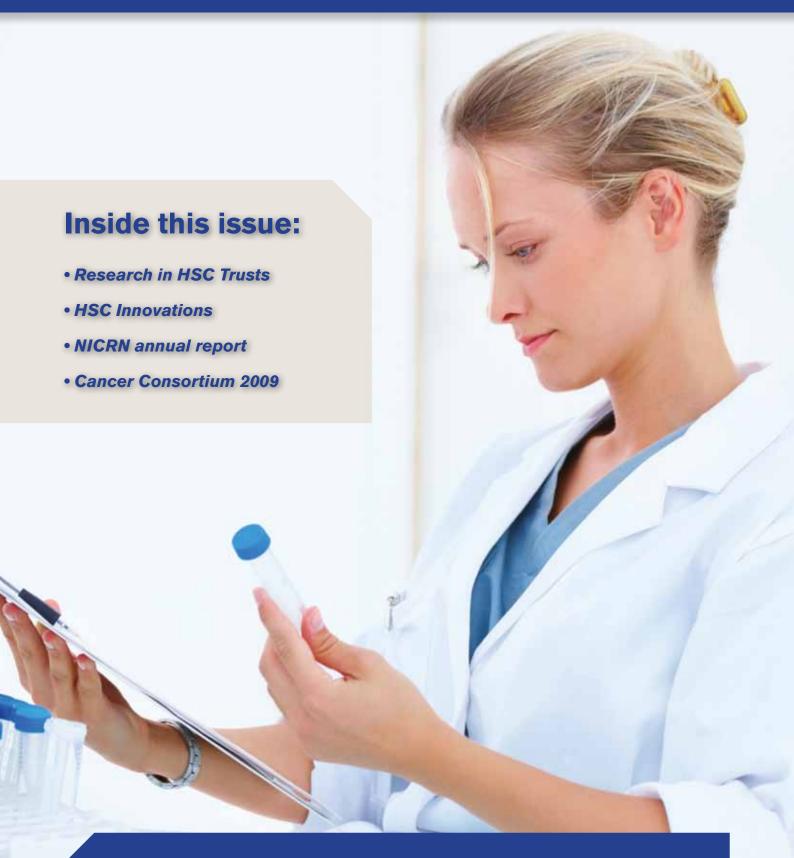
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The biannual newsletter of the Health and Social Care Research and Development Division

Issue 13 Summer 2010





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### Foreword





Thank you for taking the time to read this, the 13<sup>th</sup> issue of R&D Today, our newsletter that profiles work supported by Northern Ireland's Health and Social Care R&D fund. This issue reflects the position of HSC R&D as a division of the regional Public Health Agency.

You are more likely to be reading a PDF version as we have significantly reduced the number of printed copies we distribute. I hope that this change still enables readers to appreciate the depth and scope of R&D that we support across our HSC Trusts and universities.

There are many reasons why HSC research is valuable and, very rightly, is valued highly. The primary reason is that it delivers benefits for patients and clients. In this edition, the Northern Ireland Clinical Research Network (NICRN) article on page 17 provides an excellent example of how benefits are delivered.

More than 6,000 patients, representing a variety of different medical conditions, have had the opportunity to participate in studies on new and innovative treatments that are not yet available through routine services.

Many of those patients will have experienced better health outcomes than if they had received the standard treatments. And for those concerned with costs, the good news is that all NICRN studies receive funding from HSC R&D or other sources external to the participating HSC Trust.

Elsewhere in this issue you will read about clinicians and other researchers in HSC Trusts who are enhancing their professional practice through knowledge, technology and other evidence gained from research. In so doing, they have won awards, attracted new financial investment and stimulated further studies aimed at the continuous improvement of health outcomes.

Investment in innovation is investment in a better future for all of us. HSC R&D enables that to happen within our health and social care services.

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#### **Belfast Health and Social Care Trust**





and Development

Clinical researchers remain very active within Belfast Health and Social Care Trust, with a wide spectrum of work underway or recently approved.

One important programme of work is led by Dr Jane Woodside and Dr Michelle McKinley. who are based in the Centre for Public Health at Queen's University Belfast and who work closely with Dr Steven Hunter from the Regional Metabolic Unit and Dr David Edgar from the Department of Immunology in the Trust.

It is widely recognised that consumption of fruit and vegetables is likely to be good for health, and current public health recommendations suggest that five portions per day is a reasonable target. However, it is not clearly understood how fruit and vegetables have their beneficial effects, and these researchers are exploring the mechanisms likely to be involved. With the aid of extensive funding from the UK Food Standards Agency they are recruiting patients to clinical trials in which they receive diets containing varying amounts of different types of fruit and vegetables.

Fruit and vegetables are delivered to patients in their homes and they are given advice about how they can be incorporated into the diet in order to overcome barriers to fruit and vegetable consumption. The group have already shown that there is a significant improvement in the function of major blood vessels with each additional portion of fruit and vegetables taken in the diet. That work was described in a paper which was published research strategy within the Trust.

**Professor Ian Young,** in the journal *Circulation* last year, and the **Director of Research** researchers are currently looking at the effects on function of the immune system and metabolism of glucose. This programme of work will be important in influencing future dietary advice for various patient groups.

> The potential benefit of this research is obvious and may generate considerable publicity in due course. However, much research within the Trust proceeds quietly and has significant impact on patient care without ever hitting the headlines. It is important to capture the impact of all research and to understand why some projects are more successful than others.

> In order to do this, Ms Frances Burns, Research Manager within the Trust, is currently reviewing, as part of a PhD project, all projects which were completed between 2003 and 2006. The objective is to understand the factors which result in successful research, and to document the full impact of research and the benefits which result from different types of project. Participating in a research project may have significant benefits for members of the research team, influencing their career paths and helping them to recognise at an early stage important research findings and incorporate them into care pathways.

Some projects give rise to new knowledge which may have impacts not only locally but throughout the world by triggering new research by other research teams. Other projects may produce results which rapidly and directly result in changes to patient care. While this may be very obvious to members of the research team, often such impacts do not get the publicity which they deserve. By understanding why some projects have major impact while other similar projects fail to do so, this work will help to determine future

#### Northern Health and Social Care Trust





Dr Des Rooney, and Development

Support has been allocated from the Director's Research Discretionary Fund, provided by HSC R&D, for two anaesthetic department studies

that are well on the way to completion.

The first study is TAP block for gynaecological laparotomies – a comparison of ultrasound-guided block and blind technique and the recruitment of patients is now some three quarters complete. Pain is a major cause of postoperative morbidity in patients undergoing laparotomy and the study aims to compare two methods for the application of a relatively new regional anaesthetic technique.

The transversus abdominis plane block (TAPB) targets anterior divisions of segmental spinal nerves and has been shown in several studies to bring a significant reduction in pain and opioid consumption in the first 24 hours post-operatively. It has rapidly gained popularity as a safe and efficacious 'blind' technique with rare complications.

Ultrasound visualisation of the site being treated has, in several regional anaesthetic techniques, been shown to improve success rates and decrease complications. The researchers hope that the use of ultrasound guidance in siting TAPB will be shown to improve the reliability of the technique and further reduce the complications associated with it.

The second study is A comparison of C-Trach, intubating laryngeal mask airway (ILMA) and

I-gel for tracheal intubation. Supraglottic **Director of Research** airways in anaesthetic practice provide a dedicated airway for primary ventilation of a patient or to facilitate tracheal intubation in the event of difficulties. The C-Trach (pictured) is a relatively new videolaryngoscope designed to facilitate visualisation of the trachea for intubation, whereas the I-gel and ILMA are more conventional supraglottic airways techniques with wide-bore openings through which an endotracheal tube can be passed.

> The new C-Trach device for assisting the management of patient airway intubation



The study will add valuable additional information to the current body of literature on airway management. Although the ILMA is a currently accepted 'gold standard' for management of the difficult airway, there are only limited descriptions of the use of the other, newer devices and, to date, there have been no comparative studies of these devices in everyday clinical practice.

Further funding was also awarded for ongoing research support and development of PVA-Borax Hydro wound gels. Ethics approval is now in place for a study into the residence properties of the gel within diabetic foot ulcers and in a questionnaire study patients have been asked to describe their experiences of the gel's use. In the main study, using the gel for laceration repair, recruitment of patients is on track and has passed the 70% mark.

#### South Eastern Health and Social Care Trust





Dr David Hill, and Development

Over the last year within the South Eastern HSC Trust (SET) research activity has increased. the infrastructure has developed

and greater regional integration has been achieved.

In partnership with the Northern Ireland Clinical Research Network (NICRN) and HSC R&D. research nurses are now active in cardiovascular, stroke, diabetes and critical care.

The research nurses work closely with clinicians in these areas to open and manage a variety of studies with the potential to impact positively on the wider community that SET serves.

Funding for the studies has been attracted from both commercial and non-commercial sources. In addition, staff involved with the studies act as a key resource in developing a culture that promotes research as a core component of care as well as encouraging, supporting and educating a wide variety of professionals.

Other disciplines that have also developed infrastructure around research include rheumatology, obstetrics, gynaecology and nephrology. Different models of funding have been organised, with support from the Trust, to enable these programmes and it is hoped that these will grow.

The Trust's Research Office now operates with **Director of Research** its full complement of staff, offering advice to researchers and supporting them in the governance and management of projects. The Office also interfaces regionally through the Directors' Forum, Research Governance Working Group and the Research Managers' Forum.

> The latter group has been particularly active in a number of projects that aim to streamline the process that researchers must complete to meet the legislative and regulatory requirements for clinical research.

The SET has been involved to a greater or lesser degree in a number of these work-streams, including IRAS (Integrated Research Application System), IRMER, peer review and costing (in partnership with the Beeches Management Centre).

Research as a core activity of HSC functions is important to the Trust and with a growth in infrastructure it is expected that activity and access to a variety of studies will increase as the year progresses.

Importantly, two lay members have been appointed to the Trust's Research Committee thereby ensuring that a fresh perspective is brought to project evaluation and decision-making within the Trust Governance structure.

#### Southern Health and Social Care Trust





Dr Peter Sharpe, and Development

The Southern HSC Trust is delighted with the increase in research activity since the Trust Research and Development Office was established by HSC R&D in 2008.

There were 62 research applications received for the year ending 31 March 2010, compared with 59 in 2008/2009 and only 21 in the previous year.

During the first year of the R&D Director's Discretionary Fund (2008/2009), six applications were awarded funding, compared with 17 applications received in 2009/2010, 10 of which were awarded funding.

Applications represented a wide range of Trust services, including: forensic psychiatry, ENT, neurology, social work, occupational therapy, continence, older people, neonatology, cardiology, dietetics, obstetrics and gynaecology, medicine, histo/cytopathology and child protection.

One of the research studies awarded a relatively small amount of funding from the Discretionary Fund was RADAR-ACS – rapid diagnosis and risk stratification of an acute coronary syndrome. It progressed to attract substantial funding from Randox Laboratories in Crumlin for a three year period.

Furthermore, another arm of the RADAR-ACS study has been developed entitled Predicting safe same-day patient discharge post-percutaneous revascularisation and again was funded by Randox Laboratories.

A small amount of funding from the **Director of Research** discretionary fund has therefore resulted in very significant research which will undoubtedly benefit the population served by the Southern Trust.

> Some of the other research studies funded through the Director's discretionary fund included:

- •a systematic review of the frequency, causes and outcome of thunderclap headache;
- an examination of effective practice assessment within the direct observation of social work students in the Southern HSC Trust:
- an examination of the effectiveness sensory integration intervention in supporting a smooth transition of people with a diagnosis of autism spectrum disorder from special schools into adult services;



Mairead McAlinden, Acting Chief Executive, Southern HSC Trust; pictured with Dr Peter Sharpe, Director Research and Development; and Irene Knox, Research Manager.

#### Southern Health and Social Care Trust (continued)

- prevalence and predictors of high grade ventricular arrhythmia in a maintenance haemodialysis population;
- an exploration of the benefits of remote telemonitoring for blood pressure management in people following stroke and transient ischemic attack;
- the role of social work intervention in the implementation of the National Dementia Strategy;
- a qualitative study exploring the experience of district nurses caring for patients with long-term indwelling urinary catheters.

Craigavon Area Hospital has a proven record of undertaking multi-centre clinical trials on an international, European and worldwide basis. Examples of such trials from neurology, cardiology, dermatology and cancer services include:

- -The **Tysabri Observational Programme** (TOP) to assess the long-term safety and impact on disease activity and progression of tysabri (natalizumab) in patients with relapsing remitting multiple sclerosis in clinical practice setting. Between 3,000 and 5,000 patients will be enrolled worldwide:
- -SIGNIFY, a study of the effects of ivabradine in patients with stable coronary artery disease without clinical heart failure, a randomised double-blind placebo-controlled international multicentre study;
- Strategic reperfusion early after myocardial infarction (STREAM);

- -TRANSIT, an exploratory trial to assess naturalistic safety and efficacy outcomes in patients transitioned to ustekinumab from previous methotrexate therapy;
- Short Course Oncology Therapy (SCOT), a study of adjuvant chemotheraphy in colorectal cancer;
- POETIC, a trial of perioperative endocrine therapy – individualising care.

The Trust strives to promote the Northern Ireland Clinical Research Network (NICRN) adopted studies, particularly in the specialist interest areas of children, diabetes and critical care.

Staff of the Trust contribute to those three areas with the Northern Ireland lead for the children's group being a Consultant Paediatrician in Craigavon Area Hospital.

The support of a NICRN-funded Clinical Research Nurse post for childrens' and stroke has been invaluable in taking forward NICRN adopted studies with research nurse staff for critical care, who are soon to be appointed, will be of similar benefit in enabling NICRN studies to be opened in the Trust.

In contributing to economic development, links are on-going with Craigavon Industrial Development Organisation (CIDO), an innovation/incubation hub with extensive local, national and global links to innovators in the fields of biomarkers and medical technology.

#### Southern Health and Social Care Trust (continued)

Throughout the year several meetings and a workshop were held with CIDO. Potential areas of interest were identified in relation to point of care testing, screening tests and the development of medical devices.

CIDO wishes to support local entrepreneurs in developing medical devices with the view that, when the stage for undertaking clinical trials has been reached, research governance permission will be sought to use the facilities, patients and resources of the Southern HSC Trust.

During the past year the Trust's Research and Development Strategy was launched. The Strategy aims to build on the Trust's record of research involvement, supporting staff who wish to undertake clinical and social care research that will improve the health and wellbeing of patients and clients through improved diagnosis, treatment and prevention of disease.



Pictured at the launch of the Southern
Trust's Research and Development Strategy,
Dr Patrick Loughran, Medical Director; Dr
Peter Sharpe, Director of Research and
Development; Colm Donaghy, Chief Executive;
and Irene Knox, Research Manager.

Dr Peter Sharpe was invited to present the Strategy to the Trust's Governance Committee and also to present the *Research and Development Annual Report for 2008/2009* to a meeting of the Trust Board. These invitations demonstrate the interest and commitment to research and development at Trust Board level.

The Trust was pleased that the achievements through the Controls Assurance, Research Governance Standards have shown continual improvement in achieving substantive compliance over the past two years.

Nursing, social work and allied health professions continue to be the main priority areas for encouraging and promoting research among staff within the Trust.

#### Western Health and Social Care Trust





Dr Maurice O'Kane, and Development

The Western Health and Social Care Trust (WHSCT) has identified chronic disease as a strategic research priority.

The Research Director's Discretionary Fund, provided by HSC R&D, is an excellent opportunity to pump-prime studies in these areas. One of the supported projects is an investigation of exercise cardiac rehabilitation programmes and has been successful in obtaining additional grant funding from Northern Ireland Chest, Heart and Stroke.

Examples of other innovative projects funded in this way include the development of a sensing glove to assess hand movement in arthritic conditions (jointly with the University of Ulster) and a study of the impact of early neurological impairment on visual function (jointly with the University of Ulster).

Atlantic - ACORD, a joint partnership between WHSCT, University of Ulster and NUI Galway to promote collaborative research in diabetes in the North and West of Ireland was launched in November 2009. Funding has been obtained for a pilot study of self-monitoring of blood glucose in diabetes in pregnancy.

The appointment of Northern Ireland Clinical Research Network (NICRN) research nurses has strengthened the research infrastructure in stroke, diabetes, cardiology and critical care with network adopted studies now ongoing in each of these disciplines.

In addition, a Trust-funded research nurse **Director of Research** has been appointed in renal medicine.

> The Clinical Translational Research and Innovation Centre (C-TRIC), a joint partnership between WHSCT, University of Ulster and Derry City Council, acts as a focus for research within the WHSCT. C-TRIC is currently hosting a range of life sciences/ biobusiness companies working with clinical and academic staff in areas such as infection control and respiratory health.

C-TRIC has organised and facilitated two all-Ireland collaborative networks bringing together clinical, biobusiness and academic staff. In recognition of its achievements, C-TRIC won an Irish Times Innovation award in March 2010.

In April C-TRIC held its second annual Translational Medicine conference which focused on key themes in translational research with an array of local and international speakers and poster presentations.



Barry Henderson, Business Development Manager at C-TRIC, pictured collecting the Irish Times Innovation Award.

#### **HSC Innovations Elevation Awards**

#### Staff honoured for providing best new ideas to improve patient care

HSC Innovations officially unveiled the top innovators across the Health and Social Care (HSC) Trusts on Tuesday 25 May and rewarded them for coming up with a raft of exciting new ideas with the potential to improve patient care. All 60,000 HSC employees were challenged to put forward innovative ideas to transform health or social care or lead to vital medical breakthroughs. These were Northern Ireland's first-ever Elevation Awards. organised by HSC Innovations.

Each entry had to describe the background to their idea, the problem that they sought to address, an outline of how their idea would work and the benefits it would bring.

A total of 12 finalists from across all five HSC trusts were chosen by an expert team of health and business specialists for the inaugural awards. The judging panel evaluated each entry in three key areas:

- novelty and inventiveness;
- practicality and readiness;
- potential value within the Health and Social Care service.

From these, three entries made the top grade in the specialist categories. Stephen Wallace, an Infection Control Information Officer at the Southern HSC Trust, won top slot in the most competitive category, ICT Idea of the Year. Stephen's innovation would help hospitals to keep track of cleaning aimed at cutting hospital-acquired infection rates.

Technical Instructor at the Belfast HSC Trust, John McAuley, took the winning prize in

the **Equipment of the Year category.** John devised a new product that would save time for occupational therapists while enhancing patient care.



From left. Dr David Brownlee. HSC Innovations and Dr Janice Bailie, HSC R&D; present Stephen Wallace, Craigavon Area Hospital, with the award for the best ICT Idea of the Year.



Innovations; and Professor Alistair Fee present John McAuley, Belfast Health and Social Care Trust, with the award for the most Innovative Equipment Idea.

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#### **HSC Innovations Elevation Awards** (continued)

Belfast HSC Trust also took the lead in the **Diagnostics and Pharmaceuticals Idea of the Year category**.

Clinical Scientist, Dr Derek Fairley, accepted the winning award for developing a novel diagnostic test that uses molecular biology to help in the global fight against bacterial meningitis and septicaemia.

Guest Speaker, Dr Peter Donnelly, CEO of BioBusiness, spoke about how BioBusiness is operating to facilitate collaboration among academics, businesses and clinicians.



Dr David Brownlee, HSC Innovations; and Dr Peter Sharpe, present Dr Derek Fairley, Belfast Trust, with the award for the most Innovative Diagnostics and Pharmaceutical Idea.

In particular, Dr Donnelly mentioned the vital link between industry and clinical practice that enables innovation to succeed.

He outlined how current challenges to the economy, changing demographics and technological advances drive a requirement for the early adoption of innovations to assist with healthcare delivery.



Dr David Brownlee, Innovation Adviser at HSC Innovations, said: "Our congratulations go to each of the winners and all the finalists who were shortlisted for the first ever Elevation Awards. It's vital that we keep coming up with new, exciting and innovative ways to address unmet clinical needs, and to develop solutions that will improve patient care.

"HSC Innovations provides a platform along with our industry and clinical partners to identify, protect and develop ideas towards commercialisation and implementation."

The best overall entries from each of the five Trusts were also recognised, with Dr Philip Gardiner from the Western Trust, Patrick Maguire from the Northern Trust and Rosemary Bird for South Eastern Trust all receiving accolades for their ideas.

Stephen Wallace from the Southern Trust also won again in this category, as did Dr Derek Fairley from the Belfast Trust.

Professor Bernie Hannigan, Director of R&D for Health and Social Care, said: "The ideas put forward were really great. They demonstrate a huge range of skills and talent so we know that innovation to benefit patients is really possible across all of our Trusts.

#### **HSC Innovations, Elevation Awards** (continued)

I hope that these new awards will encourage even more of our brilliant staff to take up the innovation challenge.

"I congratulate everybody on what they have achieved already. Now let's keep the ideas flowing and use them to transform the services we deliver for our community."

HSC Innovations is a centre of expertise in intellectual property management for all HSC bodies in Northern Ireland. The service works closely with the Research Offices of the five HSC Trusts and HSC R&D.

It promotes effective intellectual property management in support of the Research Governance Framework and HSC Innovation Policy.

The HSC Innovations service can help you exploit the commercial potential of research results and innovations from clinical research and practice.

If you have an idea for new or improved therapies, devices, diagnostics and procedures that could save lives, time or money we can help you take it forward. Contact us at innovations@crsc.n-i.nhs.uk or call 028 9063 5794.

HSC Innovations is funded by the Department for Business, Innovation and Skills through its Public Sector Research Exploitation (PSRE) fund, Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D) and Invest Northern Ireland.



#### Technology to improve the management of medicines

The Northern HSC Trust and Yarra Software have recently signed a revenue sharing agreement for new 'clinical intervention' software, EPICS, (Electronic Pharmacist Intervention Clinical System) which was developed by the Trust in conjunction with the School of Pharmacy at Queen's University Belfast.

In hospitals it is the job of the clinical pharmacists to ensure the safe and effective use of medicines. Sometimes a medicine may not have the required effect, patients may be taking too much or too little, there may be adverse side effects or two medicines may interact adversely.

If pharmacists discover problems with a patient's treatment they carry out a 'clinical intervention' to ensure that the therapy becomes more effective and free from adverse effects.

Peter Beagon, Senior Pharmacist in the Northern Trust, said: "Traditionally, pharmacists have recorded their clinical interventions using site-specific paper-based systems. However, although they share some common attributes, the recording forms have never been standardised among HSC Trusts."
Now the pharmacy staff at Antrim Area
Hospital have automated the entire process
of clinical intervention with the new bespoke
EPICS software application.

Pharmacists carry their pocket PCs loaded with the software so they can quickly and easily record their clinical interventions on a continuous basis and the software automatically generates monthly reports.

In addition, the latest enhancement will enable these interventions to be incorporated into the Trust Incident Reporting system, thereby facilitating detailed analysis and subsequent learning from key medication-related incidents.

Professor James McElnay, Pro Vice Chancellor and a member of the School of Pharmacy at Queen's University, said: "In developing the new system, we have put patient wellbeing and safety at the heart of clinical pharmacy services within the hospital. EPICS is undoubtedly a major technological advance in providing optimal patient care."

#### Technology to improve the management of medicines (continued)

Professor Mike Scott, Head of Pharmacy and Medicines Management, Northern HSC Trust, said: "We want patients to make the best recovery they can and making sure their drug regime is effective is paramount to us. This new system allows us to minimise the risk of avoidable harm to patients and also maximise the benefits of their drug therapy."

The software is a result of six years collaboration between the Trust and Yarra Software and is a world first. Already it is attracting attention from Saudi Arabia, Germany and Sweden. Michael Martin, Business Development Director at Yarra Software, said: "EPICS shows that public-private partnerships can work and deliver significant returns both for patient benefits and financial efficiency."

Dr David Brownlee of HSC Innovations said: "This collaboration between industry and the HSC demonstrates the value of working with the clinical base in developing new product and technology opportunities for healthcare. These products can help to secure real improvements in healthcare practices locally (HSC), nationally (NHS) and globally."

For more information about HSC Innovations, go to the Clinical Research Support Centre website at www.crsc.n-i.nhs.uk/innovations



At the signing of the EPICS agreement, from left, seated, Mr Michael Martin, Yarra Software; and Colm Donaghy, Chief Executive NHSCT. From left, standing, Professor Mike Scott, NHSCT; Professor James McElnay, Pro Vice Chancellor, Queen's University Belfast; Dr David Brownlee; Dr Peter Flanagan, Medical Director; Peter Beagon, Senior Clinical Pharmacist; and Dr Des Rooney, Director of Research and Development.



## Success in research and development

#### A successful year for the Northern Ireland Clinical Research Network

The 2009/2010 Annual Report from the Northern Ireland Clinical Research Network (NICRN) shows that, since its inception, over 6,400 patients have entered clinical research studies throughout Northern Ireland and

NORTHERN IRELAND
CLINICAL RESEARCH NETWORK

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105 separate studies have been initiated.

Many of these studies are ongoing, and will

not have their full impact for some time, but already patients have been able to access treatments which would not otherwise have been available to them through participating in network research.

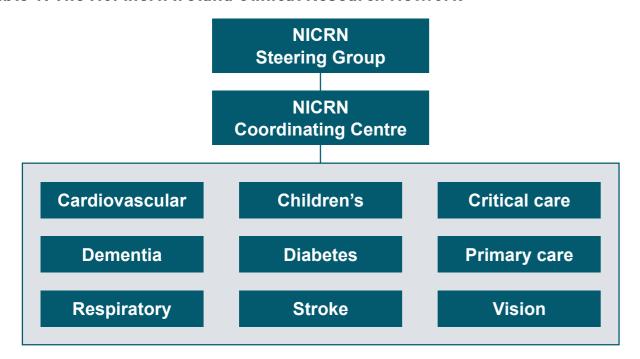
The aim of NICRN is to facilitate the delivery of clinical trials and other high quality clinical research in Health and Social Care. NICRN is part of a wider UK Clinical Research Network (UKCRN) and its existence is essential to ensure that patients in Northern Ireland have access

to new and experimental treatments in the same way as those elsewhere in the UK and Ireland. NICRN is structured as a managed single network that brings together clinical researchers with experience in disease areas that map with the topic groups from the other UK countries, thereby allowing easy embedding of Northern Ireland structures into national models.

This approach, along with the establishment of new supporting structures such as the NICRN Coordinating centre, local accredited Clinical Trials Units (CTU's) and Clinical Research Facilities (CRF's), will aid Northern Ireland researchers in their ability to design and conduct clinical research within the HSC environment to the highest national standards.

Currently the Coordinating Centre is operational. Led by Mr Paul Biagioni, the Clinical Research Support Centre (CRSC) has provisional registration as a CTU and the CRF is under development, to be completed in 2011.

Table 1: The Northern Ireland Clinical Research Network



Currently NICRN involves trials within nine disease specific clinical interest groups and a steering group led by the NICRN Clinical Director, Professor Ian Young of BHSCT/QUB.

Each interest group has two main roles:

- to recruit to and manage the care of patients enrolled on clinical studies;
- to provide scientific direction by choosing and / or designing studies that will be run by that group.

Where the NICRN interest groups overlap with those established in England under the auspices of the UKCRN, appropriate linkages are developed at the national steering group level to ensure full Northern Ireland participation and a UK wide approach.

This includes contributing to the development and conduct of studies in the UKCRN portfolio, training of research staff, development of common processes, and reporting of performance measures.

To ensure a continued programme of activity and therefore efficient use of the core staffing resource, each interest group has an agreed series of annual objectives in line with UKCRN topic groups. The objectives are based on activity, staffing levels, previous outcomes and planned developments for forthcoming year in each group.

Note that clinical trials in cancer are a very strong activity in Northern Ireland. However, the establishment of the Northern Ireland Cancer Clinical Trials Network pre-dated NICRN so, currently, they are structured, funded and reported on separately.

All NICRN interest groups are broadly achieving their objectives. Some groups have found difficulty in achieving targets due to delays in appointing core staff and changes following RPA. While a lot of activity is Belfast-focused, trials are underway across all Trusts and targets are in place to increase the province-wide reach of NICRN.



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## Success in research and development

## The Ireland-Northern Ireland-NCI Cancer Consortium Annual Activities Report 2009

The tenth North South Ministerial Council (NSMC) meeting in the Health and Food Safety sectoral formats was held in the NSMC Joint Secretariat Offices, Armagh on Wednesday, 2 June 2010.

At the meeting, Ministers Harney and McGimpsey jointly launched the The Ireland-Northern Ireland-NCI Cancer Consortium 2009 Annual Activities Report, Transcending Borders for Better Health: Empowering the Future through Research,

Education and Care. This report is especially significant as it marks the tenth anniversary of a highly beneficial collaboration.

Over the decade, the Consortium has sought to further cancer prevention and control efforts Transcending Borders for Better Health:
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Research - School Code
Research - School - and Code

on the island of Ireland by promoting the quality of care through research and education and improving disease outcomes through better prevention, diagnosis and treatment.

There is no doubt that the embedding of the Consortium within Government has been a significant asset, reinforced by the memo signed by Ministers in 2006 to extend the period of the Consortium.

The Consortium enables activities across the continuum of cancer prevention to palliative care. The need for the Consortium is evident from the stark statistic that the diagnosis of new cancer cases on the island of Ireland is increasing by 6-7% annually. One in every three people is likely to experience cancer

by the age of 75 and cancer is now the most common cause of death.

By placing education on a par with care and research, a very important focus has been on training the next generation of healthcare professionals and researchers. Those people must be resourced to apply the newest technologies and procedures to deal with the increasing burden of this illness especially as the number of older people in our population increases.

To date, almost 400 professionals from Ireland and Northern Ireland have participated in trans-national fellowships, exchanges and other projects that include epidemiology, health economics, prevention and clinical trials, all focusing on cancer.



At the tenth North-South Ministerial Council meeting, Mary Harney TD, Minister for Health and Children, Health Service Executive and Michael McGimpsey, Minister for Health, DHSSPS, jointly launch the Ireland-Northern Ireland-NCI Cancer Consortium 2009 annual activities report Transcending borders for better health: Empowering the future through research, education and care.

The report profiles the incidence of the most frequently-occurring cancers on the island of Ireland using data collated and report by the Cancer Registries in Ireland and Northern Ireland.

Access to the best knowledge and information is enabled by the Consortium by a variety of means including Telesynergy – a remote teleconferencing system that is installed in participating hospitals.

For example, Telesynergy enables nurses to share best practice with their national and international peers.

Many conferences have been organised in each of the participating jurisdictions to highlight specific aspects of cancer. These have been extremely well attended and have included four All-Ireland Cancer Conferences. In Northern Ireland, Consortium activities are funded by HSC R&D.

The report is available on the Consortium website at

www.allirelandnci.com/publications/index.shtml



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## Support for researchers

#### Northern Ireland Longitudinal Study



The Northern Ireland Longitudinal Study (NILS) is a large-scale record linkage study that has been created by linking statistical and administrative datasources within Northern Ireland.

These data include the 2001 census, Health Card Registration data, and vital events (births, deaths and marriages). NILS is hosted and maintained by Northern Ireland Statistics and Research Agency (NISRA).

The Northern Ireland Mortality Study (NIMS) is an additional major record linkage study covering the whole of the Northern Ireland population. NILS is a representative c. 28% sample of the Northern Ireland population based on 104 birthdates.

This 'core' membership of approximately 500,000 persons was drawn from the Health Card Registration system and linked to the 2001 Census returns for Northern Ireland. 2001 Census data provide a range of demographic and socio-economic variables (for example,

age and sex, country of birth, religion, marital status, economic (in)activity, (un)employment, occupational status, education, health and care-giving). More information on variables held in NILS can be found on the Available Data page at nils-rsu.census.ac.uk.

A variety of routinely collected administrative data are linked to these data – subsequent deaths and births registered to sample members, and associated migration data. Information is also collected about other people living in the same household as the NILS member at the time of the census, but these people are not followed forward in subsequent censuses.

NILS has the capacity to link health and social services data for specially defined one-off studies, although these are subject to increased legal and ethical scrutiny and privacy protection protocols.



#### The Northern Ireland Mortality Study

The Northern Ireland Mortality Study (NIMS) is a large-scale data linkage study that links the 2001 Census returns for the whole of the enumerated population (approximately 1.6 million individuals) to subsequently registered mortality data.

While larger than NILS it comprises only census-linked mortality data. The NIMS dataset is recommended for research which focuses on mortality in Northern Ireland.

#### Confidentiality

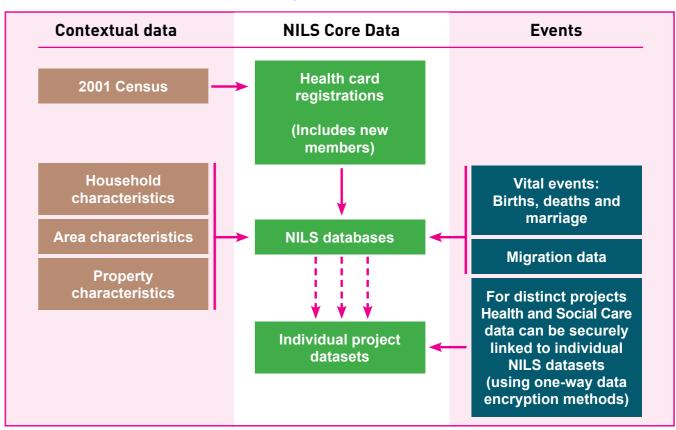
NILS and NIMS are designed for statistics and research purposes only and are managed by NISRA under Census legislation. Each project has an anonymised data extract generated for use by researchers; access is only from within a strictly controlled 'safe setting' and governed by protocols and procedures to ensure data confidentiality.

## Some examples of NILS and NIMS projects

- Individual, household and area variations in alcohol related deaths in Northern Ireland
- The Retirement Transition and the Celtic Fringe: mobility trends and migrant and rural community well-being
- Self-rated health and mortality in the UK: Results from the first comparative analysis of the England & Wales, Scotland and Northern Ireland Longitudinal Studies

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Table 2: The Northern Ireland Longitudinal Study



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## Support for researchers

#### Northern Ireland Longitudinal Study (continued)

- Predicting short run changes in fertility in Northern Ireland
- Describing and modeling internal migration in Northern Ireland 2001-2006 using the NILS: individuals, households and places
- An exploratory analysis of child dental health and use of dental care services in Northern Ireland
- Area influences on health: does the extent of community or religious segregation matter?
- The variation and determinants of the admission of older people to residential and nursing homes in Northern Ireland
- A study of the socio-demographic and area correlates of suicides in Northern Ireland
- Temperature-related mortality and housing in Northern Ireland

#### Contact and support

The NILS Research Support Unit (NILS-RSU) provides free information and advice for academic and other users of NILS or NIMS.

Anyone wishing to use NILS or NIMS data should contact the NILS-RSU who will help in defining the project, the selection of appropriate variables for research, and the completion of an application form.

Once the project has been approved by the Research Approvals Group, NILS-RSU will set up a user dataset and can assist with the analysis and interpretation of the results.

All analyses of NILS and NIMS data take place in the 'safe-setting' in central Belfast. Researchers can arrange to analyse their data there, under the supervision of their NILS-RSU support person.

Alternatively, researchers can send syntax files to be run on their data, with their results being checked and forwarded to them.

For more information on how the NILS may contribute to your research contact the NILS Research Support Unit:

NILS-RSU
Northern Ireland Statistics and Research
Agency (NISRA)
McAuley House
2-14 Castle Street
Belfast
BT1 1SA

Email: nils-rsu@census.ac.uk
Tel: +44 (0) 28 9082 8210

+44 (0) 28 9034 8199 Fax: +44 (0) 28 9034 8134

#### Supporting partners:

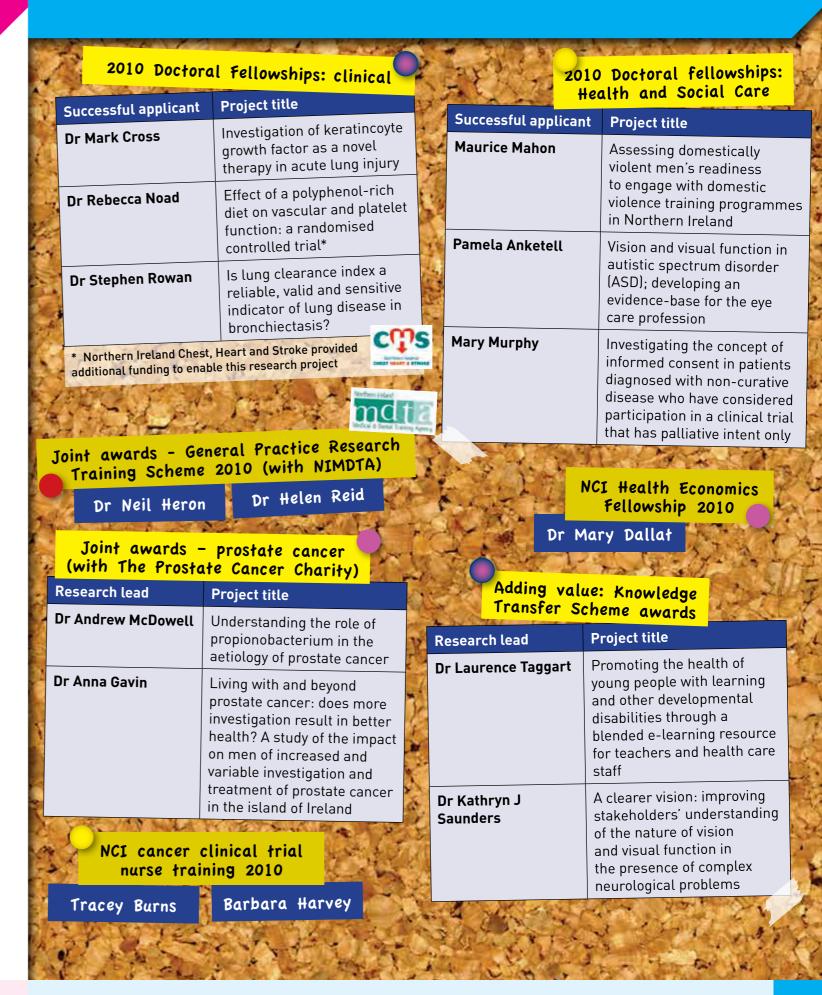






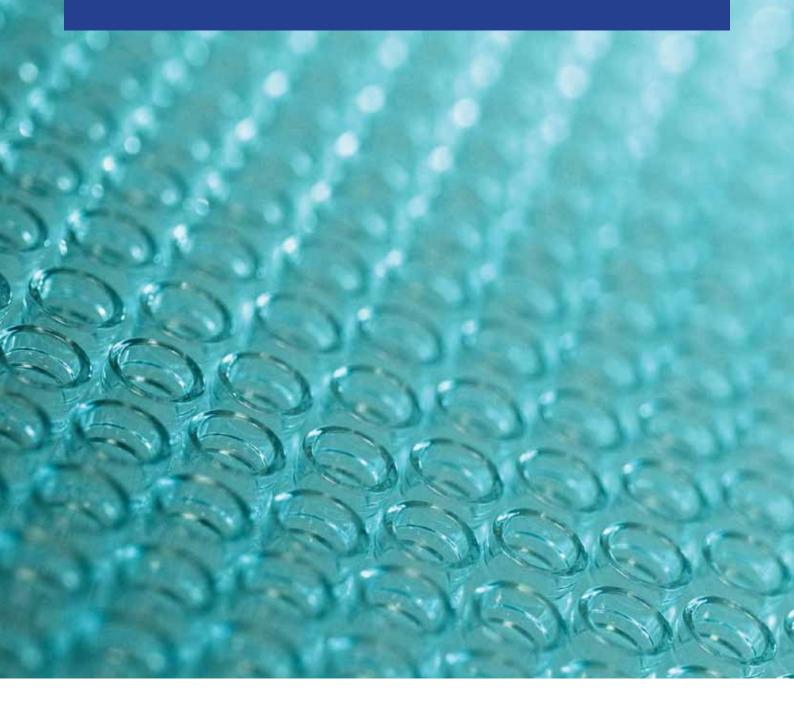


## Noticeable achievements



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AN ROINN

Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

MÄNNYSTRIE O

Poustie, Resydènter Heisin an Fowk Siccar

#### For further information please contact:

HSC Research & Development Division Public Health Agency 12–22 Linenhall Street Belfast BT2 8BS

Tel: 028 9055 3617. Fax: 028 9055 3674. www.publichealth.hscni.net