** group for over 20 years, which developed Department of Health strategies, as well as public awareness campaigns on prevention and early detection of skin cancer.

Professor Anna Gavin's retirement in 2022 marks an illustrious 28 year career as the founding Director of the NICR and as a QUB academic. NICR staff, past and present, wholeheartedly wish Anna a long and happy retirement and thank her for her dedicated service over the years.



Official Statistics for lung cancer diagnosed in 1993-2020

Official Statistics on lung cancers diagnosed during 1993-2020 were published on 15th March 2022. This release provides details of the number of lung cancer cases diagnosed each year along with incidence rates over time and data for a range of geographic areas. Survival trends and prevalence (the number of people alive) is also provided. All the statistics in this release are available at <u>http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/</u>

Impact of Covid-19 on lung cancer incidence and survival

Due to the Covid-19 pandemic, which began in 2020, a further report has been compiled detailing how incidence and survival from lung cancer has changed between April-December 2018-2019 and 2020 to provide an overview of the impact of the pandemic on lung cancer patients and cancer services in general.

Comparing the Apr-Dec 2020 period to the equivalent period in 2018-2019, the number of cases of lung cancer decreased by 7.5%, from 1,029 per year in 2018-2019 to 952 in 2020. The decrease was greater among females (12.3% decrease from 503 to 441 cases per year) than males (3.0% decrease from 527 to 511 per year).

The number of lung cancer cases diagnosed at Stage I decreased 18.4% from 196 per year in Apr-Dec 2018-2019 to 160 in Apr-Dec 2020. Between the same two time periods the number of cases diagnosed at Stage IV increased by 3.9% from 439 per year to 456. This represents a significant increase in the proportion of cases diagnosed with Stage IV disease: from 42.7% in 2018-2019 to 47.9% in 2020.



The proportion of lung cancer patients receiving treatment within six months of diagnosis decreased from 53.7% among those diagnosed in Apr-Dec 2018-2019 to 45.8% among those diagnosed in Apr-Dec 2020. Specifically, the proportion receiving surgery decreased from 12.5% in Apr-Dec 2018-2019 to 8.1% in Apr-Dec 2020, while the proportion receiving radiotherapy decreased from 33.6% in Apr-Dec 2018-2019 to 26.7% in Apr-Dec 2020. The proportion receiving chemotherapy did not change between the two time periods, with 23.5% of patients receiving this treatment type.



Survival among lung cancer patients one month after diagnosis decreased from 86.7% among those diagnosed in Apr-Dec of 2018-2019 to 83.4% among those diagnosed in Apr-Dec of 2020, while three-month survival decreased from 69.7% to 62.6%. This was partially related to deaths from Covid-19, however, even after adjustments were made to only consider death related to cancer (net survival), three-month net survival still decreased from 71.7% to 64.9%.



Further releases

Data on urinary, gynaecological, hepatobiliary and pancreatic cancers were released on 26th May with data for breast, colorectal, oesophageal, stomach and head and neck cancers released on 14th December 2022. These are available on the NICR web site (<u>https://www.qub.ac.uk/research-centres/nicr/</u>). The remaining cancer sites are due to be released in early 2023.

The impact of the COVID-19 pandemic on diagnosis

Since mid-2020 the NI Cancer Registry (NICR) has produced a monthly overviews of recent trends in the number of patients with pathology samples indicating cancer, comparing these data with similar data from 2017-2019. These reports have provided a key signal and indicator on of the impact of the Covid-19 pandemic on cancer diagnose.

These trends showed that from March 2020 to September 2022 the number of patients with a pathological sample indicating cancer (excluding non-melanoma skin cancer) was 3.9% lower than the average number for the same time period in 2017-2019. However, the impact and recovery was not the same for all cancer types with bowel, breast and haematological cancers returning to pre-pandemic levels by the end of September 2022, but lung cancer diagnoses were 20% lower than expected. Decreases of 10% or more were also recorded for gynaecological cancer, urinary cancer, cancer and non-melanoma skin cancer.





Note: Data are sourced from the four NHS pathology laboratories in NI (Belfast, Altnagelvin, Antrim, Craigavon), which are usually provided to NICR on a monthly basis. Altnagelvin laboratory is excluded from some analysis as a change in recording systems led to an undercount in the number of reported samples in Jan-Apr 2021.

More recently patient volume has returned to pre-pandemic levels. Specifically there was only a 3.8% crease in the number of patients with a pathology sample indicating cancer in the 12 weeks up to the end of September 2022 compared to the average in the equivalent weeks in 2017-2019. However, lung cancer diagnose were still one quarter lower than expected levels, which remains concerning as this is a cancer with poor survival for which early diagnosis is important. While monthly fluctuations were observed for other cancer types, non-melanoma skin cancer (NMSC) has remained consistently below expected levels in the twelve weeks to the end of September 2022 (-12%).

The monthly reports are available on the NICR web site (<u>https://www.qub.ac.uk/research-centres/</u>nicr/Publications/ImpactofCOVID-19onCancerDiagnosis).

Northern Ireland Barrett's Register (NIBR)

Over the past year the Northern Ireland Barrett's Register (NIBR) team have continued to work on the update of the register which is funded by a Cancer Research UK (CRUK) Career Establishment Award granted to Professor Helen Coleman.

Epidemiological analysis updates

The NIBR now includes diagnostic, follow-up, treatment (from 2010 onwards) and outcome information for more than 24,500 patients diagnosed with Barrett's between 1993 and 2018. The ongoing co-ordination and analysis of the updated register is being conducted by Postdoctoral Research Fellow Dr Victoria Cairnduff in collaboration with the wider study team to investigate up-to -date trends in diagnoses of Barrett's oesophagus, low and high grade dysplasia and oesophageal Adenocarcinoma which are increasingly important as now that new endoscopic therapies are now available.

Biomarker project updates

As the majority of patients living with Barrett's oesophagus will not go on to develop oesophageal adenocarcinoma, an important focus of the ongoing work of the NIBR is to establish those patients who are at greater risk of progression to cancer. It is hoped that identification of biomarkers associated with progression will assist this. The population-based nature of NIBR its and established links with the NI Biobank place NIBR in a unique position to carry out this work. NIBR has been used as a sampling frame for two ongoing biomarker studies co-ordinated by Postdoctoral Research Fellow Dr Talita Oliveira.

A CRUK funded 'Primer Award' study to investigate a biomarker for assessing the molecular age of Barrett's tissue will help estimate how long someone might have had Barrett's oesophagus before their diagnosis. This work is led by Professor Helen Coleman in collaboration with Dr Kit Curtius (University of California San Diego), Dr Richard Turkington (Patrick G Johnston Centre Cancer Research, QUB) and Professor AJ McKnight (CPH, QUB).

A CRUK funded project award granted to Dr Richard Turkington in collaboration with Professor Helen Coleman aims to compare tissue samples for patients with Barrett's oesophagus who have progressed to oesophageal adenocarcinoma with tissue from age-and sex-matched controls who did. This research applies technology called transcriptomics, aiming to identify biomarkers associated with progression to cancer.



Left front to back: Professor Helen Coleman, Mr John Clarke, Dr Victoria Cairnduff, Dr Brad Campbell, Miss Blathine Donnelly Right front to back: Mr Mark Kelly, Professor Juliette Hussey, Dr Richard Turkington, Mrs Rosemary McAnerney, Professor Jacintha O'Sullivan.

This summer marked three years since the Northern Ireland Barrett's Oesophagus Public and Patient Involvement (PPI) group was established. We celebrated by holding our first face-to-face meeting in three years at Riddel Hall in May 2022. Professor Jacintha O'Sullivan and Professor Juliette Hussey joined us from Trinity College Dublin to discuss new All-Ireland work. We would like to thank the NI Barrett's oesophagus PPI group members for their continued support and invaluable insight into living with Barrett's and ways we can improve care for Barrett's patients in Northern Ireland and beyond.

The PPI group have provided important feedback and input for a number of grants submitted in the past year, including a successful collaboration with Professor Francesca Ciccarelli at the Crick Institute, Kings College London. Professor Ciccarelli's work, funded by the Early Detection committee at Cancer Research UK seeks to explore the potential role of genetics and the tumour micro-environment in cancer progression risk for Barrett's oesophagus patients.

Another example of work initiated by the PPI group is the **co-production of a patient information leaflet** for newly diagnosed Barrett's oesophagus patients to meet the need for accurate

evidenced-based information on Barrett's oesophagus at time of diagnosis.

In August 2021, we distributed 500 copies of the leaflet to endoscopy clinics across Northern Ireland. Dr Olinda Santin (School of Nursing and Midwifery, QUB) also facilitated a patient workshop exploring patient thoughts on the leaflet. The leaflet has received positive feedback from both clinical staff and patients.

An abstract on the co-production of the Barrett's patient leaflet was presented as an e-poster at the virtual British Society Gastroenterology (BSG) conference in November 2021 (<u>https://youtu.be/</u><u>mww9mV6EX8c</u>) and is being written up as a scientific paper.



Research Highlights Northern Ireland Endometrial Hyperplasia Register



Work has continued to develop the Northern Ireland Endometrial Hyperplasia Register, which is currently funded by a 4-year UK Research and Innovation Future Leaders Fellowship awarded to Dr Úna McMenamin in 2020. There is currently no routine screening for endometrial cancer, but endometrial hyperplasia is a recognised precursor, which if detected, can help to prevent the disease progressing to endometrial cancer. Little is known on the population incidence of endometrial hyperplasia or which patients are most at risk of progressing to endometrial cancer.

The Northern Ireland Endometrial Hyperplasia Register is being developed within the Northern Ireland Cancer Registry (NICR), and will be the first of its kind in the UK. The Register will consist of incident endometrial hyperplasia cases diagnosed from 2008-2020, identified from endometrial biopsy pathology reports.

In the past year, Clerical Officer Andrew Hamilton conducted a detailed review of over 3,000 endometrial pathology reports to extract important clinical information to populate the Register. Postdoctoral Researcher, Dr Haydee Jordão, joined the team in October 2021 and has undertaken a quality check of endometrial pathology reports as well as initial data cleaning and analysis. Haydee is also assisting the supervision of undergraduate and Masters student research projects in related areas. In October 2021, PhD student Chloe McCoy joined the team and is currently conducting a systematic review to determine factors associated with inter-observer variation in the pathological diagnosis of endometrial hyperplasia. In June 2022, Andrew Hamilton left the project to take up a post in the Centre for Public Health clerical team - we wish him all the best!

In other news, in December 2021, we published a Research Letter in the American Journal of Obstetrics & Gynecology describing the impact of the COVID-19 pandemic on endometrial hyperplasia and endometrial cancer in Northern Ireland. The findings showed that between March and September 2020, there were 70 fewer endometrial cancer diagnoses than expected compared to March to December 2017-2019, a reduction of 19.1%. There were also 50 fewer endometrial hyperplasia diagnoses than expected compared to the same time period 2017-2019, a reduction of 42.9%.

AJOG American Journal of Obstatrics Gynecolog

RESEARCH LETTER | ARTICLES IN PRESS

The impact of the COVID-19 pandemic on endometrial cancer and endometrial hyperplasia diagnoses: a population-based study
James Wyle, MB, BCh, BAO, MRCOG + Declan Quinn, MB, BCh, BAO, MRCOG + David W. Donnely, PhD +
... Helen G. Coleman, PhD + Anna Gavin, MB, BCh, BAO + Úna C. McMenamin, PhD ≅ + Show all authors
Published. December 28, 2021 + DOI: https://doi.org/10.1016/j.ajog.2021.12.259

The next steps for this project will link the Register to NICR records to determine temporal trends in endometrial hyperplasia incidence and progression to endometrial cancer. Additional novel data linkages to drug dispensing and maternity records in Northern Ireland are also planned to evaluate population patterns of nonsurgical hormonal therapies in endometrial hyperplasia patients and their long-term impact on clinical outcomes such as hysterectomy, live births and progression to cancer.

The project involves valuable input from clinicians in the Belfast and Northern Trust and a small endometrial hyperplasia patient involvement group has been established to ensure the research is relevant to women diagnosed with endometrial hyperplasia.





Andrew Hamilton [

Dr Haydee Jordão

Chloe McCoy

NI Premalignant Cervical Lesions Register (NIPCLR)



Thanks to generous donations received from the Lynsey Courtney Foundation, Dr Jamie Roebuck has now completed two years work on the Northern Ireland Premalignant Cervical Lesions Register (NIPCLR).

The most common types of cervical cancer are known to develop from abnormal changes in the cells lining the cervix, which can often be detected at an early precancerous (premalignant) stage. These abnormal changes are usually triggered following infection with certain subtypes of human papilloma virus (HPV).

The aim of the register is to develop an accurate and complete database of all high-risk precancerous changes in the cervix affecting women in Northern Ireland, and to collect data relating to their diagnosis, HPV status and aspects of their treatment. This resource will be used to:

- monitor the number of cervical premalignant lesions over time
- improve our understanding of how abnormal cervical changes progress
- investigate the effectiveness of current treatments
- evaluate the impact of cervical screening and HPV vaccination programmes
- assess the effect of the COVID-19 pandemic on provision of services.

This year has focused on quality assurance, ensuring that data collected is as complete and accurate as possible.

Data collection for the most high-risk category of precancerous changes diagnosed in 2018-2020 is complete, with over 2,500 patients in the database. Data from the register has been used in Dr Sarah Alawi's PhD thesis investigating cervical cancer screening and diagnosis.

Next year we plan to continue liaising with research groups who specialise in investigating precancerous changes in the cervix, along with increasing the efficiency of our data collection and expanding the number of years data that we hold. As more categories of premalignant lesions become routinely registered, we are also looking at the possibility of integrating the NIPCLR into the main NICR database when the new system is available.

We are extremely grateful to the Lynsey Courtney Foundation who have provided the funding to allow this work to take place.



Dr Jamie Roebuck

Student projects within the NICR

Rory Jackson, 1st Year Medical Student

Rory joined the Registry on an 8-week CPH Summer Studentship 2022. He is looking at dementia and stroke as a comorbidity for cancer. This research will involve looking at the prevalence of dementia and stroke in cancer patients and assessing how the prevalence changes with age, gender, socioeconomic factors, cancer types and potentially geography. He also hopes to gain insights into how differences in the onset of dementia in cancer patients influences treatment and outcomes, comparing patients who have been diagnosed with dementia before cancer with those who are diagnosed after their cancer diagnosis and then comparing again with cancer only patients. He will also carry out survival analysis for cancer patients with dementia and/or stroke.



Michael Graham, 1st Year Medical Student



Michael Graham is a first-year medical student at Queens University Belfast taking part in the CPH studentship this summer. Prostate cancer is the most common cancer in men within the UK with 47,500 new diagnoses every year, accounting for around 12,000 deaths each year. The project he is working on is entitled "Performing an emulated clinical trial in observational audit data to test prostate cancer patient interventions". Using the NICR observational audit dataset developed for the report "Monitoring care of Prostate cancer patients in Northern Ireland diagnosed 2006", a feasibility study will be performed to see, if an emulated clinical trial can be effectively performed to test the effect of curative interventions (radical

prostatectomies, radical radiotherapy, and active surveillance) on long-term prostate-specific patient survival. This will require an assessment of whether certain conditions exist in the data set to allow confounding and immortal time biases to be adjusted for. The secondary aims of the project are to describe the association of comorbidities on the choice of treatment, and the incidence of side-effects. With more reliable evidence of the effect of curative treatment on long-term survival, coupled with summary estimates of side-effects, clinicians will be better informed in recommending treatment options to their patients.

Student projects within the NICR

Amisha Ashok, MSc Student

Dr Ethna McFerran has supervised the MSc Data Analytics student Amisha Ashok who used data from NICR to examine length of stay in unscheduled care episodes for cancer patients during the last year of life. Amisha compared regression algorithms to examine relative differences by disease type, age, stage and other factors, including the use of palliative care services during admission.

Following on from the "Emergency Admissions at end-of-life in NI 2015" report, she investigated the demographic and disease characteristics that drive length of stay in unscheduled admissions and examined the economic costs associated with unscheduled inpatient care provided to cancer patients in the last year of their lives.





Epidemiological analysis has shown that infections are thought to be among the leading causes of unscheduled admissions. Investigating the drivers of the length of stay during emergency admissions for people dying from cancer will provide information on admissions that could help manage care in the community or earlier in planned care through increased education and palliative support. This investigation would predict the length of stay and examine palliative care use to examine the effect of potential reductions of unscheduled admission in terms of the budget implications of a reduction in unscheduled end-of-life care costs.

Investigating the impact of COVID-19 on routes to hospital admission for cancer patients from March – December 2020 in Northern Ireland with comparisons to a pre-COVID era.

In 2021, Ben Alford, an MSc Student joined the registry to work on a study investigating the impact COVID-19 had on NI cancer services as a result of the nationwide lockdowns put in place from March 2020 using anonymised Public Administration System (PAS) data from 1st March to 31st December 2020 and comparing this to similar data from 2017 – 2019. This was undertaken with Helen Mitchell, NICR Statistician and Prof Anna Gavin.



Ben Alford

This study focused on patients with an emergency presentation of cancer (mix of incident and prevalent cases). Overall, compared with the pre-

pandemic era, the number of emergency admissions for cancer patients fell by 12·3% in 2020. Emergency admissions for cancer patients were significantly reduced when COVID-19 levels were highest. Females ($-15\cdot8\%$), urban residents ($-13\cdot2\%$), and age groups 0 to 49 and 65-74 (-17%) experienced the largest decreases. Significant reductions in referrals from outpatient departments (51%) and primary care (43%) were counterbalanced by admissions from other routes including confirmed or suspected COVID-19 infection (increase 83.6%).

Reductions in emergency admissions, and pathologically diagnosed cancers, indicate undiagnosed patients in the community which has implications for future workloads and survival. Data suggest undiagnosed cases may be higher for haematological, brain and CNS, and lung cancers and among females. Efforts should be made to encourage people with symptoms to present for diagnosis or reassurance.

Ben successfully completed his MSc, earning a distinction and has been accepted to undertake a PhD at QUB later in the year. Well done Ben!

This study has been published in BMC Cancer (https://bmccancer.biomedcentral.com/ articles/10.1186/s12885-022-09932-3)

Helen Mitchell is continuing work on this project, which includes the addition of 2021 PAS data and data matching with the official statistics to gain information on stage, time since diagnosis and survival.

A huge thank you to Ben, Eamon O'Callaghan, (NICR), who worked to retrieve PAS data and Simon O'Hare for his support of the analysis of this project.

Research Highlights Heart Health and Cancer



Cancer and heart diseases are two of the most common causes of death in Northern Ireland. Based on last year's work that has shown the association between pre-existing heart disease and higher mortality among cancer patients, we further investigated the interaction between both diseases through health services related outcomes.

Current research has been carried out by Prof Ciaran O'Neill, Deputy Director, NICR and Dr Hüseyin Küçükali. They linked the registry's records between 2009 and 2019 with data from other large sources such as Patient Administration System, and Systemic Anti-Cancer Therapy Dataset. This enabled a series of comparisons between patients whose record of heart disease preceded that of cancer and whose record of cancer preceded that of heart disease. After controlling for covariates such as age, sex and deprivation analyses indicated that patients whose cancer diagnosis preceded heart disease visit more frequently and stay longer in cardiac care compared to those who heart disease preceded cancer. Patients whose heart disease preceded cancer on average experience shorter waits for cancer treatment after diagnosis. The results suggest the sequence in which disease is experienced may influence clinical decision-making with respect to treatments including the priority given to access. The findings warrant further investigation given their implications for equity and public health messaging.

The research team is exploring the use of machine learning methods to uncover patterns of comorbidities among cancer patients that may be applied at scale.

NICR-Macmillan Partnership 2019-2020

The NICR-Macmillan partnership is now in its seventh year. The partnership aims to deliver insight from Northern Ireland cancer data to support improved design, testing and implementation of better models of care, to identify gaps and opportunities to enhance data collection and analysis for improved outcomes for people living with and beyond cancer in Northern Ireland. Previous phases of the partnership have involved analysis of factors associated with emergency admissions in the last year of life and breast cancer recurrence.

The COVID-19 pandemic led to a pause in the partnership but this has now resumed. The registry bid farewell to Simon O'Hare, analyst for the NICR-Macmillan partnership, who left post in April 2022.

Helen Mitchell, NICR statistician, is continuing work on COVID-19 and comorbidities to better understand the impact of COVID-19 on cancer patients and admissions to hospital during this period.

WE ARE MACMILLAN. CANCER SUPPORT

Biobank/NICR Partnership

The Northern Ireland Biobank (NIB) was established in 2011 to facilitate translational biomarker research, primarily in Northern Ireland but also further afield. The repository is based in the Patrick G Johnston Centre for Cancer Research, Queen's University Belfast. The NIB is an NHS Research Ethics Committee approved Research Tissue Bank which facilitates programmes of research.

NIB has two core 'collection' strategies. The first is a prospective collection of human samples (tissues, matched bloods and bodily fluids) which initially focused on malignancies and premalignant lesions of the gastrointestinal tract, genitourinary tract, gynaecological tract, lung and breast. Patients are asked to provide broad informed consent for the use of their samples and pseudo-anonymised data to be used for research purposes. Increasingly, the prospective collections are hypothesis led to support specific study requests from researchers.

The second collection is referred to as the NIB 'retrospective' collection. This collection avails of regulated access to samples held in Health and Social Care Trust laboratories for hypothesis led, ethically approved projects. NIB has been instrumental in creating an infrastructure to access and retrieve defined cohorts from diagnostic archives and make them available for research use.

The NICR supports the NIB's work by linking anonymised clinical and pathological information stored on the NICR database and that retrieved from HSCNI clinical information systems with pathological samples requested for NIB ethically approved studies. In the NICR, all data are examined and extracted in a confidential setting under agreed ethical and governance approvals and no personal ID are used.

During 2021 to 2022, the Data Manager and Cancer Intelligence Officer (CIO) team has provided data on various dataset requests from the NIB. For example, CIOs had to identify NICR registrations on Praxis that matched with over 150 pathology report numbers provided by the NIB. Another request involved extraction of data on variables such as CA125 levels, surgery and chemotherapy treatment for a cohort of clear cell ovarian cases. In addition, a collection of approximately 450 colorectal cases required retrieval of detailed information relating to diagnosis, stage, pre- and post- treatment, recurrences as well as molecular information for mutations of BRAF, KRAS, NRAS, Mismatch Repair genes which would influence the treatment each individual patient would receive. The NICR has recently expanded the Praxis database to collect more molecular information such as HER, ER and PR status for core work and hopefully with the development of the new Centris system, additional molecular data will be collected to facilitate researchers in identifying specific molecular abnormalities and how they influence individual patient pathways, treatment and long term outcomes.



CanStaging⁺ Cancer Staging Tool

CanStaging +

The NICR, in collaboration with the International Agency on Research for Cancer (IARC) and Cancer Council Queensland (CCQ) has further developed the CanStaging+ tool. The number of cancer sites facilitated by the updated version of CanStaging+ has been increased from 11 to 23, widening its potential coverage of newly diagnosed global cancer cases from 62.6% to 84.2% as per GLOBOCAN estimated 2020 global cancer incidence statistics. These sites include the Bladder, Carcinoma of Skin, Endometrium, Hypopharynx, Kidney, Larynx, Lip and Oral Cavity, Nasopharynx, Oropharynx, Testis, Thyroid Gland, and Cancer of Unknown Primary – Cervical Nodes. The tool can be accessed by scanning the adjacent QR code, or by visiting <u>https://www.canstaging.org/.</u>



TNM edition 8			
Bladder	Endometrium	Melanoma	Prostate
TNM edition 8	TNM edition 8	TNM edition 8	TNM edition 8
Breast (clinical)	Hypopharynx	Nasopharynx	Stomach
TNM edition 8	TNM edition 8	TNM edition 8	TNM edition 8
Breast (pathological)	Kidney	Oesophagus	Testis
TNM edition 8	TNM edition 8	TNM edition 8	TNM edition 8
Carcinoma of Skin	Larynx	Oropharynx (p16 Negative)	Thyroid Gland
TNM edition 8	TNM edition 8	TNM edition 8	TNM edition 8
Cervix	Lip & Oral Cavity	Oropharynx (p16 Positive)	Unknown Primary - Cervical
TNM edition 8	TNM edition 8	TNM edition 8	TNM edition 8
Cervix (FIGO 2018)	Liver	Ovary	
TNM edition 8	TNM edition 8	TNM edition 8	
Colorectal	Lung	Pancreas	
TNM edition 8	TNM edition 8	TNM edition 8	

Ongoing work of the CanStaging+ group includes the translation of the tool into other languages such as Spanish, Turkish, Italian and Malay. The NICR has also been involved in organizing training sessions for cancer registries that are interested in using the CanStaging+ tool.



Abigail Jeyaraj

Audits Colorectal Audit



NI Colorectal Cancer Audit: measuring the quality of care for patients diagnosed in 2018

We are proud to announce the release of the widely anticipated Colorectal Cancer Audit for patients diagnosed in 2018 in NI, which includes detailed information for 1,097 colorectal cancer patients.

This is the first audit produced by the NICR since 2007 auditing the care of colorectal cancer patients, and the first to be produced since the introduction of the Bowel Cancer Screening programme in NI in 2010. It has enabled comparison with data for English and Welsh patients from the National Bowel Cancer Audit and with Scottish Quality Performance Indicators.

This detailed audit examines provision of diagnostic services, surgical and oncology treatments, and makes a number of recommendations for future service development. Some key findings include:

- 8% of colorectal cancer patients were diagnosed via screening (21% in 60-74 year olds)
- 12% of colorectal cancer patients were diagnosed following emergency admissions
- One in three patients received adjuvant chemotherapy treatment
- Approximately half of rectal cancer patients received radiotherapy, and there is increasing de mand for radiotherapy services in NI
- Low rates of laparoscopic surgery across NI, compared with other UK nations
- Clinical trials participation rates were low, with only 1.4% of patients entered into trials
- Earlier stage at diagnosis, and improved survival outcomes were found, compared with the first audit in 1996

The report documents how colorectal cancer services were performing pre-COVID-19, providing useful evidence to measure the impact of COVID-19 and help shape post-covid recovery of colorectal cancer services in future. It will also provide an excellent resource for colorectal cancer research.

The NICR would like to thank the **Public Health Agency** for their financial support, and clinicians in the five HSC Trusts who kindly provided data and guidance to ensure that this audit report was possible, with particular thanks to members of the **NiCAN Colorectal CRG**.

The full report can be accessed by the link below on the NICR website: <u>https://www.qub.ac.uk/</u> research-centres/nicr/research-audits/Audits/

Audits

Breast Cancer Now

NICR has successfully received a grant from Breast Cancer Now to undertake a study on the impact of COVID-19 on breast cancer patients. This study will include quantitative and qualitative components.

The quantitative audit component, led by Helen Mitchell and Sinead Hawkins, will cover approximately 2200 patients diagnosed in March - December 2018 and March - December 2020 and will allow comparisons between the pre and during COVID-19 periods. Data from patient clinical records will be used to describe routes to diagnosis (screening/emergency/other), stage at presentation, treatments received, investigations undertaken, molecular markers, and survival for breast cancer patients diagnosed in 2018 (PRE-COVID-19 era) compared to 2020 (during COVID-19). Differences in socioeconomic group, patient age and comorbidities will also be examined.

Complementing the audit will be a mixedmethods study, led by Dr Charlene McShane and Dr Lynne Lohfeld at the Centre for Public Health. This study aims to document the psychosocial impact of the COVID-19 pandemic on breast cancer patients, both newly diagnosed and prevalent (existing) cases, via a crosssectional online survey, and in-depth interviews. A scoping review of the literature is curBREAST CANCER NOW The research & care charity

rently being undertaken by the study team to inform the development of the survey and interview materials.

This project aims to document the impact of COVID-19 pandemic on breast cancer patients whatever their cancer stage and make recommendations to improve patient care and outcomes.



Audits



Oesophagus and Stomach Audit

In January 2022 the 2018-2019 Oesophago-gastric (OG) cancer audit was published by NICR . This audit analysing 759 patients showed excellent adherence to NICE and professional body guidelines, with the provision of services showing similar levels to Scotland and England/Wales through comparisons of their national audit results. This audit also shows comparisons of the service from the previous 2005 NICR audit. The service has changed significantly since 2005 with centralisation of OG cancer services.

Areas of concern with the OG audit were:

- The high proportion of OG cancer patients having an inpatient stay within 30 days of their cancer diagnosis (for any reason) with 208 (27%) of all OG cancer patients having an inpatient stay.
- High rates of patients referred to OG cancer services via emergency admission in comparison to patients diagnosed in England/Wales.
- Complexity of patients presenting with OG cancer with this patient cohort having high levels of comorbidities.
- High levels of patients presenting at a locally advanced (stage III) or late stage (stage IV) with 65% of patients presenting at more advanced stages.
- NI patients wait longer across all treatment types for their first treatment than patients in England/ Wales (see Table 1 below) which is probably due to the length of time waiting for diagnostic services.

Table 1: Median length of time in days from referral to treatment by country, treatment type and treatment intent

Dissemination of Results is ongoing focusing on a range of stakeholders with OG cancer services with the

Treatment pathway	NI 2018-2019	England/Wales 2017-2019
Curative Surgery Only (median days)	89 days (range 69-130)	83 days
Curative Definitive or Neo-Adjuvant Oncolo- gy (median days)	79 days (range 71-83 days)	68 days
Palliative Oncology (median days)	62 days (range 58-73 days)	60 days
Palliative Stenting (median days)	54.5 days (range 44.5- 63days)	35 days

following presentations to date:

- NI Cancer Network Upper GI Clinical Reference group.
- Belfast Trust OG Cancer Business meeting.
- A patients and carers event hosted by OGCancerNI.
- Regional Upper GI audit meeting at Belfast Trust.

The audit can be accessed here <u>https://www.qub.ac.uk/research-centres/nicr</u>. This audit was funded by the Regulation and Quality Improvement Authority (RQIA) and local charity OGCancerNI.

The Registry's Year in Numbers

The NICR provided data and information for 174 requests in 2021 including 46 (27%) general requests and 128 (73%) genetic requests (excluding local genetic requests). A nurse from the Medical Genetics department deals with local genetic requests.

In 2021, despite COVID-19 disruption, 98% of general requests for information were completed within the recommended 20 working days and 100% of genetic requests for information were completed within the recommended 10 working days. Figure 1 below shows the source of general requests.

On average general requests took 171 minutes to complete but ranged from 10 minutes to 1920 minutes (32 hours). Genetic requests took 29 minutes to complete on average, however ranged from 15 minutes to 60 minutes.



Figure 1; Source of Requests

Key; DHSS - Department of Health and Social Services PHA - Public Health Agency PQ - Parliamentary Questions

NICR IT System Development

The current NICR IT system, PRAXIS, was developed over 20 years ago in conjunction with four English cancer registries for the purposes of collecting and collating information on incidences of cancer. For many years now, the NICR has been the last UK registry to use PRAXIS as other jurisdictions moved to the newly developed ENCORE system. Unfortunately, PRAXIS is no longer fit for purpose and it is difficult to make the changes needed for a modern cancer registry such as requirements to include comorbidities, additional treatments and recurrences, changes to diagnostic coding and pathology systems, additional data sources and genomic coding,

Tenders were invited to complete the redevelopment of the NICR cancer registry application, to clone existing functionality as well as improve the longevity of the system with enhancements and updates on to a modern, supported and easily maintainable platform. The contract was awarded to CODEC and the project is well underway.



The solution will use Microsoft Dynamics 365 and Microsoft Dataverse. Microsoft Dynamics 365 provides a powerful business application platform that will enable further development and gives technical users and non-technical users the ability to extend and provide value added solutions. Microsoft Dataverse is a low-code platform that will allow us to securely store and manage data. It plays an important role on the Microsoft Power Platform providing the basic foundation for application development, automation and analytics. Dataverse has a rich security model to protect the data integrity and privacy of users while promoting efficient data access and collaboration.

The redevelopment has provided an opportunity to have a system to meet current and future requirements. We look forward to its completion and hope that the new IT system will be in use by Spring 2023.

NICR Publications June 2021-June 2022

Inequalities in the decline and recovery of pathological cancer diagnoses during the first six months of the COVID-19 pandemic a population-based study

Hamilton, A. C., <u>Donnelly, D. W</u>., Loughrey, M. B., Turkington, R. C., <u>Fox, C., Fitzpatrick, D., O'Neill, C. E.,</u> <u>Gavin, A. T. & Coleman, H. G</u>., 01 Jul 2021, In: British Journal of Cancer. https://doi.org/10.1038/s41416-021-01472-0

International perspectives on suboptimal patient-reported outcome trial design and reporting in cancer clinical trials: A qualitative study

Retzer, A., Calvert, M., Ahmed, K., Keeley, T., Armes, J., Brown, J. M., Calman, L., <u>Gavin, A</u>., Glaser, A. W., Greenfield, D. M., Lanceley, A., Taylor, R. M., Velikova, G., Brundage, M., Efficace, F., Mercieca-Bebber, R., King, M. T. & Kyte, D., 05 Jul 2021 In: Cancer Medicine. https://doi.org/10.1002/cam4.4111

International differences in lung cancer survival by sex, histological type and stage at diagnosis; an ICBP SUR-VMARK-2 Study. ICBP SURVMARK-2 Local Leads, 19 Jul 2021, In: Thorax.

https://doi.org/10.1136/thoraxjnl-2020-216555

CanStaging+: an electronic staging tool for population-based cancer registries Soerjomataram, I., Ervik, M., <u>Fox, C., Hawkins, S., Yeung, K</u>., Napolitano, G., Tittenbrun, Z., Bray, F. & <u>Gavin,</u> <u>A</u>., Aug 2021, In: Lancet Oncology. <u>https://doi.org/10.1016/S1470-2045(21)00188-1</u>

Comparison of liver cancer incidence and survival by subtypes across seven high-income countries Rutherford, M. J., Arnold, M., Bardot, A., Ferlay, J., De, P., Tervonen, H., Little, A., Bucher, O., St Jacques, N., Gavin, A., Engholm, G., Møller, B., O'Connell, D. L., Merrett, N., Parkin, D. M., Bray, F. & Soerjomataram, I., 30 Aug 2021

https://doi.org/10.1002/ijc.33767

A summary of the updated report on the incidence and epidemiological trends of keratinocyte cancers in the United Kingdom 2013-2018

Kwiatkowska, M. M., Ahmed, S., Ardern-Jones, M. R., Bhatti, L. A., Bleiker, T. O., <u>Gavin, A.</u>, Hussain, S., Huws, D. W., Irvine, L., Langan, S. M., Millington, G. W. M., Mitchell, H., Murphy, R., Paley, L., Proby, C. M., Thomson, C., Thomas, R., Turner, C., Vernon, S. & Venables, Z. C., 26 Sep 2021 <u>https://doi.org/10.1111/bjd.20764</u>

The European cancer burden in 2020: Incidence and mortality estimates for 40 countries and 25 major cancers

Dyba, T., Randi, G., Bray, F., Martos, C., Giusti, F., Nicholson, N., <u>Gavin, A</u>., Flego, M., Neamtiu, L., Dimitrova, N., Negrão Carvalho, R., Ferlay, J. & Bettio, M., Nov 2021, In: European Journal of Cancer. <u>https://doi.org/10.1016/j.ejca.2021.07.039</u>

NICR Publications June 2020-June 2021 (continued)

International variation in oesophageal and gastric cancer survival 2012–2014: differences by histological subtype and stage at diagnosis (an ICBP SURVMARK-2 population-based study) Arnold, M., Morgan, E., Bardot, A., Rutherford, M. J., Ferlay, J., Little, A., Møller, B., Bucher, O., De, P.,

Woods, R. R., Saint-Jacques, N., <u>Gavin, A. T</u>., Engholm, G., Achiam, M. P., Porter, G., Walsh, P. M., Vernon, S., Kozie, S., Ramanakumar, A. V., Lynch, C. & 10 others, , 25 Nov 2021, In: Gut.

https://doi:10.1136/gutjnl-2021-325266

The Impact of the COVID-19 Pandemic on Barrett's Oesophagus and Oesophago-gastric Cancer Turkington, R., Lavery, A., <u>Donnelly, D., Gavin, A.</u>, McManus, D., Cairnduff, V., McShane, C., Johnston, B., <u>An-</u> <u>derson, L</u>. & <u>Coleman, H.</u>, Dec 2021. In BJS https://doi.org/10.1053/j.gastro.2021.01.208

Stability of health-related quality of life and morbidity burden from 18 months after diagnosis of prostate cancer: results of a UK-wide population-based outcome cohort

Mason, S. J., Downing, A., Wilding, S., Hounsome, L., Wright, P., Watson, E., Wagland, R., Butcher, H., Kind, P., Selby, P., <u>Gavin, A.</u> & Glaser, A. W., 13 Dec 2021, In: Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer. https://doi.org/10.1007/s00520-021-06650-7

Impact of the first wave of the COVID-19 pandemic on cancer registration and cancer care: a European survey ENCR Steering Committee , 22 Dec 2021, In: European journal of public health.

https://doi.org/10.1093/eurpub/ckab214

The Impact of the COVID-19 Pandemic on Endometrial Cancer and Endometrial Hyperplasia Diagnosis: A Population-Based Study

Wylie, J., Quinn, D., Donnelly, D., McCluggage, W. G., Coleman, H., <u>Gavin, A</u>. & McMenamin, Ú., 29 Dec 2021, In: American Journal of Obstetrics and Gynecology. https://doi.org/10.1016/j.ajog.2021.12.259

Risk factors and prognostic implications of diagnosis of cancer within 30 days after an emergency hospital admission (emergency presentation): an International Cancer Benchmarking Partnership (ICBP) population-based study

ICBP Module 9 Emergency Presentations Working Group, 06 Apr 2022, Lancet Oncology. https://doi.org/10.1016/S1470-2045(22)00127-9

Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP) ICBP Module 4 Working Group, 26 May 2022, In: British Journal of Cancer. https://doi.org/10.1038/s41416-022-01844-0

Impact of the COVID-19 pandemic on emergency hospital cancer admissions in a UK region Mitchell, H., Alford, B. S., O'Hare, S., O'Callaghan, E., Fox, C. & <u>Gavin, A. T</u>., 04 Aug 2022, In: BMC Cancer. <u>https://doi.org/10.1186/s12885-022-09932-3</u>

NICR Refurbishment

During the period of working from home in 2020-2021 QUB undertook a major refurbishment of the NICR offices. This extensive work expanded the office space for the ever growing Registry projects. The refurbishment project was completed in October 2021. Thank you to all in QUB who made this work possible, the NICR Staff and visitors love our new surroundings.









Staff News

New Staff

Dr Hüseyin Küçükali (Analyst)

Hüseyin joined the Registry in January 2022 as an Analyst for the Cardio Oncology project. In December 2022 Hüseyin left the Registry to take up a new post within CPH. We wish him every success in his new role.





Anish Chacko (IT Officer)

Anish joined the Registry in March 2022 as an IT Officer.

Andrea Bryan

Andrea joined the Registry in July 2022 as a Cancer Intelligence Officer (CIO).



Staff News

Farewell

In the past year we said farewell to Ashley Levickas who has taken up a post in within the School of Pharmacy. We wish Ashley every success in her new role.





In March 2022 we said farewell to Simon O'Hare, Macmillan Analyst. We wish Simon every best wish for the future.

In February the Registry said farewell to Ronan Campbell after 7 years. We wish Ronan every best wish for the future.





In August 2022 Prof Ciaran O'Neill stepped down from his post as joint Deputy Director after 2 years. We thank Prof O'Neill for all his help and continued support in the Cardio-oncology work and wish him well for the future.

Other News

Congratulations

Alan Turing Award

Congratulations to Dr Hüseyin Küçükali who recently won the Alan Turning Award! The Alan Turing Institute is a national organisation dedicated to advancing data science and artificial intelligence. Their Post-Doctoral Enrichment Award aims to build a post-doctoral community working on data science and artificial intelligence by supporting them to learn new skills, collaborate and develop research independence.

Using the award, Hüseyin will advance his data science skills by learning how to use AI in causal inference and apply his learnings to the registry's data to bring up new insights for better outcomes in cancer patients. Lastly, he will build an online community around the use of AI in public health.

Best Poster

A poster on the study investigating the impact COVID-19 on hospital admissions was accepted at both IARC and ENCR conferences in 2021. The poster won best poster at the ENCR conference. Congratulations to Helen Mitchell and Ben Alford!



Project updates on the NICR Website

On 8th March the NICR held a virtual information day which included updates on core work and research projects of the Registry. The recording can be viewed <u>here</u>, along with individual project updates.

Charity Donation

In lieu of Secret Santa and Christmas Dinner for Christmas 2021, the Registry staff made a donation of £200 to Macmillan.

Visit to the NICR

NICR have recently hosted visits to the newly refurbished premises for representatives from the PHA and Department of Health. If you or your colleagues wish to visit us, we will seek to facilitate you. Please contact nicr@qub.ac.uk to make the necessary arrangements.

Masters

Congratulations to Helen Mitchell who recently completed her Masters in Health Psychology!

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