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## **Building a Supportive Framework for Brain Research in Ireland: Inaugural Position Paper of The Irish Brain Council**

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## **Introduction: The Irish Brain Council**

The Irish Brain Council is an independent group of organisations which have come together to influence and impact upon brain research in Ireland. The purpose of the Irish Brain Council is to promote and advocate for brain research in Ireland. It aims to harness the expertise and experience of its membership to provide a platform for public outreach, legislative engagement and strategic partnership to foster a supportive environment for brain research that ensures Ireland's competitiveness in this area going forward and enables the attraction, retention and development of research initiatives in the understanding and treatment of brain conditions. This first inaugural position paper by the Irish Brain Council aims to outline the challenges and opportunities for brain research in this country and call for a supportive infrastructure to attract future investment, retain highly qualified personnel and ensure that research findings are effectively translated into better outcomes for people with brain conditions. Brain research was the initial focus of the European Brain Council (EBC) when it was launched 15 years ago; since then, however, the European Brain Council has expanded into many other areas such as prevention, education, the patient's journey etc. The European Brain Council has therefore recently adopted an alternative term "brain health" in place of "brain research", which is more holistic and more representative of their broader remit. For the remainder of this paper, we will use the term "brain health and research" to mirror the aims of the European Brain Council in the goals of the Irish Brain Council.

The Irish Brain Council aims to be inclusive of all areas of brain health and research aimed at improving the quality of life for people living with brain conditions. The Irish Brain Council is a group of representative organisations with the overall aim of influencing the landscape of scientific research into brain conditions in Ireland. The Irish Brain Council adopts a broad definition of brain health and research covering the spectrum from basic science and

translational research through clinical research, clinical trials to health service interventions and research into health systems aimed at improving treatment and responses to the needs of those with brain conditions.

The membership of the Irish Brain Council is currently constituted as follows:

The Irish Institute of Clinical Neurosciences (IICN)

Neuroscience Ireland (NI)

FutureNeuro Research Centre

Dementia Neurodegeneration Network of Ireland (DNNI; affiliate)

The Neurological Alliance of Ireland (NAI)

The Psychological Society of Ireland (PSI)

The College of Psychiatrists of Ireland (CPI)

The Irish Consultant Neurologists' Association (ICNA)

Table 1 indicates the main academic institutions, research centres and networks involved in brain research in Ireland. Many of these are represented through the constituent organisations that make up the Irish Brain Council. It is important to stress that the list below is not exhaustive but represents an indicator of the vibrant connectedness that is one of the strengths of brain research in Ireland. Additional national networks related to neuroscience research are listed in Table 2.

The Irish Brain Council is an affiliated member of the European Brain Council.

The mission of the Irish Brain Council is to promote brain health and research to improve the quality of life of those living with brain conditions. The Irish Brain Council will strive to work in partnership with other representative organisations to influence the research landscape in Ireland so that the needs of all stakeholders, including those living with brain conditions, are recognised and addressed.

The strategic goals of the Irish Brain Council are as follows:

- To promote a strong advocacy for investment in and support of development of brain health and research in Ireland
- To promote the development of an infrastructure for brain health and research in Ireland that ensures that the sector can attract, retain and develop high quality research initiatives and researchers.
- To ensure that the views of all stakeholders are reflected in the work of the Irish Brain Council, including those living with brain conditions and patient representative organisations
- To encourage the use of research findings to inform health policy, practice and services for people with brain conditions

Table 1: Existing neuroscience research institutions and networks in Ireland.

Higher Education Institute	Name of Centre	Research focus	Other information/links
Trinity College Dublin	Trinity College Institute of Neuroscience	All	<a href="http://www.tcd.ie/neuroscience">www.tcd.ie/neuroscience</a>
	Global Brain Health Institute	Dementia	<a href="https://psychology.tcd.ie/gbhi/">https://psychology.tcd.ie/gbhi/</a>
	Academic Unit of Neurology	Neurodegeneration Epilepsy Multiple Sclerosis	<a href="https://www.tcd.ie/medicine/neurology/">https://www.tcd.ie/medicine/neurology/</a>
Multi-Institutional (hosted at RCSI)	FutureNeuro Research Centre	Epilepsy and Motorneurone disease (ALS)	<a href="http://www.futureneurocentre.ie">www.futureneurocentre.ie</a>
Multi-Institutional (hosted at NUI Galway)	CURAM Centre for Research in Medical Devices	Parkinson's disease	<a href="http://www.curamdevices.ie/">http://www.curamdevices.ie/</a>
Multi-Institutional (hosted at UCC)	APC Microbiome Ireland	Psychiatric disease, brain-gut axis	<a href="http://apc.ucc.ie/">http://apc.ucc.ie/</a>
University College Cork	Cork Neuroscience Centre	All	<a href="https://www.ucc.ie/en/cns/">https://www.ucc.ie/en/cns/</a>
Multi-Institutional (hosted at UCC)	INFANT Research Centre	Brain development, neurophysiology	<a href="http://www.infantcentre.ie">www.infantcentre.ie</a>
National University of Ireland, Galway	Galway Neuroscience Centre	All	<a href="http://ncbes.nuigalway.ie/research/galway-neuroscience-centre/">http://ncbes.nuigalway.ie/research/galway-neuroscience-centre/</a>
	NICOG (Centre for neuroimaging and cognitive genomics)	Neuroimaging	<a href="http://www.nuigalway.ie/colleges-and-schools/arts-social-sciences-and-celtic-studies/psychology/research/research-themes/brain-behaviour/nicog/">http://www.nuigalway.ie/colleges-and-schools/arts-social-sciences-and-celtic-studies/psychology/research/research-themes/brain-behaviour/nicog/</a>
	Centre for Pain Research	Pain	<a href="http://www.nuigalway.ie/centre-for-pain-research/">http://www.nuigalway.ie/centre-for-pain-research/</a>
Maynooth University	NUIM Neurolab	Cognitive neuroscience	<a href="https://maynoothneurolab.wordpress.com/">https://maynoothneurolab.wordpress.com/</a>
	ALL Institute	Assisting Living and Learning	<a href="https://www.maynoothuniversity.ie/all-institute">https://www.maynoothuniversity.ie/all-institute</a>
	Human Health Institute	Human Health	<a href="https://www.maynoothuniversity.ie/human-health-institute">https://www.maynoothuniversity.ie/human-health-institute</a>
	Hamilton Institute	Mathematics, Computation	<a href="https://www.maynoothuniversity.ie/hamilton">https://www.maynoothuniversity.ie/hamilton</a>
Dublin City University	International Centre for Neurotherapeutics	Neurotherapeutics	<a href="https://www.dcu.ie/icnt/index.shtml">https://www.dcu.ie/icnt/index.shtml</a>
	INSIGHT Centre	Data Analytics	<a href="http://www.insight-centre.org/">http://www.insight-centre.org/</a>
University College Dublin	UCD Centre for Neuroscience	All	<a href="http://www.ucd.ie/ucdneuro/">http://www.ucd.ie/ucdneuro/</a>
	Conway Institute	Neurobiology	<a href="https://www.ucd.ie/conway/">https://www.ucd.ie/conway/</a>

Table 2: Other neuroscience-related networks in Ireland.

Type of Network	Name	Research Focus	Other information/links
Multi-Institutional	Dementia and Neurodegeneration Network Ireland	Research focus is neurodegenerative disease including: -Dementia (including Alzheimer's Disease) -Parkinson's Disease (PD) -Motor neurone diseases (MND) -Huntington's Disease (HD) -Prion Disease -Spinocerebellar ataxia (SCA) -Spinal muscular atrophy (SMA)	<a href="http://www.dementia-neurodegeneration.ie/">http://www.dementia-neurodegeneration.ie/</a>
Multi-Institutional	Neuroscience Ireland	General	<a href="https://neuroscienceireland.com/">https://neuroscienceireland.com/</a>
Multi-Institutional	Irish Institute of Clinical Neuroscience (IICN)	Clinical Neuroscience	<a href="http://www.iicn.ie/">http://www.iicn.ie/</a>
	The Neurological Alliance of Ireland (NAI)	Neurological conditions	<a href="https://www.nai.ie/">https://www.nai.ie/</a>
	The Medical Research Charities Group (MRCG)	General	<a href="https://www.mrcg.ie/">https://www.mrcg.ie/</a>



## **The Cost of Brain Disease and Proportional Investment in Brain health and research**

In November 2015, the European Brain Council produced a Consensus Statement on the Need to Expand Brain Research in Europe (EBC consensus statement, 2015). Brain disorders affect over 179 million individuals in Europe, impacting on one in three Europeans during their lifetime. The cost of brain disorders to the European economy and national health budgets is in the region of €800 billion per annum, representing 45% of the annual European health budget and comparable to that of cancer, cardiovascular disease and diabetes together. Indeed, it is estimated that over 1.1 million people in Ireland are living with a brain condition and the economic cost has been estimated at €3billion per year. The societal cost of multiple sclerosis alone in Ireland was recently estimated at €429m per year (MS Society of Ireland, 2015). As the field of medicine moves towards preventative care and early intervention, a similar shift should be reflected in the area of brain health; the potential economic and societal savings brought about by early detection and early intervention for brain diseases during critical periods of brain development far outweigh the financial costs of treatment. Such early interventions can fundamentally alter the trajectory of both disease and patient outcomes, thus preserving their capacity to effectively integrate into society.

While there are estimates of the prevalence of neurological disease for some conditions in Ireland, and very accurate data for both incidence and prevalence of some rare conditions (E.g. Motor Neurone Disease), there are insufficient accurate data at present to generate a meaningful cost of disease in terms of disease burden (to include diagnostic costs, management costs – including years of life lost, years lived with disability, and disability-adjusted life-years lost). The estimate is therefore based on an extrapolation from other countries. Clearly more work needs to be done in this area and the data cited in this paper are intended to be representative of the overall situation rather than the outcome of a systematic approach to the cost of brain conditions in Ireland.

Research investment in the neurosciences/brain research remains behind cancer and cardiovascular research and there is currently no directly targeted funding for neuroscience research. The Irish Brain Council carried out a survey of research funding income for neuroscience-related projects in 2017 across the seven Irish universities, yielding a total

investment in 2017 of €22,663,108 (please note: data from Trinity College Dublin were unavailable at the time of writing and are therefore not included). This figure includes projects addressing brain health as well as brain disease; it proved to be impossible to disentangle research funding for brain health from that addressing brain disease/disorder, as most (if not all) projects address some aspect of each.

***The Irish Brain Council supports the call outlined in the European Brain Council Consensus Statement (2015)***

It is imperative to improve the prevention, treatment and management of brain disorders for humanitarian, scientific, societal, political and economic reasons.

- We call on all European authorities to devise and implement a plan to tackle brain health in an integrated and comprehensive manner in co-operation with all EU member states
- We highlight the need to augment the support for basic and clinical brain research in Europe through current funding platforms, especially to retain promising young neuroscientists
- We recommend the European Brain Council serve as a liaison to optimise support for patients and research and to ensure funding support is best aligned with today's fundamental challenges and opportunities
- We recognise that it is the joint responsibility of all stakeholders to ensure that basic research is adequately translated into concrete applications
- Only by maintaining brain science high on the political agenda can both basic and clinical research be fortified and the burden of brain diseases reduced, preventing them from becoming a social emergency.

***Advocacy in Relation to the Consensus Statement: European Brain Council & Irish Brain Council***

A key recommendation made in the Consensus Statement is that neuroscience must receive more political attention as well as the largest part of the European budget for medical research. In view of this, the European Brain Council has made a strong case for increasing the budget of the next EU Framework Programme that will fund research and innovation

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during 2021-2027 entitled “Horizon Europe” and for making more funding available for health research. In 2018, the European Brain Council launched a position statement “Counting Down to Zero” which calls on the EU institutions to increase the Horizon Europe budget to at least €120 billion and significantly increase the budget of the “health” cluster under Pillar II. This statement has been endorsed by over thirty healthcare stakeholders across disciplines and disease areas. The European Brain Council also wrote to EU ministers responsible for research prior to the Competitiveness Council meeting in July 2017, calling on them to increase the Horizon Europe budget. The European Brain Council also provided input to a call for feedback that was launched by the European Commission in the summer of 2018 and highlighted the need for a robust Horizon Europe programme. European Brain Council also underlined that further specific objectives aimed at supporting brain research should be included in the programme. During the weeks after the consultation, six national brain councils wrote to their national governments and called for a budget increase.

The consensus statement underlines that there is a clarion call for greater ‘translational’ potential of basic science. Against this backdrop, the European Brain Council organized a session on “the Value of Innovation” as part of the event “Brain Research in Europe” on 25<sup>th</sup> April 2017. A wide range of healthcare stakeholders (patient representatives, payors, brain researchers, industries, etc.) exchanged views on issues that affect innovation and how breakthroughs can be translated into tangible solutions for patients.

The Irish Brain Council organises an annual meeting to showcase innovation in brain research taking place in Ireland, and also to promote and reiterate the messages of the consensus statement within an Irish context. Since the launch of the consensus statement in 2016, the focus of the Irish Brain Council has been on developing the umbrella in order that it is in a stronger position to be an advocate for brain research in Ireland.

### **Irish Brain Council Inaugural Position Paper**

The factors impacting on the strength and sustainability of brain health and research in Ireland are reflected across the research landscape and require systemic change. Brain health and research is an area of emerging opportunity in Ireland, but the sector is affected by

significant challenges which impact on the entire research landscape. This inaugural position paper from the Irish Brain Council highlights the critical issues facing brain health and research in Ireland. The paper also puts forward a series of recommendations to address these challenges:

The main recommendations focus on the following:

1. The importance of overall leadership and direction in relation to clinical research in Ireland
2. The importance of sustainable funding for brain health and research, across the full continuum from basic neuroscience to clinical research
3. The importance of networks and career pathways to support researchers
4. The importance of developing the infrastructure to support brain health and research
5. The need to involve patients and patient organisations as key stakeholders
6. Legislative and policy development and implementation to support brain health and research

### **1. The importance of overall leadership and direction in relation to clinical research in Ireland**

There is a critical need for a clear vision and strategy for clinical research in Ireland. The current landscape for clinical and biomedical research in Ireland is fragmented with a lack of leadership at national level to support research and translate the findings into improved patient care and practice within the health services. The Irish Academy of Medical Sciences' Position Paper (2012), "A framework for Irish clinical research in the 21<sup>st</sup> century", points out the value of the UK National Clinical Research Institute in providing a coherent approach across the health system in relation to research. The NIHR plays a key role in promoting career tracks and training for clinical scientists, developing the information technology necessary to support high quality clinical research and, importantly, identifying specific research areas for prioritisation and development.

The NIHR represents a suitable template for supporting clinical research into brain conditions in Ireland. The structure of Irish healthcare is similar to the UK, in that most care is funded directly from the exchequer through a Health Services Executive, rather than through a system of private medicine- or insurance-based funding. The acute hospitals within the public sector are grouped around academic centres with a Group CEO, and each Hospital Group has a nominated Chief Academic Officer. This existing structure aligns well with a proposed NIHR structure, in which clinical research funding is channelled through the academic and clinical facilities.

The Irish Brain Council endorses the need for a focused strategy and vision for clinical research in Ireland led by the Department of Health and addressing key areas of legislative support, funding and infrastructure to support research. The Brain Council welcomes the appointment in 2017 of a Head of Research and Development and Health Analytics in the Department of Health which provides an important focus for leadership within this area in the health services. The Irish Brain Council advocates for an Irish Institute for Health Research to integrate hospital- and academic-based research.

## **2. The importance of sustainable funding for brain health and research.**

Sustained public funding for brain health and research is critical to develop vital infrastructure and attract private and international investment. Funding challenges for brain health and research in Ireland include an overall disproportionately low allocation of the research spend across Europe, including Ireland, to brain disease in comparison to other disease areas. Other issues include the challenge of attracting international research funding to Ireland and ongoing threats to funding for basic neuroscience research.

Low levels of public investment continue to impact on the infrastructure for engaging in translational, clinically-applied and population-based research into brain conditions in Ireland and impact on this country's overall competitiveness in an area where we can provide international leadership. The strategic decision to prioritise applied/translational research at the expense of basic/fundamental science and to prioritise a limited number of research areas, has proven particularly detrimental to brain health and research in Ireland, as evidenced by

disproportionately low funding awarded to brain health and research activities (see above), and constant calls for a change in policy from senior academics in Ireland and beyond. Basic scientific research has been shown in other countries to generate a substantially greater economic return over the long term, and an active system of basic research provides the essential expertise, training and absorptive capacity to enable development and adoption of new technologies and translational opportunities. The Irish Brain Council supports the need for greater overall public investment in biomedical research in Ireland as well as the requirement to target some of this investment to brain disease areas.

Case Example: Lack of Neuroimaging Infrastructure to Support Brain Research in Ireland.

Ireland is relatively unique in comparison with other first world countries in the relative paucity of clinical research infrastructure for neurological research. Neuroimaging provides a useful example. There is only one dedicated 3T Research MRI scanner available which operates on a commercial basis, and no research PET facilities. As no public facility in Ireland has a cyclotron, it is impossible to conduct any PET imaging that requires labelled ligands with a short half-life.

A number of clinical research facilities are linked to public hospitals, but these are stand-alone units and operate at commercial rates. Because of this, collection of biological samples such as CSF and fibroblasts for biobanking purposes is logistically challenging in a clinical setting, as there are no dedicated facilities or staff. This is in part a function of the very low numbers of academic clinicians with protected research time within the Irish health system. Finally, there is a small Brain Bank in operation, but there is no sustainable ongoing funding to support this, and public awareness of the facility is low.

### **3. The importance of networks and career pathways to support researchers**

Developing networks and establishing appropriate career pathways to support researchers are crucial in strengthening and retaining research capacity in relation to brain health and research in Ireland. Support for networks both within and between disciplines in brain health and research is crucial. The creation of economies of scale in accessing emerging technologies, ensuring competitiveness, attracting international research and providing training and information through the network structure is of vital importance. Development

of coherent research networks through an Institute of Health Research can promote greater interaction between laboratory-based research, hospital research and industry are particularly important in the context of advancing understanding of the brain and development of new treatments. Such an approach could also address the current limitation of career opportunities for Irish researchers. Challenges including short term contracts and funding restrictions impact greatly on training at undergraduate and postgraduate levels. These problems are further compounded by the absence of career tracks for clinical academic researchers, and make Ireland increasingly unattractive for ambitious and competitive researchers. The Irish Health Research Forum (2016) recognized these concerns and has outlined how best to address the very serious problem of emigration of our best researchers. The Irish Brain Council calls for a national strategic approach to academic and clinical research, integrated by a National Institute for Health Research. The Brian Council calls for the prioritisation of career pathways in the neurosciences, and the provision of core infrastructure that will enable our best neuroscience researchers to remain in Ireland, and which will encourage and provide for structured engagement between academics, hospital-based stakeholders and potential industrial partners.

#### **4. The importance of developing the infrastructure to support brain health and research**

Investment in and development of new technologies and information systems to support brain health and research are vital to capitalise on niche areas where Ireland can be a leader in brain health and research. Ireland's size presents specific challenges around attracting research and engaging in collaboration with international partners. However, Ireland excels as a centre for population-based research. Because of its size, island status and genetic substructure, Ireland is ideally suited to population-based studies of complex genetic conditions, for example velocardiofacial syndrome (VCFS) and cystinosis. Irish researchers have already made significant international contributions in neuroepidemiology, deep phenotyping, population genetics and care pathways. It is important to recognise the significant return on investment that can be provided to Ireland through the development of research infrastructure in brain health and research.

However, there remains a critical need to develop the supportive infrastructure that will allow Ireland to capitalise on its important niche in these areas. The development of unique patient identifiers, electronic patient records, support for population-based registers that collect data from all patients, and access to emerging technologies including advanced neuroimaging, and functional tools for gene manipulation will be essential to remain competitive. The Irish Brain Council calls for the recognition of Ireland as a country ideally suited to population-based research in brain disorders, by providing adequate infrastructure and resources to enable detailed subphenotyping of those consenting to participate in research programmes. This would be best achieved by integration of epidemiology, clinical evaluation and genomics work through a National Institute for Health Research.

#### **5. The need to involve patients and patient organisations as key stakeholders in brain health and research**

Patient involvement is key to informing and improving brain health and research while patient organisations represent a vital link between patients, researchers and policy makers. Patient involvement describes a variety of ways in which researchers engage with people for whom their research holds relevance. There is a growing body of evidence that involving patients in research projects improves the quality, relevance and/or speed of that research. It is important that patients are facilitated to become involved at all stages of the research process so that they inform research questions, have input into the design of research protocols and play an active role in translating findings into practice (EU Parliament Interest Group on Brain Mind and Pain, 2014). Patient organisations play a critical role in promoting and supporting the involvement of patients in research. Patient organisations in Ireland currently provide significant financial support to fund medical research through providing specific research funding awards and fundraising for specific projects.

Patient organisations are also involved in informing their members about current opportunities for becoming involved in research studies, an invaluable support for recruiting participants. Patient organisations provide a critical conduit for linking patients to researchers, both in terms of recruiting participants and in communicating research findings. Patient organisations have a central role in ensuring that research findings are translated into



practice through their engagement with policy makers and advocating on behalf of the people they represent. Most importantly, patient organisations promote a positive image of brain health and research and the value of taking part in research studies in Ireland that should not be underestimated.

A report by the Neurological Alliance of Ireland (2015) found a strong commitment to supporting research among neurological not for profit organisations, including providing direct funding support for research and engaging in ongoing partnerships with individual researchers and research institutions to support participation in research and the dissemination and implementation of research findings. The Irish Brain Council is committed to promoting the involvement of patients in all stages of research and working in partnership with patient organisations as a key linkage between patients, researchers and policy makers.

Table 3 highlights a range of patient organisations providing crucial support for research into neurological conditions in Ireland.

Table 3: Support for Brain Research among Irish Neurological Patient Organisations.

Patient Organisation	Support for Research
<p>Progressive Supranuclear Palsy Association of Ireland (PSPA Ireland)</p> <p><a href="http://www.pspaireland.ie">www.pspaireland.ie</a></p>	<p>The organisation established a dedicated research fund in 2017 to support research into Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).</p> <p>The organisation aims to improve the opportunity for their membership to take part in research and trials here in Ireland, to engage with researchers to get a better understanding of the status of this condition in Ireland, to advance knowledge in these progressive conditions which will hopefully lead to finding a treatment or a cure.</p>
<p>Migraine Association of Ireland</p> <p><a href="http://www.migraine.ie">www.migraine.ie</a></p>	<p>The organisation supports researchers in the design, recruitment and dissemination of research findings into migraine and quality of life of migraine sufferers both in Ireland and internationally</p>
<p>Multiple Sclerosis Society of Ireland</p> <p><a href="http://www.ms-society.ie">www.ms-society.ie</a></p>	<p>Research is one of five Strategic Priority areas in MS Ireland's Strategic Plan for the period 2015-2019. The organisation also has a dedicated research strategy and research committee.</p>
<p>Headway Ireland</p> <p><a href="http://www.headway.ie">www.headway.ie</a></p>	<p>Headway supports people with Acquired Brain Injury to live in the community through a range of rehabilitative services. Research has always been undertaken within the organisation both as a means of ensuring we adopt evidence based practice but also as way to contribute to the field of rehabilitation studies. Current projects include a collaborative study to establish the epidemiology of Traumatic Brain Injury in Ireland, a study on the mental health impact of aphasia, therapeutic filmmaking and qualitative research on service interventions, amongst others.</p>
<p>Epilepsy Ireland</p> <p><a href="http://www.epilepsy.ie">www.epilepsy.ie</a></p>	<p>Supporting Irish epilepsy research is a key strategic objective of Epilepsy Ireland. Since 2010, over €1m has been invested in a variety of projects across basic science, genetics, health services, epilepsy deaths and psychosocial aspects of epilepsy. In 2017, new funding was provided for a study on ketogenic diet biomarkers, while projects on the impact of epilepsy specialist nurses and on epilepsy disclosure were completed. Epilepsy Ireland also continues to fund the Irish Epilepsy Deaths Register and is actively collaborating with research partners on studies on patient centred care, PPI, e-health development and valproate risk minimisation. The organisation also focuses on communicating to patients both the latest research developments and opportunities to volunteer in ongoing studies.</p>
<p>Acquired Brain Injury Ireland</p> <p><a href="http://www.abiireland.ie">www.abiireland.ie</a></p>	<p>Acquired Brain Injury Ireland is strategically committed to supporting research that generates an evidence base and advances knowledge and understanding to inform service developments, ensure best practice and engage in effective policy advocacy. It does so in a range of ways including funding external research, engaging in research internally, directly commissioning research to inform policy development and facilitating, where appropriate, the active participation of people using our services and their families in research projects. It also hosts an annual seminar for clinicians to showcase brain injury research in Ireland and uses national and international events to share and disseminate research</p>
<p>Alzheimer Society of Ireland</p> <p><a href="http://www.alzheimer.ie">www.alzheimer.ie</a></p>	<p>The Alzheimer Society of Ireland has developed a research strategy (2017-2020). The strategy sets out a plan to amplify the voice of the person with dementia and carers by developing and implementing PPI strategies. The research strategy also acknowledges the various gaps in knowledge and understanding of dementia, and plans to address these research gaps through avenues, such as a PhD scholarship programme. The ASI aim to increase their research budget over the coming years.</p>

## **6. Legislative and policy development and implementation to support brain health and research**

Legislative change, policy implementation and overall leadership are required to support and develop brain health and research in Ireland. Important legislative developments are required to support research into brain conditions in Ireland and provide important assurance for members of the public in areas such as oversight and ethics, data protection, the use of human tissue etc.

In 2017, the Department of Health in Ireland launched a public consultation to develop a national Health Information Policy. The comment below by HIQA (Health information and Quality Authority) is a good summary of the challenges faced by Ireland in this area and the requirement for appropriate legislation and policy to address the current shortcomings:

*“Ireland needs to develop strong health information policies and legislation to advance the eHealth agenda and to support, for example, the introduction of electronic health records. Ireland’s health information landscape is currently highly fragmented and legislation is vital to ensure that valuable information is accessed, shared and governed appropriately and that an individual’s personal health information is protected.”*

The Department of Health in Ireland also carried out a public consultation in 2017 on proposals for a Human Tissue Bill. Progressing these areas of legislation will be key to improving the regulatory framework in Ireland going forward.

The European Data Protection Directive replaced the 1995 Data Protection Directive and came into force in Ireland in May 2018. The implications for research are still uncertain with legislation due to be introduced early in 2019. The Irish Brain Council will monitor these developments closely, given the implications for patient-oriented research.

## Conclusion

Our recommendations can be summarised as follows (see Box 1).

Box 1: Summary of recommendations by the Irish Brain Council.

The IBC calls for the following actions:
Political focus on brain health and research – legislative and policy development/implementation
Facilities to maintain a Brain Bank
Funding for training/career pathways for researchers
Infrastructure for maintaining talent in Ireland/attracting talent back – including neuroimaging infrastructure
Infrastructure to facilitate translational, bench to bedside treatments – medical centre/academic centre
Developing/maintaining a system for electronic medical records
Sustainable, targeted funding opportunities
Working with patient organisations to engage patients at all stages of research

There is a vital need to invest in brain disorders. This should include the funding of career paths for laboratory-based neuroscientists while at the same time implementing programmes for clinician scientists. These researchers must be facilitated in the development of bench to bedside research, and in the provision of evidence-based models of care for neurology and neuro-rehabilitation within the health services. This would be best achieved through the development of managed clinical networks that are extensively networked with academic centres of excellence engaged in neuroscience research, and with access to information technology and the provision of opportunities for ongoing training and development of staff. The Irish Brain Council calls for leadership at a national level to drive a focused agenda around brain health and research that provides critical overall strategic direction in relation to all aspects of research within the health services.

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