

# Health Research in Action

[#HRBResearchInAction](#)

Research.  
Evidence.  
Action.

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# HRB by numbers

– a snapshot of work completed in 2018

Serviced **197** requests for data from our National Health Information Systems

Published **7** peer reviewed journal articles

Published **3** annual reports and **2** national bulletins on disability, drugs and psychiatric inpatient data

Published **3** evidence reviews

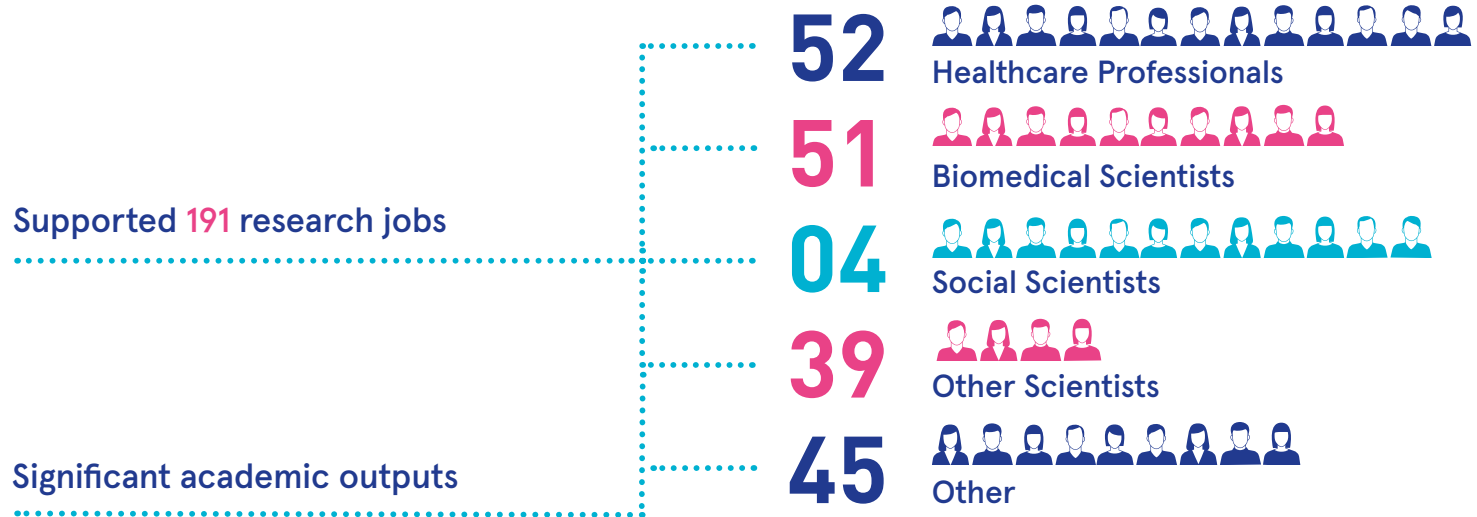
## In terms of funding

**77** awards completed in 2018,

worth a total of **€23,000,000**

This research resulted in:

- 64** new methods or materials (e.g. assays, databases, training materials)
- 22** healthcare innovations (e.g. medical devices, therapies or interventions)
- 66** influences on policy or practice (e.g. new clinical guidelines, policy reports)
- 150** engagements with public bodies and media



- 68 PhDs completed or in progress
- 439 Peer-reviewed publications
- 75 Non-peer reviewed publications
- 732 Presentations at scientific conferences
- 134 Academic collaborations with national colleagues
- 108 Academic collaborations with international colleagues

### The economic impact



In order to illustrate some examples of our research in a user friendly way, we captured a few of the success stories, summarised them and turned them into tweets we can share on social media.

So in just a few seconds, you should get a good sense of some of the great discoveries and outcomes that the Health Research Board is supporting across many areas of health.

Thanks to @claireoconnell and all the researchers for helping us to pull this together.

@hrbireland research @RCSI discovered a factor that helps children's bones heal quickly and this could lead to new treatments for children and adults

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### In summary

Large breaks or defects in bone may need grafts or transplants to help them repair. Research into tissue engineering at RCSI is developing biodegradable scaffolds and therapies that can be implanted into damaged bone to promote healing.

In a HRB-funded collaboration with clinicians from Temple Street, they identified a factor in stem cells from children that helps bones to heal. The researchers loaded a biochemical to boost this factor onto implantable scaffolds and showed that the system speeds up bone healing in the lab. The next step is to develop the system for use in humans.



## Towards speedier bone healing: clues from kids

Researchers: Dr Arlyng Gonzalez Vazquez, Professor Fergal O'Brien, Royal College of Surgeons in Ireland

### The problem

Children typically heal faster than adults. Finding out what is behind this could lead to new treatments to help bones heal, both in children and adults.

### The project

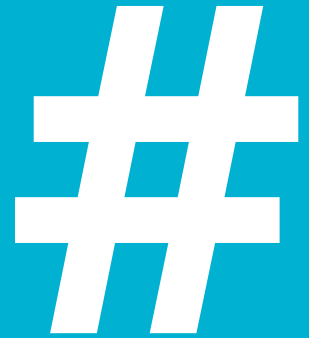
Researchers at RCSI and clinicians at Children's Health Ireland (CHI) at Temple Street in Dublin examined stem cells from bone marrow in children and adults, then designed and tested a biomaterial scaffold implant to deliver the factor to accelerate bone healing.

### The outcomes

- » Pinpointing of a biochemical involved in healing that was more active in stem cells from children than from adults.
- » The researchers designed a way to speed up bone healing that worked faster in the lab than currently available options.
- » New projects between RCSI and Temple Street, including one to examine the process of how skull bones fuse in children.

Dr Arlyng Gonzalez Vazquez, Research Fellow in the RCSI Tissue Engineering Research Group, says:

"We have developed a new way of stimulating bone cells to heal, and so far the results suggest that it works more quickly and specifically than products that are in use in the clinic."



@hrbireland is actively building awareness, capacity and engagement for public and patient involvement (PPI) in Irish health research

#HRBResearchInAction

### In summary

Public and Patient Involvement, or PPI, is an approach that includes patients, the public or both in decision making about research. It means the research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them, and it strengthens the impact of that research.

The HRB has put together an implementation plan to support PPI both within the HRB and through HRB-supported projects and programmes and is the first public funding agency in Ireland to do so.



## Nothing about me without me – HRB builds capacity in Public and Patient Involvement

Researcher: Dr Anne Cody, HRB

### The problem

If patients and the public have no input into planning and delivery of health research, the research outputs may not fully align with the needs of patients and others affected.

### The project

The HRB established the PPI Ignite network in NUI Galway, University College Dublin, Trinity College Dublin, University of Limerick and Dublin City University. The HRB asks researchers to consider PPI and include 'lay' abstract when applying for funding, and members of the public give feedback on some applications.

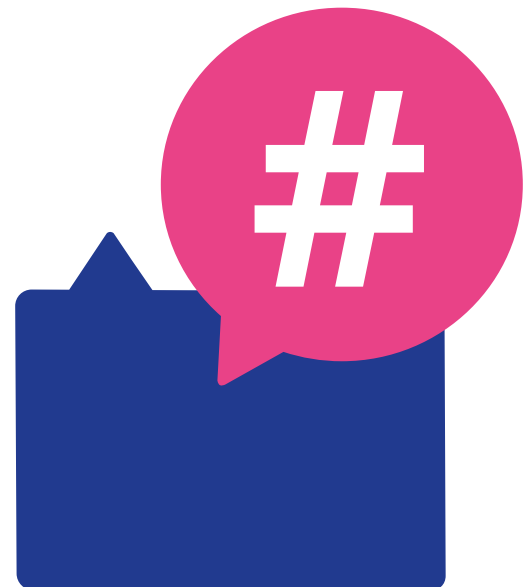
### The outcomes

- » HRB is the first funding agency in Ireland to implement plans to actively support PPI.
- » Five universities in Ireland have been awarded funding to develop local capacity in PPI and start a national network, PPI Ignite.
- » Thousands of people have engaged with PPI Ignite, for example through online resources and on-campus workshops.

- » In 2019, public reviewers provided feedback on all 133 applications to the HRB Investigator-Led Projects scheme. From 2020, the public review of HRB applications will become a more formalised part of funding assessment.

Dr Anne Cody, Head of Pre-Award, HRB, says:

"We are working to build public and patient involvement into the culture of research in Ireland. That means building awareness and capacity in the Irish system. We are on this journey with other organisations to make PPI a core part of health research design, so the research will be more tailored to benefit patients."



An online course developed in a @hrbireland project led by @NUIGalway is guiding doctors and nurses on how to help patients stick to long-term medication regimes

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### In summary

In Europe, more than half of people older than 65 years need to take multiple medications long term. But many do not take their medication as prescribed, meaning they don't get the benefits and their health may be at risk.

A team led by researchers at NUI Galway developed a short, online educational course for GPs, nurses and medical students about supporting patients to take multiple medicines. The team worked with patients, GPs, community pharmacists and psychologists to inform the content of the course, which is being used by doctors, nurses and students around Ireland.



## A guide to help patients stick to medication regimes

**Researchers:** Professor Andrew Murphy, Dr Gerry Molloy, NUI Galway

### The problem

Each year, medication non-adherence costs the EU €125 billion and results in 200,000 premature deaths. GPs and practice nurses need guidance on how to help people adhere to medication regimes for long-term conditions.

### The project

A HRB-funded project led by NUI Galway ran a day-long session with patients, pharmacists, psychologists, GPs and practice nurses to gather 'collective intelligence', then the research team developed a 30-minute learning session for delivery online.

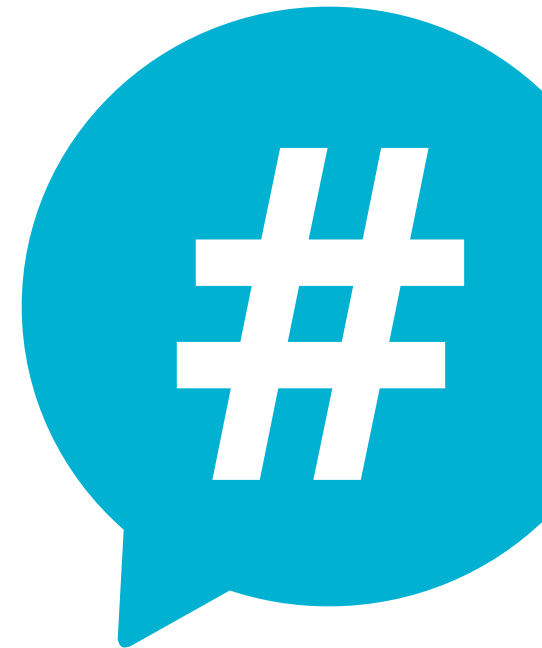
### The outcomes

- » A free, online educational resource to help healthcare professionals and patients improve patient adherence to multiple long-term medications.
- » The Irish Practice Nurses Association have encouraged their members to take the course.
- » The Irish College of General Practitioners have approved the course for conferring a continuous medical education credit for GPs.
- » The e-learning package is now being used in NUI Galway and being offered externally for Continuing Medical Education.

Dr Gerard Molloy, Lecturer at the School of Psychology, NUI Galway, says:

"One of the real strengths of this HRB project was to work with patients and healthcare professionals on the course content, and to hear about the real-life experiences they have."

See: [www.aminuteforadherence.ie](http://www.aminuteforadherence.ie)



TILDA has built a rich bank of evidence about growing old in Ireland, and with @hrbireland support it is influencing policy, practice and new research

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### In summary

In the early 2000s, we had very little health, economic and social data for the ageing population in Ireland. This meant we could not develop policies or plan for the future based on evidence.

Starting in 2006, TILDA (The Irish Longitudinal Study on Ageing) began a pilot to collect such information in a systemic way from a nationally representative group of people aged over 50 years. The result is a rich, national database that is influencing policy, and helping to support the older population in Ireland. TILDA was originally funded primarily through the Department of Health, Atlantic Philanthropies and Irish Life and has been supported by additional grants, including funding from the HRB.



## TILDA: Towards making Ireland the best place in the world to grow old

Lead Researcher: Professor Rose Anne Kenny, Trinity College Dublin

### The problem

Before TILDA started, we had little data about the health, economic and social activity of the ageing population in Ireland.

### The project

Since 2009, TILDA has routinely collected information on health, economic and social circumstances from people in Ireland over the age of 50.

### The outcomes

- » Ireland now has a core dataset on a nationally representative, longitudinal sample of people aged 50 and over in Ireland, to examine the principal influences on successful ageing.
- » TILDA has been cited in 70 Oireachtas documents, and its findings have been used in 52 policy and strategy documents.
- » TILDA has already engaged with thousands of older people through talks and events and has now partnered with the GAA to reach more communities around Ireland.

Professor Rose Anne Kenny, Professor of Medical Gerontology at Trinity College Dublin and Principal Investigator at TILDA, says:

“Because of TILDA we have been able to make differences to Irish policy and to craft important new research to inform a better understanding of the aging process and a better knowledge of risk factors for common age-associated disabilities and potential new interventions to prevent disability. Ireland now has a dataset that is of national and international import, which continues to influence health campaigns and policy in Ireland and reach new communities.”

### Some recent practical examples of TILDA research being put into practice include:

- » TILDA found that two thirds of older people have high blood pressure. HRB funding supported a nationwide programme to encourage more frequent blood pressure monitoring.
- » TILDA revealed that one in three older adults cannot cross the street in the time allotted at signalised crossings. This is leading to signal timing settings being assessed and public safety campaigns with the Road Safety Authority.
- » TILDA found that 20% of men aged over 80 years have a heart issue called atrial defibrillation. The Irish Heart Foundation translated these findings into a national awareness campaign and the National Screening Programme Guidelines now use TILDA data.



@hrbireland developed a publishing platform and national framework to make research findings and data more open, transparent and accessible

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### In summary

When research is 'open', that means that its data and findings are transparent and freely accessible where possible so that others can use and build on them. The HRB is committed to ensuring that its funded research is open, accessible and usable, so it can have the greatest possible impact. This includes, among other approaches, publishing findings on platforms that are free to the public and gathering data in a way that others can access and use it. Through widespread engagement and HRB guidance, the Irish Government has published a national framework to guide Ireland on open research.



## Opening up research for greater health impact

Researcher: Dr Patricia Clarke, HRB

### The problem

If research findings or data are not easily accessible and useful, it can slow down the progress or impact of health research.

### The project

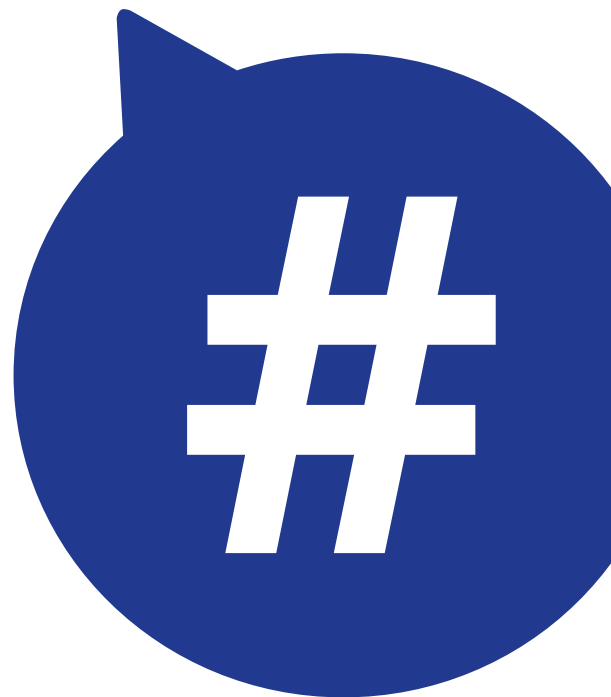
The HRB launched an open platform for publishing all findings, with F1000 publishers and worked with stakeholders in research (including universities and Government departments) to develop a framework for open research in Ireland.

### The outcomes

- » A national framework for open research in Ireland, that provides clarity and guidance for making research more open and aligned with European open research initiatives.
- » An open publishing platform for HRB-funded research publications that allows quick publication and open, transparent access, including open peer review.
- » A proof-of-concept call for enabling a data linkage environment for health and related research in Ireland.
- » Numerous public events to promote awareness of open research in Ireland.

Dr Patricia Clarke, Programme Manager for Policy and EU Funding, HRB, says:

"At the HRB we have been working with others to build a framework and system of open research in Ireland, which means that more people can engage with research and drive outcomes that will ultimately improve health and patient care."



@hrbireland has reviewed healthy workplace initiatives in Australia, Canada, New Zealand, Scotland and the USA to inform a national programme in Ireland

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### In summary

The workplace can be an ideal place to engage people, providing information on how to change their behaviours to improve their health. The Department of Health is developing a national healthy workplace framework for Ireland, in conjunction with the Department of Enterprise, Business and Innovation. To support this, the HRB was commissioned to carry out a review of healthy workplace initiatives in five English-speaking countries outside Ireland. The findings will inform how national healthy workplace tools are delivered in Ireland.



## Healthy workplace programmes: lessons from abroad

Researchers: Dr Anne McCarthy, Joan Quigley, Dr Jean Long, HRB

### The problem

Ireland is developing a national healthy workplace framework and can learn from the experience of other countries.

### The project

The HRB reviewed healthy workplace initiatives in Australia, Canada, New Zealand, Scotland and the USA.

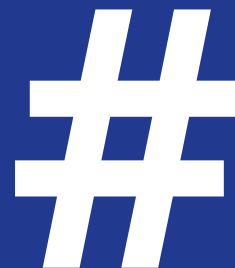
### The outcomes

- » A report showing how the five countries adopt a range of tools to implement healthy workplace initiatives, including surveys, print and social media and face-to-face engagement.

- » Evidence to inform the National Healthy Workplace Framework and implementation plan, and data to make the business case for healthy workplace programmes in Ireland.
- » Information to build an accreditation programme for trainers in healthy workplace initiatives in Ireland.

Dr Anne McCarthy, Senior Researcher, HRB Evidence Centre, says:

“By finding out how national healthy workplace programmes are funded, designed and implemented in other countries, we have been able to provide a resource to help inform such programmes in Ireland.”



A @hrbireland project @tcddublin found new immune cells in the liver and clues about their role against cancer

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### In summary

Our immune systems can help to protect us against cancer, but cancer treatments that look to support the immune system are not always successful in the liver. To explore this, researchers at Trinity College Dublin looked at cancerous tumours that had spread from the gut to the liver. They found a previously unknown type of immune cell in these samples, and high levels of a substance called lactic acid. Also, patients who had higher levels of immune cells tended to live longer. The results are now informing a new study on immune-based therapy with patients in Ireland who have liver cancer.



## New clues about the liver, the immune system and cancer

Researchers: Professor Cliona O’Farrelly, Dr Cathal Harmon, Dalal Almuaili, Trinity College Dublin

### The problem

Many new treatments for cancer target the immune system, but these ‘immunotherapies’ are not so successful in the liver, particularly when the cancer has spread from the colon, or gut, to form secondary cancers called colorectal metastases.

### The project

The project analysed liver tissue and tumours from patients at the National Liver Transplant Centre at St Vincent’s University Hospital (SVUH), who had surgery to remove tumours that had spread from their guts to their livers. The scientists examined the immune system cells present in the liver around the tumours.

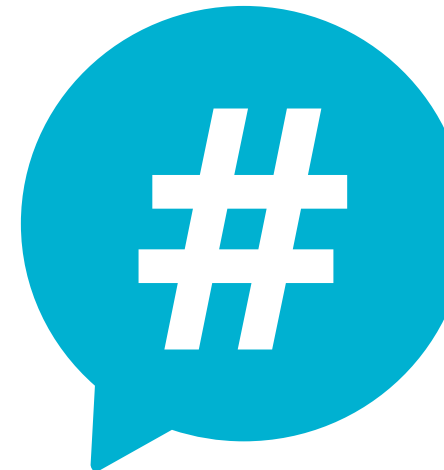
### The outcomes

- » The study discovered a new type of ‘natural killer’ immune cell in the liver and high levels of lactate around the tumours. These findings are informing a clinical trial with patients at SVUH.
- » We now know that patients have better outcomes from colorectal metastases when they have lots of immune cells in their liver.
- » A HRB-Knowledge Exchange and Dissemination (KEDS) award supported two public debates at Trinity about the liver’s immune system, which were attended by hundreds of people.

- » Another HRB-KEDS award enabled a Transition Year programme at Trinity where 20 secondary school students learned about cancer, cell biology, the liver and the immune system.

Professor Cliona O’Farrelly, Professor of Comparative Immunology at Trinity Biomedical Sciences Institute, says:

“The liver has a unique and complex immune system, and we wanted to understand more about how that system behaves around liver cancers that have spread from the gut. Our basic research findings are exciting, because they point towards potential new ways to help make immunotherapies in the liver more successful against cancer.”



Research misconduct and poor practices can damage healthcare. @hrbireland contributes to policy and mandates training for its researchers in research integrity

#HRBResearchInAction

### In summary

Research improves health and lives, so it is important that research is of high quality and as accurate as possible. Serious cases of misconduct in research, such as someone fabricating results, are rare. Poor practices are more common: perhaps something 'has always been done this way' in a lab, or old protocols have not been updated. The HRB takes an active role in building research integrity in Ireland and in Europe, including contributing to national policy and facilitating training and opportunities for researchers to improve their awareness and practice of research integrity.



## Research gets an integrity boost

Researcher: Dr Maura Hiney, HRB

### The problem

Research can be compromised by fraudulent practice. Poor or sloppy research behaviours are less serious, but may affect as much as 30-40% of research.

### The project

The HRB has contributed to policy development on research integrity in Ireland and Europe, and has encouraged all research funding awardees to undertake training on research integrity.

### The outcomes

- » Research integrity training will be mandatory for all HRB-funded researchers from the end of 2019.
- » Dr Maura Hiney from the HRB chaired an update of the European Code of Conduct, which is now being used around the world as a guide to improve research integrity.
- » Dr Hiney is also on the National Research Integrity Forum, which has published a national policy for Ireland on research integrity.

Dr Maura Hiney, Head of Post-Award and Evaluation at the HRB, says:

"I am one of several people in Ireland working together to improve research integrity. By increasing awareness and training, we hope to reduce the incidence and sharing of poorly produced results, which will in turn improve the quality of evidence for informing healthcare."



Can we build health literacy in primary school children aged 8-12? Researchers @HRBTMRN have explored how to use materials in the classroom

#HRBResearchInAction

### In summary

We are bombarded with statements and claims about what is 'healthy' and what is not. For children, learning to approach such claims critically and understand what is behind them could encourage life-long health literacy. HRB-funded researchers at NUI Galway took a health literacy education programme developed in Norway and tested it out in Irish primary schools. Their findings lay the foundation for embedding health literacy and critical thinking about health into the Irish primary school curriculum.



## A primary-school approach to thinking about health claims

Researchers: Dr Linda Biesty, Dara Glynn, Professor Declan Devane, NUI Galway

### The problem

As a society we are exposed to claims made about health on product labels, ads, media and social media. If young children can develop skills to assess and understand such claims, it will boost their health literacy now and into the future.

### The project

Researchers at NUI Galway began with a book and 8-week health literacy programme developed in Norway for children in Uganda. The researchers worked with primary school children (aged 8-12) and teachers to see whether and how the material could be used in the Irish context.

### The outcomes

- » To date, 60 children and 3 teachers have engaged with the Informed Health Choice programme materials. The resources and programme have been reviewed by 10 experts in the space of primary school education in Ireland.
- » Children liked the Ugandan story and wanted to add Irish examples – such as figuring out whether a dock leaf is good for nettle stings.
- » Teachers wanted support with their own health literacy so they could deliver the programme.

- » Teachers suggested reflective exercises with parents, and a whole-school approach to build wider awareness and health literacy beyond the 8-12 year olds.

Dr Linda Biesty, NUI Galway researcher with the HRB-Trials Methodology Research Network, says:

“If we want people to be able to engage with health claims and make informed choices about the healthcare options that are presented to them, we have to develop the right skills early. Thanks to this project, we now have lots of insights into how to deliver a primary-school education programme in Ireland to build children’s critical thinking skills around health information.”



@hrbireland-funded research at @UL has shown acute kidney injury has risen in hospital patients in Ireland

#HRBResearchInAction

### In summary

When a person becomes acutely ill and requires hospitalisation, the conditions they have or the treatments that they receive could result in sudden kidney damage. Little was known about how many patients in hospital in Ireland experience Acute Kidney Injury (AKI), or its complications. In a HRB-funded project, researchers at the University of Limerick discovered that AKI is extremely common in Ireland and has risen substantially over the past decade. The project has informed national policy on the scale of the problem and its consequences. It has also set in motion new strategies to identify AKI early on, so that patients can get appropriate preventive treatments.



## Acute Kidney Injury on the rise in Ireland

Lead Researcher: Professor Austin Stack, University of Limerick

### The problem

Little was known about how many patients in the Irish hospital system experience Acute Kidney Injury and its effects.

### The project

Researchers at UL analysed blood levels of creatinine (a marker of kidney function) in more than 451,000 patients from the mid- and north-west of Ireland between 2005 and 2014 to identify cases of Acute Kidney Injury, even where the patient had not been diagnosed with the condition.

### The outcomes

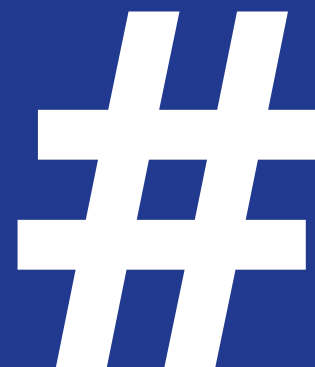
We now know that:

- » Acute Kidney Injury in hospitalised patients in Ireland rose from 5.5% in 2005 to 12.4% in 2014.
- » In 2014, more than 1 in 8 patients in the Irish hospital system had AKI.
- » Older patients and men are more likely to experience AKI.

- » AKI is associated with increased risk of dialysis and death.
- » The study prompted a new project to build an alert into the hospital blood test system to highlight when a patient has AKI. This will lead to earlier detection and more rapid intervention.

Professor Austin Stack, Consultant Nephrologist at University Hospital Limerick and principal investigator for the UL Kidney Health Consortium, says:

“Through this HRB-funded research we have shone a light on a significant problem in the Irish health system that is growing year by year. Now we can take the next steps to alert the medical team when a patient is experiencing Acute Kidney Injury and ensure prompt intervention.”



Research @hrbireland shows alcohol is a factor in half of fatal fires in Ireland, and older people, single people and rural dwellers are at higher risk of dying in house fires

#HRBResearchInAction

### In summary

Between 2014 and 2016, more than 100 people in the Republic of Ireland died in house fires. By looking at closed coroner files, HRB researchers found that people aged 65 or older, farmers/agricultural workers and smokers are over-represented among fire fatalities in Ireland. The analysis also showed that alcohol had recently been consumed by more than half of people who died in house fires in Ireland. The data will help to inform trends and policies for fire prevention and safety in Ireland.



## Fire deaths in Ireland: who is at higher risk?

Researchers: Anne Doyle, Dr Suzi Lyons, Ena Lynn, HRB

### The problem

Fire deaths in Ireland are decreasing, but people still lose their lives in fires here each year. Understanding more about the contributory factors can inform prevention and safety measures.

### The project

In July 2015, the Department of Housing, Planning and Local Government (then the Department of the Environment, Community and Local Government) asked the HRB to collect data on all fire-related fatalities. The HRB reviewed closed coroner files on 101 fires with 106 fire-related fatalities recorded between 2014 and 2016.

### The outcomes

- » The first analysis of closed coroner files from all of Ireland for fire deaths.
- » Awareness that in Ireland people over the age of 65 years, those living alone, men and those living in rural areas are at higher risk of dying in residential fires.

- » Evidence that alcohol was present in more than half of fire fatalities in Ireland.

Anne Doyle, Research Officer with National Health Information Systems, HRB, says:

“The data from Coroner files helps to provide a more complete picture of the circumstances and trends surrounding fires. This can support the development of policies to reduce the number of such deaths in the Republic of Ireland.”



@hrbireland research at @tcddublin identified how hospital design can help reduce distress for people with dementia

#HRBResearchInAction

### In summary

Hospitals are complex and confusing environments for people with dementia, adding to distress and disorientation. Researchers at TrinityHaus Research Centre, Trinity College Dublin and Tallaght University Hospital carried out an extensive study of hospital design in Ireland, and identified areas that could be improved in existing hospitals or in future designs. They include clearer signage and pathways, reducing harsh lighting and noise and dedicating more space for social engagement and mobilisation.



## How to design more dementia-friendly hospitals

Lead Researchers: Professor Desmond O'Neill, Thomas Grey, Trinity College Dublin

### The problem

Hospital design can negatively affect people with dementia.

### The project

Researchers gathered information about hospital design in Ireland, with deeper studies at Tallaght University, Naas General, and Peamount Hospitals, interviewing management, staff, patients and family members.

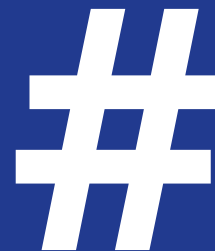
### The outcomes

- » The first analysis in Ireland of whole-hospital design considering people with dementia and their carers.
- » The first dementia-friendly survey in the world of hospital facilities and technical managers.
- » The study identified key ways to improve design, including more space for sitting, clear signage and the reduction of noise.

- » A set of design guidelines for new build and retrofit in Irish hospitals called Dementia-Friendly Hospitals from a Universal Design Approach Manual for new builds and retrofits in Irish hospitals.
- » A follow-on HRB Cochrane systematic review of evidence for dementia-friendly design in in-patient wards.

Professor Des O'Neill, Consultant physician in geriatric and stroke medicine and Professor in Medical Gerontology, Tallaght University Hospital and Trinity College Dublin, says:

"We took a whole-hospital approach to examining design, we mapped out the pathways that people with dementia take and we spoke with patients and staff. Addressing the design issues that we highlighted – more seating, reduced noise and better wayfinding – will help not just people with dementia but everyone in the hospital."





@hrbireland research identified interventions between community and hospitals that could reduce pressure on acute hospitals

#HRBResearchInAction

### In summary

Acute hospitals, where patients go to be treated for emergency cases, short-term illness and surgery, are under pressure. The Department of Health asked the HRB to review the evidence for integrated interventions to reduce this pressure. Integrated interventions work across acute and community settings to reduce unplanned admissions to hospital, readmissions, length of stay in hospital, emergency department visits and healthcare costs. The review identified promising approaches targeting chronic disease, and highlighted the need for greater research on interventions that focus on elderly people.



## How can we reduce pressure on acute hospitals

**Researchers:** Martin Keane, Dr Camille Coyle, Louise Farragher, Dr Gerald O’Nolan, Dr Aoife Cannon and Dr Jean Long, HRB

### The problem

Acute hospitals in Ireland are under pressure. This can lead to delays for patients seeking treatment.

### The project

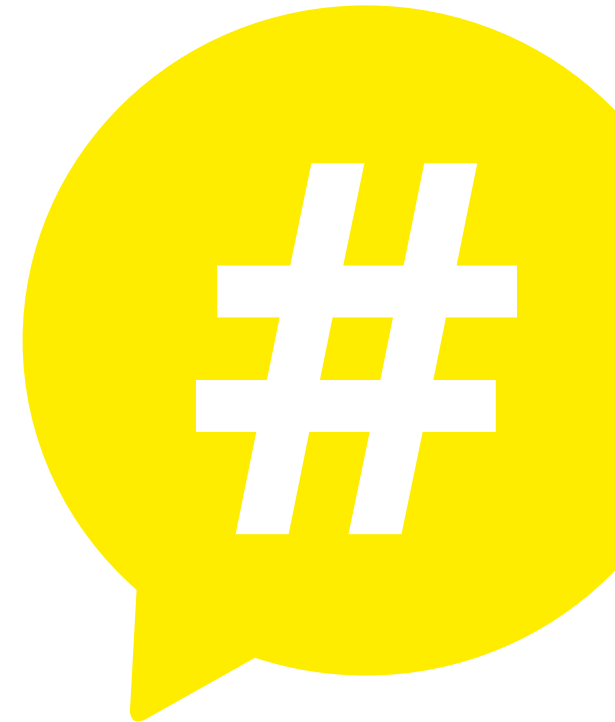
The HRB analysed 36 published systematic reviews and one umbrella review of integrated interventions and pressure on acute hospitals.

### The outcomes

- » The study identified several promising interventions relating to chronic diseases and some surgeries.
- » For chronic diseases, self-management demonstrated good effectiveness, while others such as managing discharge, treatment at home and telemedicine were moderately effective.
- » There was a lack of studies on interventions specifically focused on older people.

Dr Camille Coyle, Research Officer at the HRB Evidence Centre, says:

“Through this study, we found evidence for interventions that could effectively reduce pressure on acute hospitals, particularly relating to chronic conditions. We also highlighted the need for more research on interventions focused on older people and how to implement interventions in practice.”



@HRBTMRN supports researchers in Ireland to consider the methods used in randomised trials and boosts public awareness of randomised trials

#HRBResearchInAction

### In summary

Randomised trials are important for testing potential new treatments before they are approved for wider use. It is important to design and carry out clinical trials so they can yield the most accurate and useful results. In 2014, the HRB funded a group of experts to set up a network in Ireland to help improve and strengthen clinical trial design and practice. The HRB Trials Methodology Research Network has successfully worked with several researchers in Ireland to improve trial methods and processes. The Network also engages with the public to increase general awareness and understanding about clinical trials.



## How to do a better clinical trial: HRB network boosts quality and awareness

Researchers: HRB Trials Methodology Research Network team

### The problem

Clinical trials are important, but if they are not designed and carried out using the best methods, they may not provide accurate and useful information about the new treatments they test.

### The project

Since 2014, the HRB Trials Methodology Research Network has built a group of experts in Ireland to support people who are designing and carrying out clinical trials.

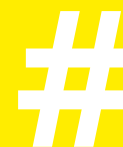
### The outcomes

- » More than 11,000 people in Ireland have undergone training about trials methods and research.
- » The Network communicates with 2,500 people regularly and has more than 3,000 followers on Twitter.
- » Through the Network's START initiative, 45 randomised trials have been carried out by primary school children in Ireland.

- » The People's Trial in 2019 has encouraged members of the public to come up with fun and engaging questions to test in health-related trials, reaching people in 90 countries.

Dr Sandra Galvin at NUI Galway, National Programme Manager for the HRB Trials Methodology Research Network, says:

“One of our biggest challenges when we set up the HRB-TMRN was the culture shift, getting people to understand that trial methodology is its own area of research. We fund research on trial methods, we have trained thousands of people in this area and we are seeing members of the public of all ages getting a deeper understanding of how trials work and how to decipher health information.”



@hrbireland research  
@UCC has identified ways to  
develop greater breast health  
awareness among women with  
intellectual disability

#HRBResearchInAction

### In summary

Women with intellectual disability (ID) tend to have limited understanding about how to check their breasts for signs of cancer. This can mean that if they develop the disease, it is not diagnosed early and the outcome can be worse for the woman.

A HRB-funded project at University College Cork engaged with women with ID, their families and health professionals about breast cancer and health. From this the multi-disciplinary researchers identified several important factors that will support a future, technology-enhanced health awareness programme.



## Breast cancer and health: how can we support women with intellectual disability?

Researcher: Susan Walsh,  
University College Cork

### The problem

Women with ID who develop breast cancer tend to be diagnosed at a late stage of the disease. If they had greater awareness of breast checking and health, it could lead to earlier diagnosis and better outcomes.

### The project

Research at UCC identified a lack of evidence-based awareness programmes around breast health and breast cancer in women with ID. The researchers spoke with 14 women who have mild to moderate ID, families of women with ID and health professionals working in ID or cancer.

### The outcomes

The project identified that a breast cancer awareness programme for women with ID should:

- » Target information to the women, their families and supporting health professionals.
- » Minimise the focus on cancer, as it invokes fear among the women and their families.
- » Offer simple information about breast health, checking and healthy lifestyle in general.

- » Deliver the information in different formats – text, pictures and props – that can be used as appropriate for the women.

Susan Walsh, Specialist Breast Check Nurse and researcher, says:

“There are around 11,600 women in Ireland with ID, and we want them to be aware of breast health from early adulthood onwards wherever possible. The HRB project has allowed us to find out some of the best ways to present that information so that it engages women with ID effectively and hopefully leads to earlier diagnoses and better outcomes for them.”



A personalised exercise and nutrition programme improves fitness and confidence in patients following oesophageal cancer, says @hrbireland research at @tcddublin

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### In summary

In recent decades, the likelihood of surviving cancer of the oesophagus (the tube that links the mouth and stomach) has increased, but little is known about the specific rehabilitation that best suits survivors of oesophageal cancer. The HRB-funded Rehabilitation Strategies in oesophagogastric Cancer (RESTORE) trial at Trinity College Dublin and St James's Hospital developed and ran a nutrition, exercise and education programme for people who had undergone treatment for oesophageal cancer. The programme improved fitness and confidence and reduced fatigue. A larger trial is now in preparation.



## RESTORE: What rehab helps patients after oesophageal cancer?

Researchers: Linda O'Neill, Dr Emer Guinan, Professor Juliette Hussey, Trinity College Dublin

### The problem

We know little about what specific rehabilitation works well for people who have had oesophageal cancer and treatment.

### The project

The RESTORE trial tracked 44 people who had previously undergone treatment for oesophageal or stomach cancer. Half of the participants attended 14 supervised exercise classes, individual appointments with a specialist dietitian, and eight education sessions, and they wore a heart monitor while doing personalised exercises in between the classes.

### The outcomes

- » The rehabilitation programme increased cardiovascular fitness and reduced fatigue in people post-oesophageal cancer, while maintaining a stable weight.

- » Taking part in the rehabilitation offered social support, and led to stronger confidence and getting back to pre-cancer activities.
- » A larger trial involving 120 people will take place starting in early 2020.

Professor Juliette Hussey, Professor of Physiotherapy at Trinity College Dublin, says:

"We have seen a huge emphasis on rehabilitation and exercise for patients following breast, prostate or colon cancer. Through this project, we have been able to evaluate a holistic approach to rehabilitation for patients who have had oesophageal cancer, to help improve their quality of life in the longer-term following treatment."

“

I just go out, maybe I go to the shop – I don't buy anything but I just get out of the house – and I come back fresh as a daisy!

“

It gave you an idea that there is a good living, you can live good now after it [treatment]. The negativity is gone in me – I can't say 'I'm not able' or 'That's wrong if you do that, you're lifting too much or you're doing too much'. You can do it.

@hrbireland supports researchers on different career paths to build flexibility and capacity in health research

#HRBResearchInAction

### In summary

Health research benefits from being carried out by people who have different backgrounds, interests and experiences. The HRB has been restructuring its funding initiatives to ensure that awards can support researchers in different career stages and paths, including academic-based researchers and health and care practitioners. The resulting initiatives are empowering people, through their research, to build workforce capacity in health research in Ireland.



## Health research funding: tailored to support diverse careers

Researcher: Dr Annalisa Montesanti, HRB

### The problem

If health research is carried out only by people with particular skill-sets or experience, it restricts the scope and application of that research.

### The project

Since 2016, the HRB has developed a strategy to ensure that HRB funding can support people in diverse career paths. This involved identifying core principles in research (such as open science, cross-disciplinarity, collaboration and training), talking with researchers to learn more about the challenges they face, and redesigning or refining funding calls.

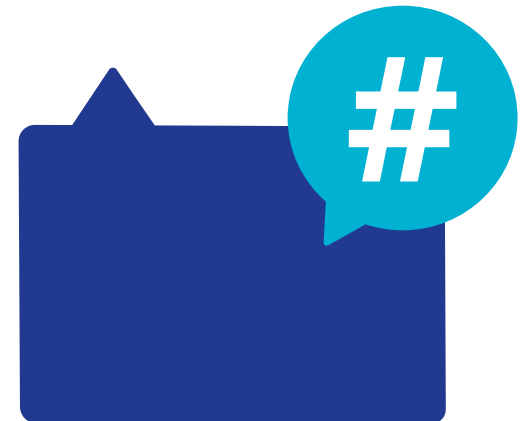
### The outcomes

- » Funding to support two career pathways for either health and care practitioners or academic-based researchers or in some instances both.
- » A Research Leaders Award scheme to provide 7.5 million Euro to support up to five researchers in academia to build capacity in their field and transition to research leadership in health research.

- » HRB-funded post-doctoral researchers will spend time in healthcare settings, to enrich their research and prepare them for a wide range of future opportunities.

Dr Annalisa Montesanti, Programme Manager, HRB, says:

“As a funding agency we support not only academic researchers but also people working in healthcare settings such as doctors, nurses, pharmacists, dentists, and health and care professionals. By developing a new strategy and creating new paths for funding, we are able to attract and support a more diverse range of researchers.”



The @hrbireland SPHeRE programme has trained more than 65 researchers in population health and health services research and built a national network

#HRBResearchInAction

### In summary

The Structured Population and Health-services Research Education (SPHeRE) programme is Ireland's national PhD research training programme for population health and health services research (PHHSR). Funded by the HRB, it is driven by the Royal College of Surgeons in Ireland, Trinity College Dublin and University College Cork, and has collaborators in all other universities in the Republic of Ireland. Since 2013, the SPHeRE programme has graduated more than 65 PhD researchers in PHHSR, with an additional 55 scholars currently registered. Crucially, SPHeRE has built a national network of PHHSR researchers alongside health policy makers and practitioners. The majority of SPHeRE graduates are now working in health research, health services, or academia in Ireland.



## SPHERE: Building health services and population health research in Ireland

Lead Researcher: Professor Anne Hickey, Royal College of Surgeons in Ireland

### The problem

Ireland needed to build capacity in research relating to population health and to health services.

### The project

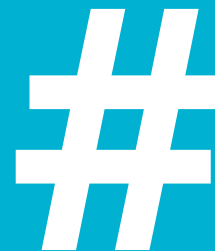
The HRB-funded SPHeRE programme was set up to deliver structured PhD programmes and build a national network of researchers in population health and health services.

### The outcomes

- » More than 65 PhD graduates trained in PHHSR, most of whom are now employed in Ireland.
- » A national network of researchers in population health and health services.
- » Modules, seminars and workshops are also available to non-SPHeRE researchers, to maximise impact of PHHSR.

Professor Anne Hickey, Director of the SPHeRE programme, says:

"In Ireland, we needed to build capacity in health services and population health research. The HRB identified this gap and their strategic vision allowed us to build this programme. We have been consistently oversubscribed with each intake of students every year, with annual cohort numbers continuing to increase."



@hrbireland-funded work at @ucddublin progressed gene therapy research for the painful skin condition EB

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### In summary

An estimated 500,000 people worldwide are affected by the painful condition epidermolysis bullosa (EB), sometimes known as butterfly skin disease, where the skin breaks at the slightest touch. People with a type called recessive dystrophic epidermolysis bullosa lack enough collagen VII to keep skin anchored.

HRB-funded researchers at University College Dublin developed a polymer that can carry the gene for collagen VII and deliver it to the skin. The gene-delivery system was tested in the lab and the technology has been licensed by a biopharmaceutical company to bring it towards the clinic.



## Towards new therapies for 'butterfly skin' disease

**Researchers:** Professor Wenxin Wang, Dr Yixiao Dong, Dr Udo Greiser and Dr Irene Lara-Sáez, Charles Institute of Dermatology, University College Dublin. **Collaborators:** DEBRA Ireland and Dr Fernando Larcher Laguzzi, CIEMAT Madrid (Spain)

### The problem

People with recessive dystrophic epidermolysis bullosa cannot make enough collagen VII, meaning their skin blisters, peels, wounds and becomes infected easily.

### The project

Researchers at UCD developed a polymer-based technology that can carry the collagen VII gene and deliver it to the skin.

### The outcomes

- » A prototype technology that can deliver collagen VII genes to the skin, to help reduce skin tearing and wounds.
- » The technology has been licensed to a Dublin-based biopharmaceutical company.
- » The research paved the way to develop a gene-editing system to address EB, which is a finalist for the 2019 Science Foundation Ireland Future Innovator Prize.

Dr Irene Lara-Sáez, Post-doctoral Researcher at UCD Charles Institute, says:

"The HRB funding allowed us to carry out research on the gene-delivery system and better understand the biology of it. That work is now enabling exciting steps towards better treatments for people with EB."



@hrbireland research at @nuigalway finds that membrane sweeping may help avoid induction of labour in late pregnancy

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### In summary

At the end of pregnancy, clinicians can help trigger a woman's labour using specific drugs. But there is another, less resource-intensive way: during an examination, the clinician can 'sweep' the membrane at the neck of the woman's womb.

Researchers at NUI Galway carried out a Cochrane systemic review of published studies, and found with low certainty that women who underwent membrane sweeping were less likely to need formal induction of labour involving drugs. This has prompted a new study of membrane sweeping in two maternity hospitals in Ireland.



## Membrane sweeping to induce labour: how well does it work?

Researchers: Elaine Finucane, Professor Declan Devane, NUI Galway

### The problem

Formal induction of labour involves drugs and the woman staying in hospital. Membrane sweeping may offer a less resource-intensive approach to triggering labour, but the evidence for its effectiveness had not been updated since 2006.

### The project

Researchers at NUI Galway carried out a Cochrane systematic review of the global body of evidence on membrane sweeping, updating the records.

### The outcomes

- » The systematic review on membrane sweeping to trigger labour has been updated and can now inform clinical guidelines.
- » The work suggests, with low certainty, that women who had a membrane sweep were more likely to go into spontaneous labour and less likely to need formal induction.
- » A new feasibility study in Limerick and Dublin (Coombe) maternity hospitals to evaluate the effectiveness of membrane sweeping, at different times and frequency, to prevent post-term pregnancy.

Elaine Finucane, midwife, Cochrane fellow and research associate in the Centre for Health Evaluation, Methodology Research and Evidence Synthesis (CHEMRES), NUI Galway, says:

"Membrane sweeping is a simple approach for women and clinicians that can help to avoid a more resource-intensive induction of labour. We have updated the Cochrane systematic review on membrane sweeping, and we hope to build on that to provide more evidence-based healthcare in the maternity services."





A @hrbireland study at @ucc is building awareness of parent-child interaction therapy for speech and language in children with Down Syndrome

#HRBResearchInAction

### In summary

Ireland has one of the highest incidences of Down Syndrome in the world. Children with Down Syndrome are delayed in learning language and speaking, and building their communication skills early on could increase their chances of greater independence later in life. A HRB study at University College Cork examined the published evidence for programmes that train parents to support early language development in children with Down Syndrome. It found the approach improves parent-child interaction and the analysis is now informing more intensive interventions for speech and language.



## The parent's potential in speech and language support for children with Down Syndrome

Researcher: Dr Ciara O'Toole, University College Cork

### The problem

A speech and language intervention that trains parents to support their children is called parent-child interaction therapy. There has been little research about the outcomes of such programmes for children with Down Syndrome.

### The project

The project at UCC involved a systematic review, or study of published, randomised controlled trials to measure the outcomes of parent-child interaction therapy for speech and language where the child has Down Syndrome. It included three studies involving 45 children.

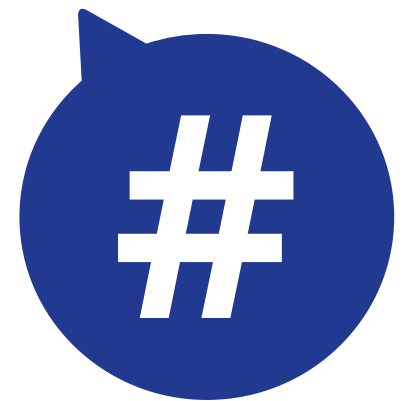
### The outcomes

- » We now know that parent-child interventions for speech and language improve interactions between parents and their children with Down Syndrome.
- » Focus groups or 'cafes' linked to the project encouraged parents of children with Down Syndrome to identify areas of research they would like to see prioritised.
- » A HRB conference grant supported a linked day-long conference at UCC, where more than 100 delegates (parents and clinicians) learned about speech and language therapy for Down Syndrome.

- » The findings were presented in a 2018 talk at the World Congress of Down Syndrome in Glasgow.
- » More evidence is needed to say whether such interventions reliably improve speech and language in children with Down Syndrome, possibly because the current interventions are too short and non-intensive.
- » Down Syndrome Ireland has funded a Master's project to adapt current parent-child interaction therapy to better suit children with Down Syndrome.

Dr Ciara O'Toole of the Department of Speech and Hearing Sciences at UCC says:

"Based on this study we are looking to build up speech and language therapy approaches that train parents of children with Down Syndrome, and we hope to test more intensive interventions in Ireland in the future."



@hrbireland gathered international information about barriers, facilitators and impacts of regionalised healthcare systems to inform Irish plans

#HRBResearchInAction

### In summary

Regional health organisations offer a way of providing health services to meet local needs. The Department of Health asked the HRB to carry out systematic reviews of the impacts of regional health organisations in other countries, as well as the key barriers to and facilitators of regionalisation. The study showed some evidence that a regional approach can ultimately lead to a healthy population and an efficient health system. However, it also highlighted the complexity of such systems. The findings have been used to map and implement regional health organisations in Ireland.



## Going regional: evidence for meeting local health needs

Researchers: Joan Quigley, Dr Camille Coyle, Claire O'Dwyer, Dr Gerald O'Nolan, Louise Farragher, Dr Jean Long, HRB

### The problem

Ireland was considering creating regional health organisations, and the Department of Health commissioned the HRB to carry out research on international practice and outcomes.

### The project

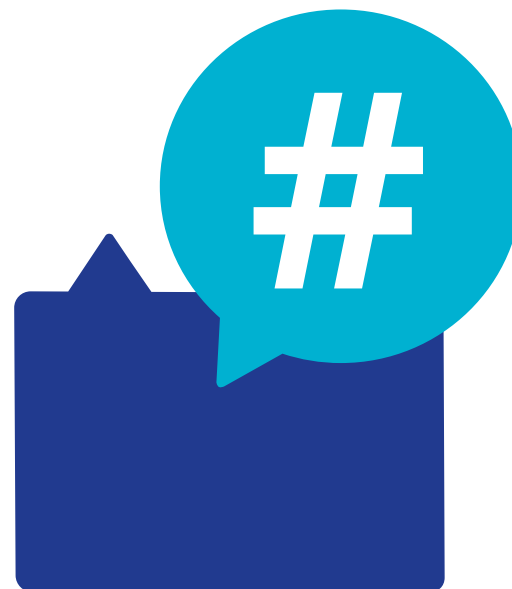
The HRB carried out systematic reviews of barriers, facilitators and impacts of adopting regional health organisations in OECD countries.

### The outcomes

- » The study provided evidence that regional healthcare organisations can improve health and healthcare efficiency.
- » The HRB evidence review of regionalised healthcare organisations has been cited in the Sláintecare implementation plan.
- » The HRB's analysis informed the mapping of Irish regional health organisations and their phased implementation.

Ms Joan Quigley, Research Officer, HRB Evidence Centre, says:

"We carried out this review when regional healthcare organisations were being considered for Ireland. Being able to learn from international experience helped to inform how those regional healthcare organisations were planned."







**#HRBResearchInAction**

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