

# Health Research in Action

Research. Evidence. Action.

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# Introduction

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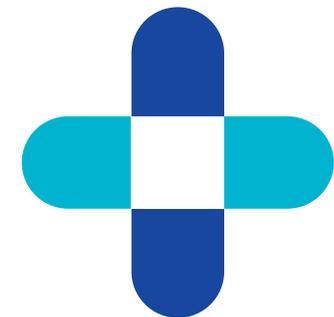
**The Health Research Board (HRB) is Ireland's lead public funding agency supporting innovative health research and delivering data and evidence that improves people's health and patient care. We are committed to putting people first, and ensuring data and evidence are used in policy and practice to overcome health challenges, advance health systems, and benefit society and economy.**

This year's *Health Research in Action* highlights some of the many notable impacts and outcomes of our work during 2020. Firstly, we present a timeline providing an overview of our huge contribution to Ireland's efforts to combat COVID-19. This includes funding and enabling clinical trials to evaluate treatments, supporting research into medical, social and policy countermeasures, and providing evidence reviews to inform policy.

Secondly, we provide a snapshot in numbers of other work completed in 2020, followed by 22 success stories of wide-ranging health and social care research across four themes. That all of this was achieved despite the challenges of COVID-19 makes it even more impressive. It

also further highlights the importance of health research, not just in the fight against COVID-19, but for the health and wellbeing of society and economy overall.

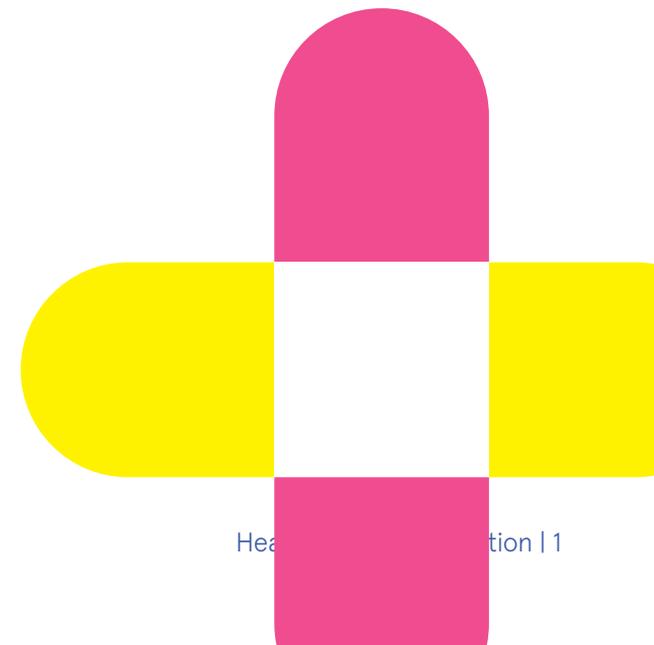
Thanks to science writer Dr Claire O'Connell and our valued HRB and HRB-funded researchers for helping us compile this. Sincere acknowledgement also to the public, patients and carers, as well as the health and social care professionals, that make so much of our work possible.



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# The HRB's key initiatives in response to the COVID-19 pandemic during 2020



## March

- Facilitated a smooth transition to remote working by ensuring excellence in information and communications technology (ICT) and facilities
- Collaborated with the Irish Research Council (IRC) and Science Foundation Ireland (SFI) to co-fund a national COVID-19 Rapid Response Research, Development and Innovation programme
- Committed to data sharing in public health emergencies – a development expedited by COVID-19
- Began delivering evidence products to inform policy and practice
- Supported and funded Ireland's participation in the REMAP-CAP response to the COVID-19 pandemic
- Optimised HRB Open Research



## April

- Established a temporary National Research Ethics Committee for COVID-19 research
- Supported the Health Research Consent Declaration Committee's COVID-19 activity



## May

- Supported iHealthFacts, a new website to help people make well-informed health choices, particularly in relation to COVID-19





## June

- Supported Ireland's participation in Solidarity, the international clinical trial to help find an effective treatment for COVID-19, launched by the World Health Organization and partners

## September

- Co-funded the REMAP-CAP trial, which showed that a common steroid improves recovery and survival for critically ill COVID-19 patients

## November

- Recorded further success for the REMAP-CAP trial, after it was shown that a new treatment using an arthritis drug, tocilizumab, proved effective for the sickest COVID-19 patients

## August

- Began collaborating with the Department of Health and the Central Statistics Office to create safe access to COVID-19 data for research



## December

- Funded 14 additional projects jointly with the IRC under the COVID-19 Rapid Response Research, Development and Innovation programme
- Launched a funding call to establish a National COVID-19 Biobank

# HRB by numbers

- A snapshot of work completed in 2020

## The team managing our National Health Information Systems:

Serviced **101** requests for data

Published **6** peer reviewed journal articles

Published **4** annual reports and national bulletins on drugs and mental health

## The HRB Evidence Centre:

Completed **15** evidence products for the Department of Health:

**6** evidence reviews

**8** evidence briefs

**1** comprehensive search

## In terms of funding

# 59

## awards

completed in 2020,  
worth a total of

# €19,372,354

## This research resulted in:

# 44

new methods or materials (e.g. assays, databases, training materials)

# 10

healthcare innovations (e.g. medical devices, therapies or interventions)

# 77

influences on policy or practice (e.g. new clinical guidelines, policy reports)

# 229

engagements with public bodies and media

# 55

instances of public and patient involvement (PPI) in research



## Supported **137** research jobs

**47**  health and allied health professionals

**22**  biomedical scientists

**24**  social scientists

**18**  other scientists

**26**  other



## Significant academic outputs

**34** PhDs/MScs completed or in progress

**515** Peer-reviewed publications

**40** Non-peer reviewed publications

**621** Presentations at scientific conferences

**79** Academic collaborations with national colleagues

**68** Academic collaborations with international colleagues



## The economic impact

 Leveraged **€28,901,451** total funding on foot of these awards

 Negotiated **one** licence with industry

 Started **four** industry collaborations

 Filed **seven** patents

 Developed **one** spin out company

# Improving health behaviour and healthcare processes



# A psychological boost for changing health behaviours

Lead researcher: Professor Molly Byrne, NUI Galway

## The problem

Behaviours such as smoking, exercise and diet are closely linked with our health. So, it's important to include behavioural scientists when designing initiatives to promote good health. But traditionally they have not been involved.

## The project

Through a five-year HRB Leadership Award, Professor Molly Byrne created the Health Behaviour Change Research Group at NUI Galway, which has amassed research, expertise and training in Ireland in the areas of behaviours which are important in diabetes, heart disease and primary care (GPs, public health nurses, pharmacies etc).

## The outcomes

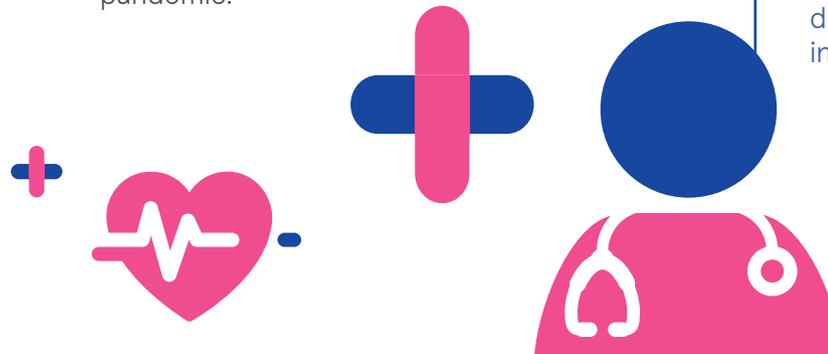
- The Health Behaviour Change Research Group (HBCRG) was established, and is now an international centre of excellence for behaviour change research
- Identifying and tackling barriers to people attending support programmes for diabetes

or rehabilitation following heart-related issues, and encouraging them to get the help needed to improve their health

- The HBCRG is delivering training on behaviour change to wider communities through partners, including Sport Ireland
- Researchers at the HBCRG are working closely with the Healthy Ireland Programme and the Health Service Executive (HSE) to implement a framework to train healthcare professionals in behaviour change and the importance of every interaction with patients
- The award has strengthened international networks and enabled Ireland take a leadership role in initiatives such as the International Behavioural Trials Network
- Health psychologist Professor Molly Byrne was on the Communications sub-committee that advised the National Public Health Emergency Team in the first 20 months of the COVID-19 pandemic.

**Professor Molly Byrne, Director of the Health Behaviour Change Research Group, NUI Galway, says:**

“In 2014 the HRB saw the opportunity and took a chance on investing in me to build health behaviour change research in Ireland. This award has allowed me to develop, train and mentor a cohort of researchers, some who are still with the HBCRG and some who have since assumed their own leadership roles. We have brought psychology and behaviour change more to the fore when thinking about health interventions in Ireland, from seeing if patients will attend cardiac rehab more if it is online, to training GPs on how to help patients manage behaviour change, to encouraging people to boost physical activity through sport. The gap was there, and in five years we have established health psychology and behaviour change as an important discipline for designing policies and interventions in Ireland.”



# Improving attendance for diabetes eye-screening – what do people with diabetes and healthcare professionals find acceptable and feasible?

Researchers: Lauren O Mahony, Dr Sheena McHugh, Dr Fiona Riordan, University College Cork (UCC)

## The problem

People with diabetes should have regular eye screening to check if their eyes are being damaged by the disease. An HRB-funded project called IDEAS (Improving Diabetes Eye-Screening Attendance) is developing new approaches to encourage people to attend eye screening.

## The project

Lauren O Mahony, a former BSc student of Public Health Sciences in UCC, received a HRB Summer Studentship Award to analyse data gathered in the IDEAS project. She compared the perspectives of 13 people with diabetes and 17 healthcare professionals about suggestions to encourage eye screening among people with diabetes such as reminder prompts or information campaigns. She wanted to discover and compare what intervention content each group felt was workable and acceptable and why.

## The outcomes

- Healthcare professionals and people with diabetes had similar concerns. For example, they wanted to ensure that interventions would inform people about the need for regular eye screening in diabetes, but not in a way that scared them
- Sometimes perspectives on intervention content differed between healthcare professionals and people with diabetes. For example, healthcare professionals were concerned about the extra resources needed to change people's behaviour around eye screenings, while people with diabetes stressed the need to protect patient privacy with any intervention
- The results were presented at the 2020 New Horizons Research Conference in UCC
- Lauren O'Mahony is continuing the analysis in a post as a Research Assistant at UCC.

**Lauren O Mahony, Research Assistant, UCC School of Public Health, says:**

“

“When you are developing an intervention to encourage a health behaviour – in this case going for regular eye screening if a person has diabetes – it is important to involve different kinds of intervention end-users and see what their preferences are and whether they overlap. Since completing the HRB Summer Student project, I have continued to develop research on how to involve different groups of stakeholders when designing interventions to guide behaviour change in health.”



# Like a good red wine, stored red blood cells improve with age

Lead researchers: Professor Alistair Nichol, University College Dublin (UCD); Professor Jamie Cooper, Monash University, Melbourne

## The problem

Patients who are critically ill may need a transfusion of donated red blood cells (RBCs), but these are in short supply and have a shelf life of just a few weeks. To protect the supply, blood transfusion services have traditionally tried to use the older stored products first, but there has been a recent trend to use fresher stored RBCs in case they are better, which puts further pressure on blood supplies. But are older blood stocks just as good?

## The project

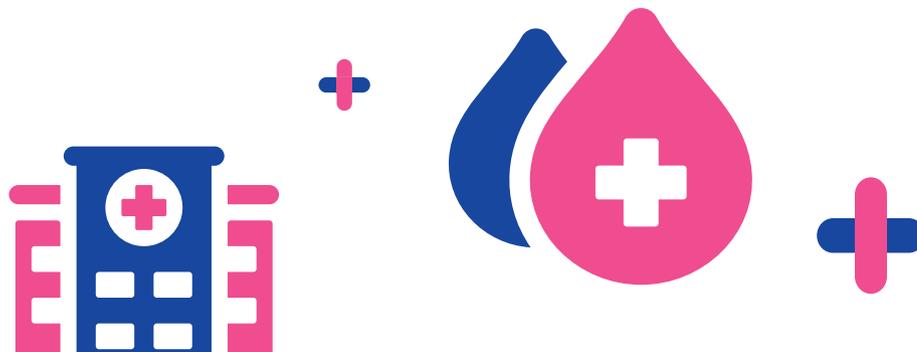
To determine the best practice, the TRANSFUSE (Standard Issue Transfusion versus Fresher Red-Cell Use in Intensive Care) trial recruited 4,919 critically ill patients in Ireland, Finland, Saudi Arabia, Australia and New Zealand. Around half of them received the standard, aged RBC products and the other half got the freshest available products.

## The outcomes

- As the largest study of its kind, the TRANSFUSE trial determined that standard, older red blood cell products are slightly better for critically ill patients in intensive care, compared to the freshest available products
- We now know the age of transfused red blood cells does not impact patient survival rates among critically ill adults, and older cells are associated with fewer fevers
- A smaller trial in Canada found a similar result
- The findings are changing practices among blood transfusion services and the clinicians that use blood products in critical care
- The TRANSFUSE trial will boost the available stock of donated red blood cells globally for patients, ensuring that older products are used before fresher ones and reducing the pressure on transfusion services.

**Professor Alistair Nichol, Chair of Critical Medicine in UCD, Director of the HRB Irish Critical Care Clinical Trials Network and Consultant Intensivist/Anaesthetist, St. Vincent's University Hospital, says:**

“Given the large amounts of red blood cell donations transfused globally, making even a small difference to the supply can have a huge impact. In the absence of evidence, some blood transfusion services were reducing the shelf life of RBC products, but with this large study we saw a very clear signal that in the Intensive Care Unit the freshest available blood is not better, and that for critically ill patients the current standard of care is desirable. This has closed the chapter on that question, and will have the knock-on effect of reducing the pressure on blood donation and transfusion services around the world. These findings are saving money and lives.”



# A helping hand for hand hygiene in the Intensive Care Unit (ICU)

Lead Researchers: Dr Paul O'Connor, NUI Galway; Dr Michael Power, National Clinical Programme for Critical Care, Health Service Executive (HSE)

## The problem

Globally, hundreds of thousands of patients die each year from new infections contracted in healthcare settings. Hand hygiene, which has been in the spotlight due to COVID-19, is an important step to reducing the spread of a wide range of potentially dangerous infections. But it is not always performed effectively.

## The project

HRB-funded research at NUI Galway assessed hand hygiene practices in ICUs in Ireland.

## The outcomes

- ICUs in Ireland generally have the supplies for hand hygiene and staff are aware of its importance in preventing infection
- ICU staff may overestimate how often they carry out hand hygiene
- The researchers developed a new toolkit of 21 interventions to help ICUs find the best way to boost effective hand hygiene practices.

## Dr Paul O'Connor, says:



“Although hand hygiene is simple, the related behaviours are complex and not always easy to change, and interventions aimed at improving compliance are often not based on scientific knowledge and may not be that effective. By this rigorous analysis of the factors influencing hand hygiene behaviour in ICUs in Ireland, we could develop a toolkit to help ICU staff in Ireland and internationally use approaches to improve hand hygiene and thereby reduce infections, protecting the vulnerable patients in their care.”



# SPECPREDICT: A new imaging tool to predict outcomes in cancer patients

Lead researchers: Dr Aidan Meade, Technical University (TU) Dublin; Professor William Gallagher, Dr Arman Rahman, University College Dublin (UCD) and Professor Jacintha O'Sullivan, Trinity College Dublin (TCD)

## The problem

In as many as 60% of patients with breast and oesophageal cancer, treatment does not control the disease effectively. It is also difficult to predict how a tumour will respond to treatment, or how the disease may progress over time.

## The project

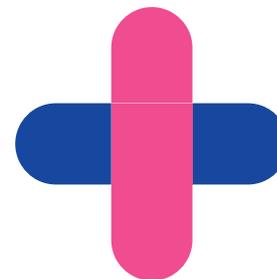
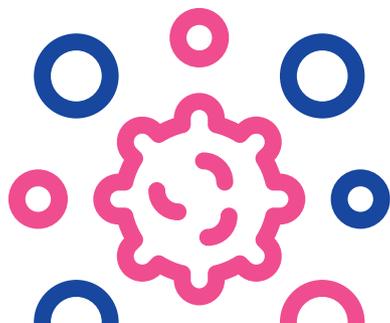
The SPECPREDICT project led by TU Dublin analysed samples of tumours from breast cancer and oesophageal cancer patients to develop a method for predicting patient outcomes. The researchers used spectral imaging technology and deep-learning software to look for features in the tumours of patients who were receiving the standard-of-care treatment. They wanted to find out if features of the tumours could help to predict patient outcome when receiving standard-of-care therapy.

## The outcomes

- New characteristics identified in breast and oesophageal cancer tumours that predict patient outcome following standard treatment
- New funding from Science Foundation Ireland (SFI) to expand the study and improve deep-learning technology for prediction on whether the cancer will come back after treatment.

**Dr Aidan Meade, Lecturer in Physics at TU Dublin and Principal Investigator and Researcher with the SFI ADAPT Centre, says:**

“Many cancer patients don't respond fully to treatment, or the cancer returns after a time. We are trying to reduce the number of people undergoing treatment that doesn't suit their cancer. By giving clinicians tools to analyse a tumour that are based on deep-learning, as well as quick and cheap to use, we hope to help them more precisely identify the treatment approach that is the best fit for that patient.”



# AllHPC – research to meet the growing need for palliative care

## The problem

Almost three in four people who die in Ireland have conditions where they could benefit from palliative care. And as people tend to live longer and more diseases become manageable for longer, the need for palliative care is expected to double over the next three decades. We need to understand how to meet these needs to improve people's quality of life during illness.

## The project

The Health Research Board (HRB) and The Health and Social Care Research and Development Division in Northern Ireland provide funding to the All Ireland Institute of Hospice and Palliative Care (AllHPC) to support the Palliative Care Research Network (PCRN). The network has 49 members from across the island of Ireland in disciplines including medicine, nursing, psychology, allied health professions, health economics, pharmacy and law.

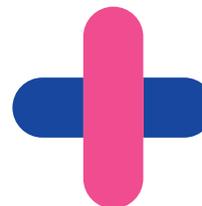
## The outcomes

- AllHPC has created two posts (the PCRN Project Manager and the Knowledge Transfer Project Manager) to provide additional support for researchers in the network and help them raise funding for research projects and widely communicate the findings of their studies
- AllHPC has supported the next generation of research leaders through the Early Career Researcher Forum, which has 205 members
- Between 2017 and 2020 the PCRN secured an additional €5.3 million to support research projects
- PCRN members published more than 400 peer-reviewed papers between 2017 and 2020
- Between 2017 and 2020, there were 50 research engagements with AllHPC's Voices4Care Public, Patient and Carer involvement in research (PPI) panel of people with life-limiting conditions, carers, former carers and interested citizens.

**Karen Charnley, Director of All Ireland Institute of Hospice and Palliative Care (AllHPC), says:**

“

The funding that AllHPC receives from the HRB is crucial to us being able to support the Palliative Care Research Network, and it is highly valued. Through that funding we have been able to support different types of research on how palliative care can best be delivered, from models that analyse how services can operate through to testing interventions to support patients. This research is extremely important as the need for palliative care services is increasing fast and we must know how to grow services and support people's quality of life in their time of need.”



# Empowering diverse voices in health

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# The patient perspective on improving day-to-day tasks with Multiple Sclerosis

Researcher: Robert Joyce and Dr Sinéad Hynes, NUI Galway

## The problem

People with Multiple Sclerosis (MS) can experience cognitive difficulties, making it harder to focus on and carry out day-to-day activities. This can lead to them feeling tired, frustrated and irritable and attempting fewer tasks.

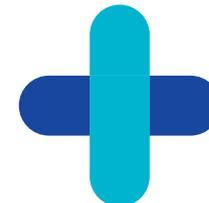
## The project

With HRB funding, a team at NUI Galway, led by Dr Sinéad Hynes, is trialling a cognitive occupation-based programme for people with MS (COB-MS), where they work with an occupational therapist on an eight-session programme focused on various techniques such as setting goals and pacing to help them accomplish day-to-day tasks. Importantly, a patient-researcher (Robert Joyce) was involved from the outset, to ensure the study incorporates the needs of people with MS.

## The outcomes

- Patient-researcher Robert Joyce, who has MS, has worked on the project from the start in the first role of its kind at NUI Galway
- By having patient input, the project has been designed to work for people with MS

- The trial recruited many participants through Robert Joyce telling his own story of living with MS in local and national media including the Irish Independent and the Farmer's Journal
- The manual used by participants in the project was specifically made to suit the sensory and mobility requirements of people with MS
- While the trial is ongoing, participants have anecdotally reported success in completing tasks after they practiced the techniques in the study
- Robert Joyce, Dr Sinéad Hynes and Dr Christopher Dwyer have published an open letter in HRB Open Research about the experience and impact of Patient, Public and Carer Involvement (PPI) in research on the project.



## Robert Joyce, Patient-researcher at NUI Galway, says:



“It is critical that patients have a voice in shaping research. Only by having that day-to-day lived experience of a condition can you understand what the potential obstacles are in a research project. One example in this case was the manual describing the techniques in the intervention, which was bound in a way that people with MS could find difficult to use. Because I have MS, I could see that, so we changed the design and it was not the obstacle it could have been. I see myself as a bridge between the patient community and the researchers, helping to ensure that they understand each other's needs. And while the study is ongoing, it's heartening to hear from some participants that they are feeling a tangible benefit of the intervention.”

# IPPOSI – giving patients the skills and confidence to shape research

## The problem

Because of their lived experience, patients have a huge amount of valuable information for improving care. But it may not be easy for them to communicate their insights to industry groups and researchers and influence more effective research.

## The project

The Irish Platform for Patient Organisations, Science & Industry (IPPOSI), works with patients, the healthcare industry and the academic research community to enable more fruitful conversations about research and improve patient care and outcomes. With support from the HRB, IPPOSI runs an 11-month Patient Education Programme every two years with modules about clinical trials, safety regulations for drugs/devices and how drugs are assessed for public funding with supplemental workshops on social media and communication skills, how advocacy campaigns work and more.

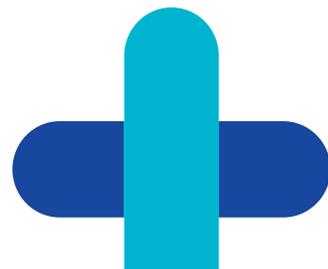
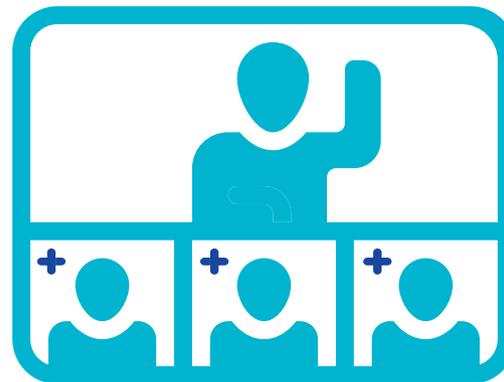
## The outcomes

- By the end of 2021, more than 60 people will have graduated from the IPPOSI Patient Education Programme in Health Innovation
- Peer mentoring (where previous graduates of the programme help patients who are currently enrolled) has proved a major success
- Because of the programme, patients have built networks with researchers from industry and academia, and are maintaining contact with other patients through WhatsApp groups
- Patients report feeling more confident to participate in research, and inform campaigns about improving care.

## Caroline Whelan, Education and Outreach Manager at IPPOSI, says:



“We have a rainbow of backgrounds in our patient groups, including people advocating from their kitchen table and people joining the online courses from their hospital beds. They have a lot to teach everyone, and through our Patient Education Programme we are helping them to develop the knowledge and skills to share their insights with people working in industry and academia as well as with politicians and policymakers.”



# HRCI-HRB joint funding enables health charities to do research

## The problem

Health charities may not be able to afford research to help the patient communities they represent, particularly small charities and those representing rare diseases.

## The project

Health Research Charities Ireland (HRCI), the national umbrella organisation of charities active in health, medical and social care research, represents more than one million people in Ireland. Through a joint funding scheme with the HRB, HRCI facilitates co-funding for charities to support projects of up to €300,000 (over one to three years), thereby encouraging public participation in the research.

## The outcomes

- 134 research projects have been jointly funded by HRCI member charities and the HRB across 10 rounds
- Around €13 million has been granted by the HRB, which has been matched by the charities to support the research
- The scheme has benefitted Ireland's participation in rare diseases research, including in areas such as cystic fibrosis and various forms of blindness and rare cancers, as well as supporting research into many more common conditions.

## Dr Avril Kennan, CEO of HCRI, says:

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“The joint funding scheme has been a huge success. We are not aware of any other scheme like it in the world and we have charities in the UK now looking at the model. The uniqueness is that the focus of the research is driven by the charities. They open the call and determine what their patient communities need and how research can meet those needs. It really is public and patient involvement in action, and the research findings have strong relevance to Ireland.”



# The People's Trial: A health study designed by and for the public

Lead researchers: Dr Elaine Finucane and Professor Declan Devane, NUI Galway

## The problem

It is important that the public understands what randomised trials are and why they matter. Otherwise, public support for clinical trials may be negatively impacted and fewer people may take part in them.

## The project

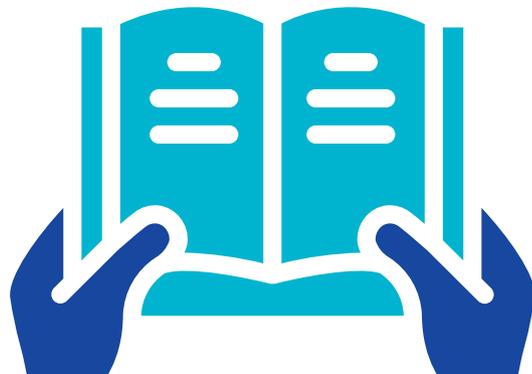
The HRB-Trials Methodology Research Network (HRB-TMRN) ran The People's Trial to help the public learn about randomised trials, understand why they matter, and be better equipped to think critically about health claims. More than 3,000 members of the public helped plan, design, conduct and report a randomised trial, called 'The Reading Trial'. The question chosen by the public for The Reading Trial, was: Does reading a book in bed make a difference to sleep, in comparison to not reading a book in bed?

## The outcomes

- The custom designed The People's Trial website had 9,500 visitors and involved participants from 117 countries. 32% of people who took part in The Reading Trial reported some or no understanding of randomised trials at the start of the trial
- The Reading Trial showed that in a group of people like those who took part in the trial, reading a book in bed before sleeping improves sleep quality, compared to not reading a book in bed
- Participants told researchers they wanted the findings of the trial shared in plain, understandable language and through infographics
- The team is now busy working on a 'sibling' project that involves children.

**Dr Elaine Finucane, HRB-Trials Methodology Research Network & Evidence Synthesis Ireland, School of Nursing & Midwifery at NUI Galway, says:**

“We know there is demand for reliable, robust evidence the public can use to make informed choices about their health. The People's Trial has shown, in a fun and engaging way, that you can involve the public in designing, carrying out and analysing the results of a randomised controlled trial and achieve quality evidence, while also supporting people to learn about trial processes. We hope participation in The People's Trial has given the public the opportunity to discover why clinical trials are important, while also providing insights into how researchers can engage the public in the steps of a trial, potentially influencing how future trials are designed and implemented.”



# The power of the patient effect on health research

Lead researchers: Professor Andrew Murphy and Martha Killilea, NUI Galway

## The problem

Patients and the public can play important roles in participating in and shaping health research. However, we need more of them, as well as clinicians and academics, to be aware of how they can get involved, and the difference it can make when there is Public, Patient and Carer Involvement in research (PPI).

## The project

At NUI Galway, the HRB Primary Care Clinical Trials Network Ireland and PPI Ignite Network worked with CÚRAM (an SFI Centre for Research in Medical Devices) and the Galway Film Festival to commission and screen a documentary about three patients who got involved in research. The HRB supported the project.

## The outcomes

- Patients and members of the public advised on and were involved in the documentary project from the start
- The documentary, *The Patient Effect*, was produced by Ishka Films and directed by Mia Mullarkey, and showed the power of including public and patient voices in research. It told

the stories of Sophia Ryan, who was born prematurely at 25 weeks, Cameron Keighron who has Type 1 diabetes, and Margaret Devaney, who has arthritis. All three helped to further health research

- *The Patient Effect* was premiered at An Palás Cinema, Galway, to 150 attendees and has been shown at numerous scientific conferences, public events and film festivals internationally
- It is now used as part of medical, nursing and health sciences education at NUI Galway.

**Professor Andrew Murphy, Director of Primary Care Clinical Trials Network Ireland, a HRB research network to enhance primary care and outcomes, says:**

“As a Network, we want to involve patients and the public in clinical trials and research, not only taking part but being involved in the governance and design of studies and advising on how they want the findings to be reported accessibly. But to widen the PPI contributors involved, we need to raise more awareness among

patients, clinicians and academics about the impact of PPI, and a documentary is an effective way of doing that.”

**Martha Killilea, Programme Manager of the PPI Ignite Network @ NUI Galway, says:**

“As well as the tangible output of the documentary, this project has built an enormous sense of achievement and pride among the patients and researchers who were involved in advising or appearing in the film. It has also helped put PPI more on the map among colleagues in academia whose research can benefit from it from the early stages.”



**Watch the trailer**

To access the full film, please email [martha.killilea@nuigalway.ie](mailto:martha.killilea@nuigalway.ie)

# Ethnic minorities – data can drive more equitable healthcare

Lead researchers: Professor Anne MacFarlane and Professor Ailish Hannigan, University of Limerick (UL)

## The problem

Ireland's diversity of language, culture and ethnicity has increased due to a rise in immigration. But we lack information about the ethnicity and culture of people in Irish healthcare settings, making it more difficult to know about differences in health between groups. We need this information so the healthcare system can adapt and ensure more people have the opportunity of good health.

## The project

The Ethnic Minority Health in Ireland project was co-designed by academic, community and health sector partners. It mapped where information about ethnicity and culture was already being collected in relation to health. It also focused on what enables or stops ethnicity data collection in primary care settings from the point of view of Irish Travellers, refugees and immigrants, as well as GPs.

## The outcomes

- The study supported priority actions in the Health Service Executive (HSE) Second Intercultural Health Strategy 2018-2023
- We know more about the scale of the issue: of the 97 national health and social datasets examined, only 14% had information about ethnicity and culture

- GPs reported they lacked the time to gather information about ethnicity and culture during consultations, and worried that asking about this sensitive issue might damage doctor-patient relationships. They were not convinced about the relevance of gathering ethnicity data for their consultations
- Minority communities could see the potential value of having these data collected but had concerns about the categories used to record ethnicity and were concerned that ethnic and cultural data would be misused against them and/or not used to inform healthcare adaptations
- The research team prepared a community drama called *Diversity in Data* based on the study's findings and it was performed for GPs and in community settings. The drama is now being used in medical students' training in the University of Limerick
- A policy brief arising from the research for the Department of Health recommended collecting ethnicity and immigration data using an Individual Health Identifier and linking data across the healthcare system
- Study findings were used to help train HSE contact tracers about ethnicity data collection during COVID-19.

**Professor Anne MacFarlane, Director of WHO Collaborating Centre for Migrants' Involvement in Health Research and Chair of Primary Healthcare Research at UL, says:**

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“To provide equitable healthcare for everyone, we need to understand who has access to services, what their experience is and what their health outcomes are. Currently, the way we collect data does not reflect the increased diversity of ethnicities in Ireland, and we are using the findings of the Ethnic Minority Health in Ireland project to help change that.”

This research was developed through the Partnership for Health Equity, which is a partnership between the HSE National Social Inclusion Office, North Dublin City GP training programme, Irish College of General Practitioners and the University of Limerick School of Medicine. The research was participatory, meaning that it was designed and conducted with community partners from the Intercultural and Diversity Education Centre, Ireland and Shannon Family Resource Centre, as well as with partners from the HSE National Social Inclusion Office.



# Stop the clot! Raising awareness of thrombosis in pregnancy

Lead researcher: Professor Fionnuala Ní Áinle, University College Dublin (UCD)

## The problem

Pregnant women have a higher chance of developing blood clots (thrombosis) in veins that can cause serious health problems and can even be fatal. So, it is important that women who are or could become pregnant and their families are aware of their risk factors and to get medical care quickly if they have signs of a clot.

## The project

The HRB (in collaboration with the Ireland East Hospital group, NGO Thrombosis Ireland and Healthy Ireland), jointly funded a roadshow to travel around Leinster on a dedicated bus in late 2019, visiting maternity hospitals, general hospitals and communities (in pharmacies, GP surgeries and libraries) for lectures and events to increase awareness of clots in pregnancy. The project also produced leaflets, ran social media campaigns and appeared in media to widen the reach with information. GAA stars including members of Dublin women's and men's Gaelic football senior team and the Wexford men's senior hurling team helped out.

## The outcomes

- The information campaign won the prestigious World Thrombosis Day Event of the Year Award for 2020

- The hashtag #PregnancyVTE had 1.4 million impressions on social media during the campaign, and the 'Stop the Clot' social media accounts had 1.5 million impressions in that time
- The campaign was featured in local, national, print and broadcast media
- More than 10,000 HSE/Thrombosis Ireland VTE alert cards highlighting signs and symptoms of clots in pregnancy were given to healthcare professionals.

**Professor Fionnuala Ní Áinle, Consultant Haematologist at the Mater Misericordiae Hospital and UCD, says:**

“We achieved a huge amount in the six weeks of the campaign, and it really was a collaboration between patients, clinicians, hospitals and researchers. By travelling with the bus, we could reach not only maternity hospitals and general hospitals in the Ireland East Hospital Group region, we also got to meet and talk to people in communities about what we all need to know about clots in pregnancy in order to get pregnant women help quickly if they need it. Winning the World Thrombosis Day award was a big recognition of that.”

## KNOW THE RISKS, KNOW THE SIGNS, STOP THE CLOT

If you are pregnant, you are at higher risk of developing a clot that can travel to your lungs and make you and the baby seriously ill. Spotting the signs early and getting medical help quickly can make a big difference.

### To reduce the risk of clots:

- Avoid smoking
- Keep at a healthy weight
- Tell your doctor if anyone in your family has suffered from a clot before

### Get to hospital immediately if you have:

- Chest pain
- Shortness of breath
- Leg pain or swelling



# More awareness needed to prevent harm from an anti-epileptic medicine in pregnancy

Lead researcher: Professor Kathleen Bennett, Royal College of Surgeons in Ireland (RCSI university of Medicine and Health Science)

## The problem

Some medicines can harm the developing baby during pregnancy, so it is important that doctors, pharmacists and other healthcare professionals know the risks. One example is sodium valproate, a medicine used to treat epilepsy and bipolar disorder. In 2018, the Health Products Regulatory Authority (HPRA) in Ireland provided information to healthcare professionals about pregnancy prevention with the use of sodium valproate. But how much awareness and use of this information was there among healthcare professionals in practice?

## The project

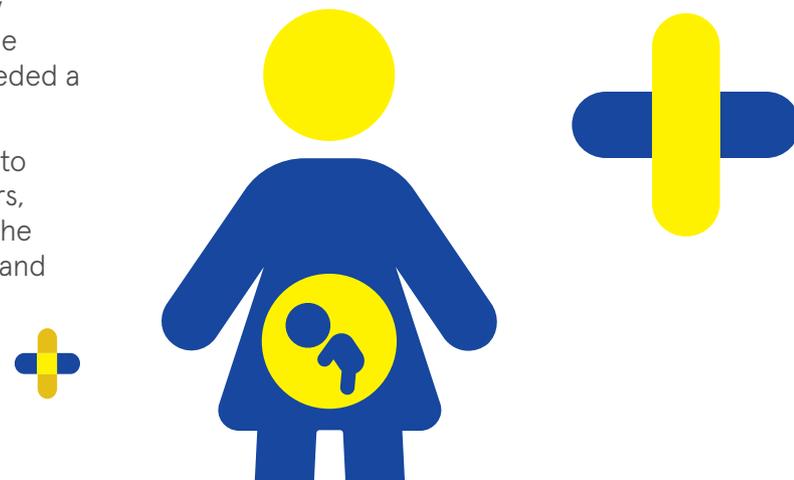
Working with the HPRA, in 2019, researchers at RCSI University of Medicine and Health Sciences sent an online questionnaire to approximately 3,820 GPs, pharmacists and specialist consultants, to see if they were aware of the risk management measures for women needing to prevent pregnancy when on sodium valproate. The researchers also looked at whether prescription patterns of sodium valproate changed after the HPRA campaign.

## The outcomes

- The survey had a low response rate (5.8% of the GPs, 10.7% of the pharmacists and 7.6% of the specialists answered the questionnaire), which may limit the generalisability of the findings, that is, the extent to which we can generalise the findings from a sample to an entire population
- Most who answered the survey knew that sodium valproate can cause harm during pregnancy, but many were unsure of or underestimated how big the risk is
- Between 2014 and 2019, prescriptions for sodium valproate among women aged 16–44 years in Ireland fell from just under 2000 to just over 1500, particularly among women aged 16–24
- Healthcare professionals were generally unaware that women who could become pregnant while on sodium valproate needed a review with a specialist every year
- The study findings were made available to the Irish College of General Practitioners, the Pharmaceutical Society of Ireland, the National Medicines Information Centre and medical specialist groups.

Professor Kathleen Bennett, Associate Professor in Biostatistics in the Division of Population Health Sciences, RCSI university of Medicine and Health Science, says:

“We found that there needs to be continued effort and collaboration with doctors and pharmacists about the magnitude of the risks of sodium valproate during pregnancy. The research provides evidence that we need new ways to intervene, and we identified the areas where it is important to focus. For example, we could see that more effort is needed to support awareness among GPs and community pharmacists, in particular, as they would have most regular contact with women.”



# The search for early signs of cognitive delay in children

Researchers: Louise Howe and Professor Deirdre Murray, University College Cork (UCC)

## The problem

Children who are late to develop skills such as talking, spatial awareness and solving problems can quickly fall behind in school, with a long-lasting impact on their education and even their health. Are there early signs when they are babies or young children that they could do with more support?

## The project

In her third year of studying medicine, Louise Howe carried out statistical analysis of data gathered in the HRB-funded SCOPE and BASELINE studies to seek answers. She analysed a dataset of almost 3,000 children from birth to age five, to see if there were identifiable risk factors for cognitive delays.

## The outcomes

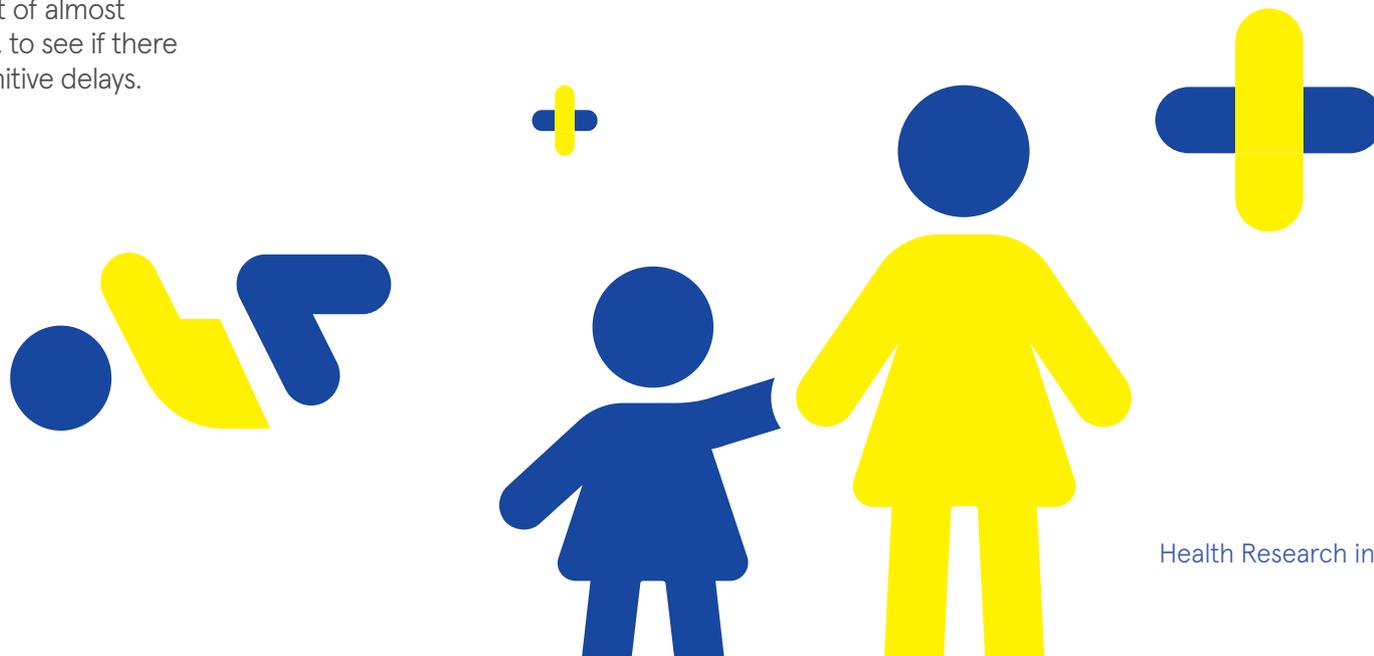
The statistical study found that -

- Being male and a lower household income are predictors of delays in a child's verbal ability
- Lower socio-economic status, type of accommodation and larger numbers of people in the household predict delays in a child's non-verbal ability
- Type of delivery at birth, household income, immigration status and the mother's level of education predict overall cognitive development.

**Louise Howe, medical student at UCC, says:**

“

“We wanted to see if there were factors that GPs and public health nurses could spot early on that increase the risk of a child developing cognitive delays, so the child could get more support if needed. I plan that when this study is published, I will present it at conferences and share it with the wider community in primary care.”



# Peer Power: Empowering adolescents in at-risk communities to develop more positive health behaviours

Lead researcher: Professor David Hevey, Trinity College Dublin (TCD)

## The problem

Adolescence is a time when people may start to smoke, drink too much alcohol or reduce their physical activity. If these behaviours persist into adulthood, it increases the risk of conditions such as heart disease, diabetes, cancer and stroke. Adolescents in low socio-economic settings are particularly at risk.

## The project

A project led by TCD worked with the Health Service Executive (HSE) and local community workers to train adolescents from socio-economically deprived communities in motivational interviewing, a technique that empowers a person to make healthier choices. The project was funded through the HRB and Health Charities Research Ireland.

## The outcomes

- Fruitful working relationships were built between the researchers, youth workers and young people in multiple at-risk communities, including inner city and Traveller groups
- 12 young people were trained and paid to deliver sessions with motivational interviewing to encourage positive health behaviours

- The project made a workbook to support peer-led sessions on changing behaviours around drinking alcohol, smoking and physical activity
- Sessions were well attended, and almost all participants returned for further sessions
- Compared to a control group that received peer-delivered health education, participants who engaged with motivational interviewing changed their behaviours around excessive drinking and became more active over the following months
- The researchers and youth workers involved have received several queries about the peer-led programmes from other communities who are keen to implement the motivational-interviewing intervention for their at-risk youth.

**Professor David Hevey, Professor in Clinical Health Psychology at TCD School of Psychology, says:**

“

“Lots of studies have taken an expert-led approach to changing health behaviours, where a trainer parachutes into a community and presents education or talks about negative consequences. Communities may not identify with these experts, and then the experts leave. In this project, we showed that by training adolescents to deliver an intervention in their own community in the form of motivational interviewing, you can empower young people to change their health behaviours around drinking and physical activity. It creates a more sustainable approach, where the skills and expertise to improve health stays within the community.”

## Research Team

Angela Hickey (TCD), Professor Margaret Lawler (TCD) Professor Frank Doyle (RCSI), Professor Elizabeth Nixon (TCD), Professor Catherine Darker (TCD), Professor Margaret Barry (NUI Galway), Professor Catherine Anne Field (NUI Galway)

## Collaborators

Youth Work Ireland (YWI); National Youth Council of Ireland (NYCI); Health Service Executive

# A new insight into stress responses in adolescents

Lead researchers: Jenna O'Shea and Dr Samantha Dockray, University College Cork (UCC)

## The problem

Early in life, our bodies 'learn' how to individually respond to stress. If a person has a trauma in childhood, that can lead to them having negative responses to stress, which over a lifetime can increase the risk of ill health. But while we learn our stress responses early in life, it has not been clear if stress reactivity continues to change in adolescence.

## The project

As a student of Applied Psychology in UCC, Jenna O'Shea looked at whether the 'learned' stress response can change in adolescence, itself often a stressful time. With the support of a HRB Summer Student Scholarship, she analysed a dataset from the USA of 120 adolescents measured at time points over 18 months for levels of a stress hormone (cortisol) and explored links with factors such as a person's sex and the age when puberty started.

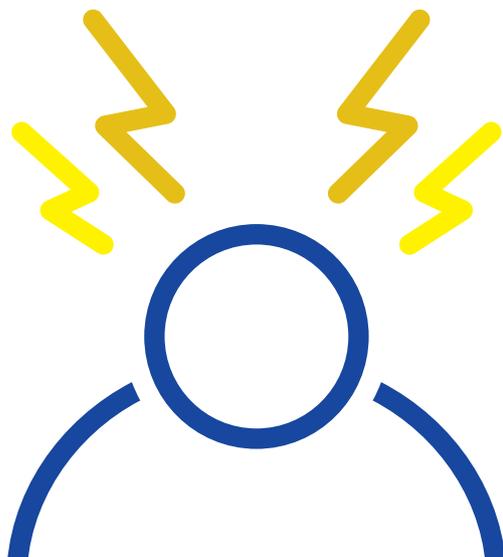
## The outcomes

- The study showed that stress hormone responses increase during adolescence
- There were no measurable differences between males and females, and the age at which puberty starts had little impact
- The findings add to a growing interpretation of adolescence as a time of recalibration and a potential window to intervene and support people at risk.

**Jenna O'Shea, graduate of Applied Psychology in UCC, says:**



"If a person has excessive or prolonged negative responses to stress, that can contribute to many conditions, such as heart disease, cancer and issues with mental health. For someone who is at risk of this from early life, if we can target interventions in adolescence, there is a huge opportunity to improve the lives of those who have experienced early life trauma and how that can affect the trajectory of their lives."





# Electronic cigarettes – what are the risks for health?

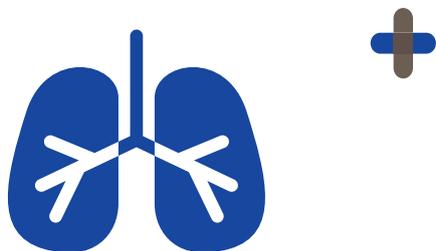
Researchers: HRB Evidence Centre

## The problem

Electronic or e-cigarettes are relatively new (introduced in Europe in 2006) compared to conventional tobacco cigarettes. But what are their implications for health? Research is growing on their effects, and reviewing large numbers of studies together can allow deeper insights.

## The project

Researchers at the HRB Evidence Centre identified and analysed more than 360 published studies about e-cigarettes and health. This systematic review found that e-cigarettes were linked with acute health issues including poisonings, burns, lung injury and worsening of asthma as well as early signs of damage to blood vessels. An analysis of seven studies showed e-cigarettes are no more effective than approved and regulated nicotine replacement therapies (NRTs) to help people stop smoking, and a separate analysis of 9 studies concluded that e-cigarettes increase the risk of adolescents starting to smoke tobacco cigarettes.



## The outcomes

We now know that –

- E-cigarettes are no more effective than medically approved and regulated nicotine replacement therapies to help people stop smoking
- Adolescents who use e-cigarettes are three to five times more likely to start smoking tobacco cigarettes compared to those who never used e-cigarettes
- E-cigarettes can lead to poisonings, burns, lung injury and asthmatic attacks. Some of the chemicals in e-cigarettes are thought to cause tissue and cell damage and are linked to cancer. The long-term health effects beyond 24 months are not researched.

### The research on e-cigarettes produced three publications, which are freely available on the HRB website:

-  *Electronic cigarette use and tobacco cigarette smoking initiation in adolescents: An evidence review.*
-  *Electronic cigarettes and smoking cessation: An evidence review.*
-  *Harms and benefits of e-cigarettes and heat-not-burn tobacco products. A literature map.*

Dr Jean Long, Head of the Evidence Centre at the HRB, says:

“

HRB evidence shows that e-cigarettes are no more effective than approved and regulated nicotine replacement therapy to help people stop smoking. They can cause harm to health and our findings also highlight that e-cigarettes have the potential to make adolescents more likely to start smoking tobacco. These factors need to be considered as part of any smoking harm-reduction strategy.”



# Drug poisoning deaths in Ireland – unmasking trends among women

Lead researcher: Ena Lynn, HRB

## The problem

Globally, people are dying from drug (including alcohol) poisoning, but it has not been clear whether there were differences between men and women in relation to trends and drugs involved in these deaths.

## The project

HRB-led research analysed data from the National Drug-Related Deaths Index (NDRDI) and prescription data from the Primary Care Reimbursement Service for the years 2004 to 2017 in Ireland, taking sex into account.

## The outcomes

We now know that –

- The rate of drug poisoning deaths in Ireland has gone up from 6.86 per 100,000 in 2004 to 8.08 per 100,000 in 2017
- More than half of all drug poisoning deaths involving alcohol featured multiple drugs
- The proportion of women who died of drug poisoning deaths involving alcohol decreased, and there was no significant change among men

- For men, drug poisoning deaths involving cocaine, benzodiazepines, antidepressants, and/or prescription opioids increased significantly between 2004 and 2017
- For women, drug poisoning deaths involving antidepressants, benzodiazepines, and/or prescription opioids increased significantly between 2004 and 2017, with a significant increase involving cocaine between 2011 and 2017
- There has been a significant increase in reports of two or more central nervous system (CNS) depressant drugs involved in drug poisoning deaths in men and women.

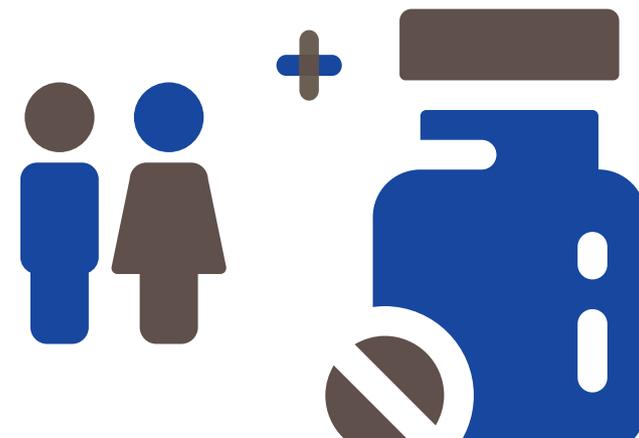


The HRB has a policy of publishing the findings of its research in journals that are free to access online. The research on drug poisoning deaths resulted in a paper in the Open Access journal *BMJ Open*: *Trends in drug poisoning deaths, by sex, in Ireland: a repeated cross-sectional study from 2004 to 2017*.

Ena Lynn, Research Officer at the HRB says:



“The increasing trend of two or more drugs that depress the central nervous system being involved in drug poisoning deaths is of concern, especially among women. This more nuanced data by sex highlights the need for an increased understanding among prescribers, and among people who use drugs and policymakers, of physiological differences between men and women and how this affects drug activity, especially for drugs that suppress the central nervous system. The evidence points to the need for harm reduction initiatives, along with treatment interventions, which include pharmaceutical combined with psychosocial assistance to focus on the full range of problematic drugs.”



# Drinking in Denial: In Ireland we underestimate harmful alcohol consumption

Lead researcher: Dr Deirdre Mongan, HRB Evidence Centre

## The problem

Alcohol causes one in 10 global deaths among those aged 15–49 years annually. Results from previous alcohol consumption surveys in Ireland don't match up with alcohol sales figures, suggesting that people tend to under-report or underestimate how much alcohol they drink.

## The project

HRB research analysed data from Ireland's 2014/2015 Drug Prevalence Survey, which explored alcohol consumption among 7,005 individuals over the age of 15 years, and particularly looked at their self-awareness about their drinking patterns.

## The outcomes

- Almost one half of drinkers (2,420) had a hazardous or harmful pattern of drinking, and 10.5% were dependent on alcohol
- Among regular binge drinkers, only one person in three recognised that they regularly binge drink, which is concerning as this pattern of alcohol consumption increases a person's risk of experiencing alcohol-related health harms

- One third of the people who were dependent on alcohol described themselves as 'light' or 'moderate' drinkers
- Women who were alcohol dependent were less likely to describe themselves as heavy drinkers (1 in 10) compared to men (1 in 5)
- The people who most accurately estimated how much alcohol they drink were those deemed low-risk drinkers
- The findings were shared with the Department of Health in Ireland to inform policies on preventing harm from alcohol consumption.

**Harmful drinking**, or regular binge drinking, is defined as consuming approximately six standard alcohol drinks in one sitting.

**Hazardous drinking**, or alcohol dependence, is defined as experiencing alcohol cravings and a lack of control when it comes to drinking.

**Low-risk drinkers** were those drinkers who were not alcohol dependent and who did not engage in regular binge drinking.

Dr Deirdre Mongan, Research Officer at the HRB, says:

“

“In Ireland we live in a culture where alcohol is everywhere, and binge drinking has been normalised compared to other countries. We found there was low awareness among drinkers with harmful drinking patterns that they consumed alcohol in this way. Many people just don't realise they are drinking at that level. The study highlights the need for more interventions and labelling on alcohol products to increase awareness of the harm it can cause.”



The research on alcohol consumption and awareness resulted in a paper published in the Open Access journal *BMJ Open*: *Drinking in denial: a cross-sectional analysis of national survey data in Ireland to measure drinkers' awareness of their alcohol use.*

# Providing older people with care and their own front door – how is housing with support perceived?

Researchers: HRB Evidence Centre

## The problem

**Housing with support aims to enable older people to age with dignity, independence and their own front door. It provides them with care services and support in purpose-built, non-institutional accommodation. But for it to work, we need to know what people think about it, and what impact it could have on their lives.**

## The project

The Department of Health and the Department of Housing, Local Government and Heritage commissioned an evidence review, arising from the Joint Policy Statement ‘Housing Options for our Ageing Population’. Researchers at the HRB Evidence Centre analysed 75 papers on housing with support across 10 countries (including the USA, Israel, Australia, New Zealand, Canada, the UK and several European countries) to explore older people’s perceptions and impacts of housing with support.

## The outcomes

The evidence review found that –

- Older people transitioned to housing with support more successfully if they had choice about where they went and the type of accommodation to which they moved

- It is important to recognise the emotional impact of moving to new accommodation, particularly if meaningful objects can’t be moved too
- It is easier for older people to move to housing with support if they can maintain their existing social networks and their familiar community services
- Having opportunities to socialise as much as possible in a vibrant community with enjoyable activities (such as gardening, dinner clubs, and cafes) help to promote successful transition to housing with support.

“Olivia Cagney, HRB Evidence Centre, says: In Ireland, we often rely on nursing homes to support older people as they require more care and services. We wanted to look at a different experience, one where the older person lives more independently and has their own front door, but is in purpose-built accommodation and small communities where services are provided. By learning more about the perceptions and impacts of housing with support in other countries around the world, we have gathered important evidence that can inform the expansion of this kind of accommodation for older people in Ireland.”

**Welcoming the publication of this HRB evidence review, Mary Butler, TD, Minister of State for Mental Health and Older People, said:**

“We all want opportunities to live full and meaningful lives on our own terms. A key principle underpinning government policy is to support older people to live independently in their own homes and communities. The findings of this evidence review will feed into the government’s work in this area. By understanding the perceptions of older people themselves, we can reflect their preferences in future policies – helping shape housing models that meet their needs. Older people must have choice when it comes to housing options. Having a say on where they live and who they live with should be at the heart of any housing policy for older people.”



Read *Housing with support for older people, an evidence review*.

# Treatment for cocaine rising in Western Europe

Researcher: Dr Suzi Lyons, HRB

## The problem

Concerns have been raised about the evidence of harms caused by increasing cocaine use in Europe. Looking at treatment for cocaine can give some indication of trends in its use in societies. Knowing about these trends can help to inform measures and services to reduce cocaine-related harm.

## The project

HRB researcher Dr Suzi Lyons worked on an international study that examined data from around 700,000 cocaine treatments between 2011 and 2018 across Belgium, England, France, Germany, Ireland, Italy, Luxembourg, Spain, Switzerland and the Netherlands as part of the work of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA).

## The outcomes

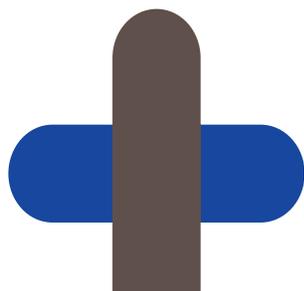
We now know that -

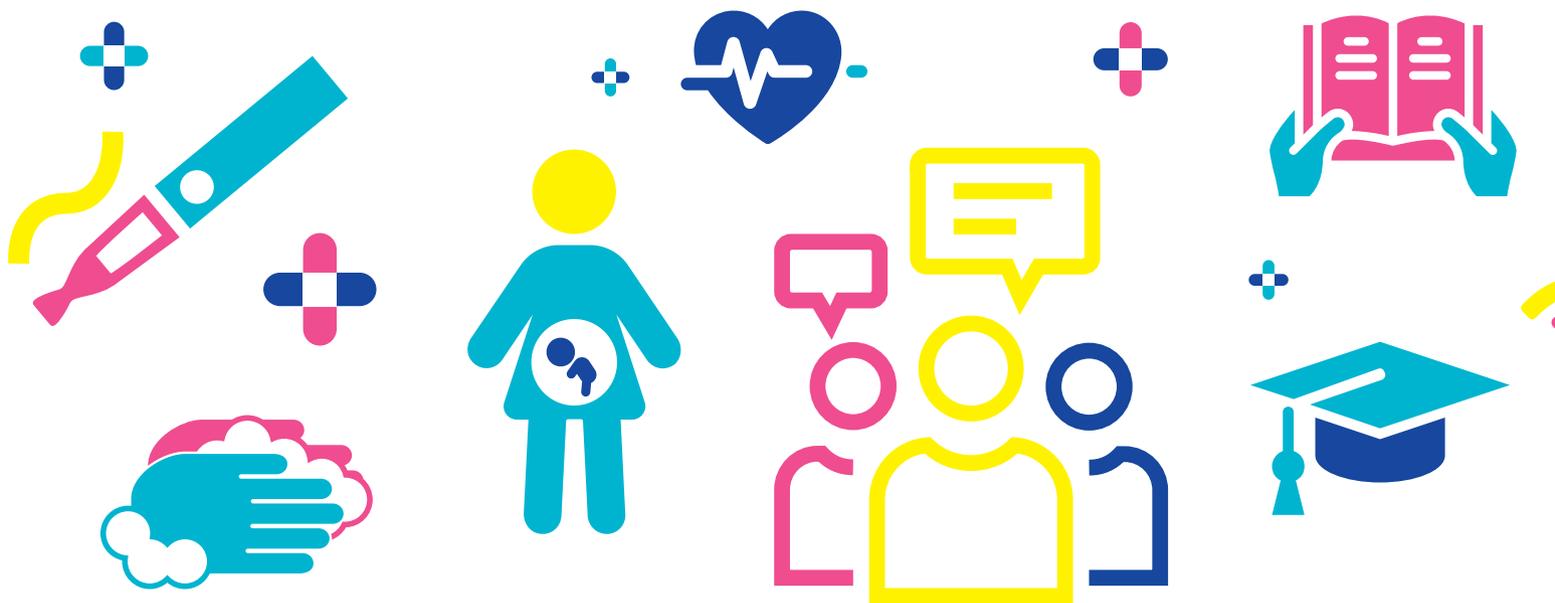
- Cocaine treatment, and therefore likely wider use of the drug in society, rose sharply in Western Europe between 2015 and the end of the study period in 2018
- In Europe, between 2011 and 2018, the vast majority of people in treatment for cocaine use were male, with an average age of 35.

 Cocaine treatment demands in ten Western European countries: observed trends between 2011 and 2018 was published in the journal *Addiction*.

Dr Suzi Lyons, Senior Researcher at the HRB, says:

“The strength of this study is that it brings together drug treatment data from 10 countries in Western Europe. The trends we saw in cocaine treatment, including the sharp rise in treatments between 2015 and 2018, can assist in planning services. The paper has been widely shared because it was published in a high-impact and accessible journal.”





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