



# ACQUIRED BRAIN INJURY IRELAND



**Trinity College Dublin**  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

## Stakeholder Policy Roundtable

How Irish health policy is  
responding to the  
rehabilitation needs of  
people with acquired  
brain injury.

18.02.2019



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## Acknowledgements

The hosting of the policy roundtable was made possible by the contribution of several people. Acquired Brain injury Ireland extends a sincere thank you to the following:

- Our partners Dr. Sarah Barry and Dr. Sara Burke from the Centre for Health Policy and Management, Trinity College Dublin who contributed their time and expertise pro bono.
- The participants who attended and actively contributed on the day and who took time out of busy schedules to be with us.
- Dr. Karen Foley, National Service Manager, Acquired Brain Injury Ireland for her participation in the project.
- The notetakers who took comprehensive notes and recorded the discussion.

Gráinne McGettrick  
Policy and Research Manager  
February 2019

## Introduction

Acquired Brain Injury Ireland hosted a policy roundtable with key stakeholders on the theme 'How Irish health policy is responding to the rehabilitation needs of people with acquired brain injury (ABI)' on 21 February 2019.

A range of expert stakeholders attended (see Appendix 1) and participated in a structured and facilitated agenda (See Appendix 2). The roundtable format started with a presentation on some of the key policy issues on brain injury and was then followed by a roundtable discussion in small groups with a key question posed to discuss. A second presentation was made on how systems thinking can address the ABI pathway, and this was followed by a plenary roundtable discussion, guided by a key question. Some final conclusions were made, and next steps/potential actions identified. The session was facilitated by an independent facilitator. This report follows the sequential format of the agenda and is a summary of the extensive inputs on the day. Chatham House Rules were applied.

## Background to the policy analysis project

The roundtable event is part of a larger policy analysis project that Acquired Brain Injury Ireland is working in partnership with Dr. Sarah Barry and Dr. Sara Burke from the Centre for Health Policy and Management, Trinity College Dublin (TCD).

The challenge that faces the brain injury community in Ireland is that there are so few policy resources and limited published work on brain injury from a policy perspective in Ireland. Therefore, to start to fill that gaps, the discussions with TCD led to an agreement to write a policy paper examining how Irish health policy is responding to meet the rehabilitation needs of people with ABI. Part of the process in drafting the policy paper was the need to engage with the broad range of expert, high-level stakeholders to shape, input and inform it.

## Aims of the roundtable

The roundtable engaged with a range of stakeholders who are the leading experts on brain injury rehabilitation in Ireland. It provided an opportunity for the brain injury community in Ireland to come together to discuss policy issues and explore collectively how they can be addressed.

The aims of the roundtable were to:

- Discuss brain injury specific policy developments in the context of Irish health policy
- Agree the key policy issues for this community
- Explore how to elevate brain injury as a specific policy issue in Ireland and finally
- Talk about building our community of interest in terms of brain injury and see how we can work collectively to bring about change.



**Input 1: Context setting and overview of the policy landscape**

**Presenters: Grainne McGettrick, Acquired Brain Injury Ireland**

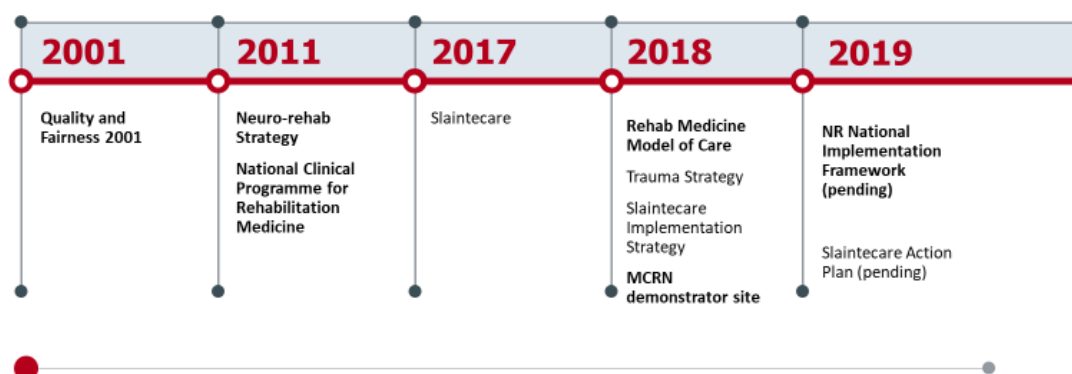
**Dr. Sara Burke, Trinity College Dublin**

Grainne outlined the main policy initiatives on rehabilitation for people with brain injury as plotted out on the timeline below (See Slide 1). Starting in 2001, the Health Strategy, Equality and Fairness stated that “an action plan for rehabilitation services will be prepared” with explicit mention of people with ABI. The expression of this commitment was the publication a decade later in 2011 of the Neuro-rehabilitation Strategy, by the Department of Health and the Health Service Executive (HSE). It set out a policy framework in terms of developing neuro-rehabilitation services in Ireland for the period 2011-2015. It acknowledged the level of underdevelopment of services and the many gaps across the pathway and stated that an implementation plan is needed to set out clear actions and timeframes.

The establishment in 2011 of the National Clinical Programme for Rehabilitation Medicine and the appointment of a clinical lead was noted as a significant development concurrent with the publication of the Neuro-rehabilitation Strategy. The clinical programme published the Model of Care for the Provision of Specialist Rehabilitation Services in Ireland in 2018. It proposes a hub and spoke model of service delivery with a national specialist centre linked to managed clinical rehabilitation networks. Seven years after the 2011 commitment to publish the implementation plan, work has now progressed on drafting a National Implementation Framework, due to be published in early 2019<sup>1</sup>.

## Key health policy milestones

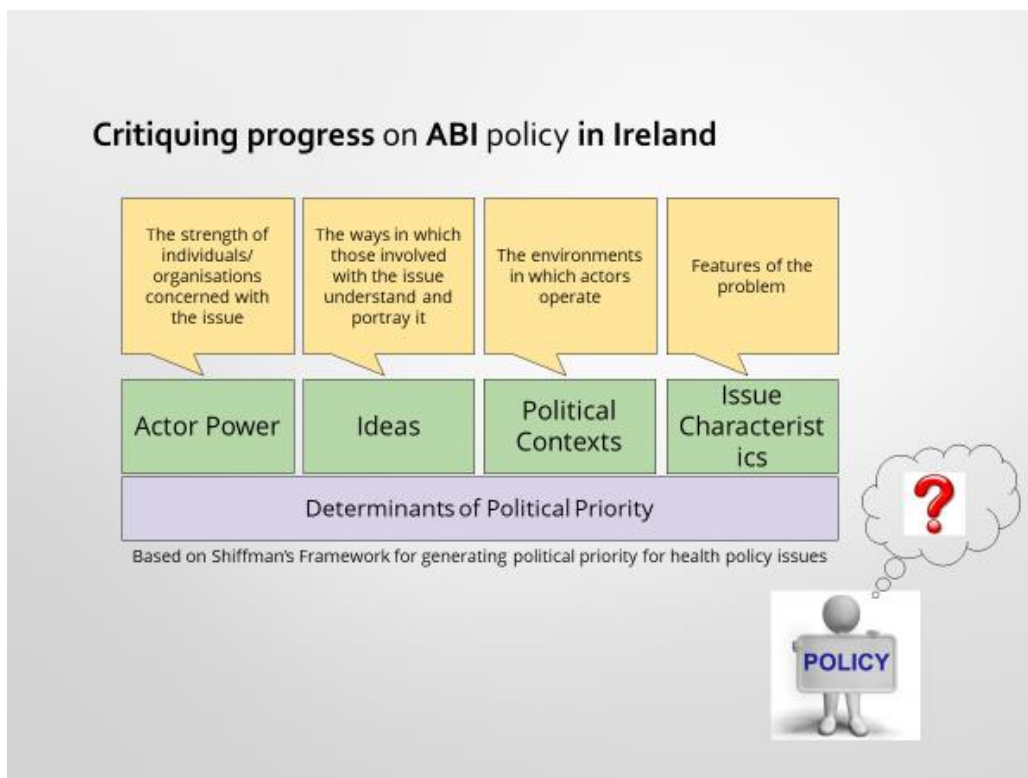
*Neuro-rehabilitation and brain injury*



Slide 1

<sup>1</sup> The Neuro-rehabilitation National Implementation Framework was posted to the HSE website two days after the roundtable event on 20.02.2019

Sara's presentation critiqued and analysed the progress or critically the absence of it in relation to neuro rehabilitation policy for people with ABI in Ireland. She used the work of Jeremy Shiffman, a political scientist and global health policy expert based in John Hopkins University in the USA. Shiffman has done a lot of work looking at what health issues gain political priority in low in middle income countries and from this work devised a framework of the determinants of political priority (See Slide 2). Shiffman's work is so useful in an Irish context is that he pays equal attention to how the political sphere influence political priority, policy choices and implementation.



Slide 2

Specifically, he draws on the work of John Kingdon policy streams and how the problem, policy (solution) and political stream come together to open policy windows of opportunity. And as advocates for policy change you need to be aware of potential policy windows of opportunity and be ready to ride the wave. Kingdon describes policy entrepreneurs like surfers, out in the deep waters, paddling, waiting for the big wave to come along so when it does they are ready to ride it and seize the policy window. It is what Shiffman refers to as political moments when conditions align favourably for advocates to influence decision makers.

Using Shiffman to assist a critique of ABI policy development for people with ABI the following conclusions were drawn:

- ✚ Despite the policy intent in relation to developing rehabilitation services for people with ABI since 2001, it has been largely not delivered, milestones have been continually missed and progress has been very slow.
- ✚ Despite good and increasing knowledge on what to do in terms of clinical pathways and how to deliver effective rehabilitation especially in the community, services have improved but are still way below the levels of what they should be.
- ✚ Policy commitments and policy implementation have been constantly stalled and delayed and even when the Implementation Framework is ready to be published, it remains unpublished and critically not costed.
- ✚ The invisibility of people with ABI and the difficulties in people with ABI being advocates for themselves must be a contributory factor to the lack of political priority, policy implementation and service change.
- ✚ Poor data must also contribute to this lack of political priority.
- ✚ There has been and continues to be a stark absence of political or institutional leadership on meeting the needs of people with ABI.
- ✚ The current policy environment of Slaintecare and the unpublished Implementation Framework perhaps suggests a potential window of opportunity. While progress has been slow on Slaintecare, a few developments worth watching are the potential of new regional integrated care organisations to deliver neuro-rehabilitation services. Minister Simon Harris said his two Slaintecare priorities for 2019 are the regional alignment of CHOs and hospital groups called Regional Integrated Care Organisations (RICOs) and an Integrated Care Fund. If used properly, these provide good opportunities for neuro-rehabilitation policy and better meeting the needs of people with ABI.
- ✚ Critical to all this work is that you have ABI advocates providing leadership and a cohesive front to ensure that ABI becomes a political priority.

### Feedback from the roundtable discussion 1

Following the presentation, there was a roundtable discussion in smaller groups based on a key question. The feedback from the groups were themed into key headings.

**KEY QUESTION:** How can we as key stakeholders and advocates for people with ABI ensure that the rehabilitation needs of people with brain injury become a political priority?

#### Definition of ‘acquired brain injury’

What are we talking about when we say, “acquired brain injury”? How do we define ABI? It is a very broad term that includes TBI, mild brain injury, stroke, tumour, concussion, disorders of consciousness and other forms/causes of brain injury. The complexity and variation in the symptoms and presentation of ABI is challenging. It is difficult to talk about this heterogenous population in a general sense and equally difficult to try to convey that to policy makers and politicians. In addition, the rehabilitation needs of people with ABI vary



hugely and explaining these nuances in the public/political realm is challenging. Stroke is not readily identified as a brain injury and has a better understanding in the public arena. The big question to answer is focusing on the diagnosis useful or not?

### **Messaging around brain injury**

As a result of the challenges around the definition of acquired brain injury, the messaging around it is difficult. We need to find the language and a way to describe brain injury that is easily understood. We also need to think creatively around how to get the key messages across and what it is we are asking for. Given the level of under-development, there needs to be priority issues identified and key messages formulated. We need to come with the solutions and the messaging must be clear.

### **Data and evidence**

The lack of data on ABI is a massive issue as the problem cannot be quantified or understood. The lack of data on the population is also a major stumbling block in developing coherent policy and makes service planning very challenging. Not being able to present data on this population is a major stumbling block in terms of engaging in policy and political advocacy.

In addition, there is not enough evidence from a health economic perspective in relation to the impact rehabilitation has on the individual, the health services and society in general. There is need to generate such evidence not only around improvements in quality of life but to show the cost savings as well. Savings at the acute hospital level are particularly important to establish. Then such evidence needs to be translated into an easily understood and digestible format for engaging with policy and political stakeholders.

### **Finding a 'home'**

ABI doesn't sit neatly into any one policy area or health service structure given the nature and expanse of rehabilitation services that the person with ABI requires. There is no one 'home' or overall ownership for ABI/neuro-rehabilitation and therefore, the accountability and transparency is challenging. It was described as a 'hot potato situation', shifting to different providers with different funding streams and funding silos. The Managed Clinical Rehabilitation Network (MCRN) model with a dedicated Neuro-rehabilitation Office in the HSE with its own budget would be a way to address the lack of a home and the current siloed approach to funding. In the US, there are efforts to get ABI defined as a chronic illness.

### **Political engagement**

There is a lack of political awareness around what brain injury is and what is needed in terms of a policy and service response. It is not on the political agenda and the problem is a complex one to try to get across. Advances in stroke services have been made and stroke has experienced greater levels of political awareness. The reason for the lack of political engagement is that politicians are not aware as people who are affected by brain injury are

not mobilised nor having their voice heard. Alignment with others neurological groups who require neuro-rehabilitation services is important. Should brain injury advocacy extend to represent neuro-rehabilitation in general? The roll out of the trauma strategy and alignment with rehabilitation for major trauma patients is another opportunity. There has not been any real political leadership to date and very often it is the personal experience of politicians that ignites interest.

### **Voice of people affected**

Getting people with the lived experience to tell their story is a very powerful tool. Some people with brain injury may face challenges in engaging but good advocacy should be inclusive of the myriad of voices. Mobilising people to engage with politicians locally is important to raise the profile. The emotional connection must be made through lived experience narrative. Enabling the voice of the lived experience will increase the visibility, awareness and understanding of brain injury. The challenge of invisibility is that 'you're OK' and the complex needs remain invisible.

**Input 2: Can systems thinking address a fragmented brain injury pathway?**

**Presenters: Dr. Sarah Barry, Trinity College Dublin**

**Dr. Karen Foley, Acquired Brain Injury Ireland**

Sarah used systems thinking approach to illustrate the level of fragmentation in the ABI pathway and highlighted fragmentation in terms of the data, the services, personnel, resourcing of services and the limited engagement of people with ABI and their families in policy formulation.

There is a fragmented vision of neuro-rehabilitation services, including fragmented voice, policy process, ownership and buy-in, political commitment and policy coherence. There is also a fragmented delivery system with fragmented neuro-rehabilitation services indicating a system that is unfit for purpose. In order to deliver services that are complex, person-centred and long term it requires system design and delivery that is person/population-focused, realistic, iterative, distributed, customised, subsidiary, coordinated and supported. This requires dedicated programmatic and change management resources, that are both responsive to change and adaptive. Central to the systems approach and creating change is understanding and creating connections and empowering relationship building within the system.

The systems thinking approach was illustrated using the HSE Integrated Care for Older People and the 12 pioneer sites that used a ten-step framework to develop cohesive primary and secondary services for older people with complex needs. The learning from the work is presented in Slide 3 below. An integrated care approach is a disruptor in the system and one where the population's needs are prioritised over the organisation's needs. We must learn how to do integrated care and we need to have resources in the system to facilitate this change led nationally with local systems co-designing and co-creating the response.

## Learning from Integrated Care for Older Persons



### Slide 3

Karen's presentation focused on how the fragmented pathway translated to the reality on the ground and used case studies to illustrate this impact on individuals and their families. The ideal pathway is where the person would move seamlessly from one service to the next and with each service on the pathway fully resourced with the full complement of multi-disciplinary staff and dedicated brain injury services in place (see Slide 4). The current pathway where the person with ABI moves in a truncated way to services that are not properly resourced is both limited in scope and limited in the opportunity to refer on to an appropriate service. For many, they are lucky to get access to the rehabilitation services they need, particularly in the community; families struggle to cope; people with brain injury struggle to return to their roles in the family (s.a. parenting) and getting in back to work/college. The case studies talked about individuals who are in hospital ready for discharge but have nowhere to go and people living in nursing homes. In addition, there are individuals who wait months, some years, to get access to rehabilitation services across the pathway. The lack of a comprehensive case management service across the country was highlighted. The case studies essentially highlighted the "lost potential" for the individual, their family and society.

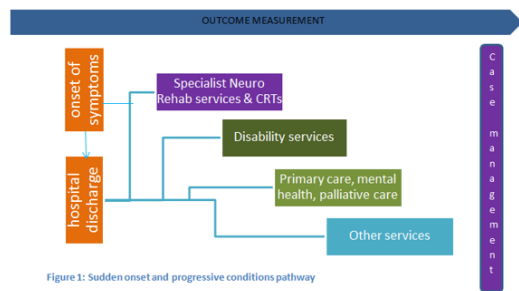


Figure 1: Sudden onset and progressive conditions pathway

2. Types of community services

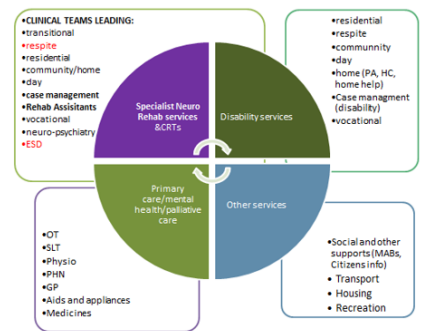


Figure 2: Pathways in the community

# What should the Pathway Look Like?

Slide 4

## Feedback from roundtable discussion 2

Following the presentation, there was a plenary roundtable discussion based on a key question. The feedback from the groups were themed into key headings.

**QUESTION:** Given that change needs to be both policy and practice focused ('top-down, bottom up') what practical actions can be taken from within the **system** to create the conditions for an improved brain injury rehabilitation pathway?

## Integration and brain injury

There is very little integration on the brain injury pathway. Currently, much of the integration is being done organically by families. There are a number of brain injury case managers in the community supporting people with their transition from hospital to home. These are highly trained and expert in their field, but the issue is that they are not available across the whole country and therefore, limited to geographical areas. Any integration in the system is not systematic and there is no-one leading it out. Where there is integration, it is an individual or small group of people working within the system, rather than been driven systematically. A key issue for developing an integrated approach is that there are services there to integrate, however, currently in brain injury, there are not enough services and we do not have the clinical or support personnel in place. Therefore, any integration is limited when you have patchy and fragmentation in services. Key questions were posed including: what is the vision for integrated care and what role is the Department of Health playing in promoting this approach? What role has primary care in delivering integrated care as currently GPs have a very low awareness of ABI? Brain injury requires integration across

multiple sites, multiple services and multiple providers and within each setting/service a range of clinicians are required.

There are some good examples of integrated care for stroke patients which in turn helped to illustrate where patients didn't get integrated care the impact it had on their outcomes and quality of life. It would be useful to find examples of practice where integrated care is working and the learnings shared.

### **Highlighting the gaps**

We all know anecdotally about these gaps in the services across the pathway, however, we need to find a way to build the evidence about the gaps, where they are and their consequences for the individual with ABI and their family.

As brain injury services providers, we typically do well for the people that are in our services. However, what about the people who are on our waiting lists? We need to expose the failures and gaps in a public way. We need to expose the numbers of people who are still waiting to access rehabilitation services (hospital and community), what are the waiting times and highlight the challenges if an individual with ABI needs to re-access the service. Organisations could use their annual reports to paint the wider picture of what's happening. We need to have standards in place to measure current delivery against and this again will expose the gaps.

Typically, as service providers we are responding to the needs of the most complex cases, but what happens to the large portion of the population with mild brain injury who present to A&E but are sent home? What about their rehabilitation needs? They usually only encounter services when there is a problem/issue with their symptoms.

Data gaps need to be filled. We should look at the data we already have as service providers and use that to start to fill data gaps. The Hospital In-patient Enquiry (HIPE) data is only capturing TBIs, and not all TBIs if there is another diagnosis along with the TBI. A question was asked is it possible to get changes to the data collection in HIPE to include a wider range of ABIs? Also, is it possible to get non TBIs to be recorded as part of the trauma data collection? Not having a unique patient identifier system in place is a major barrier and until this is established, services will have to continue to manually link an individual's data.

### **Creating a unified vision**

We are lacking a vision for brain injury policy. We have seven years of learning from the clinical programme and how do we take these learnings and unify that into a vision for the stakeholders in the brain injury community? What role has the Department of Health in delivering such a vision? Within the HSE there is a disconnect between HSE central and local HSE CHOs. There is no one united vision or consistency in approach.

We need clarification on what the role of the Department of Health is in providing policy leadership. In addition, identifying who are the named senior policy people in the Department of Health who have this responsibility is important.

## Next steps: possible areas for action

Several possible actions were identified throughout the roundtable discussions including:

- Examining the possibility of current service providers and other stakeholders sharing the data they already have and using it to generate evidence.
- Getting HIPE to collect more data on ABI (as they do with stroke).
- Slaintecare has €20m Integration Fund: could brain injury become a test case?
- Model of Care has a flow chart for ABI pathway and additional work on this to add in the more detailed steps would be useful.
- A service mapping project was carried out by the HSE as part of developing the Implementation Framework, is there a way to work with the HSE to do something with this data and validate it? (possible role for the local implementation teams when established).
- Using personal stories to advocate for change and simplify the messages around the 'asks' in terms of policy and services.
- Developing a clear and easily understood definition of brain injury and an explanation of what it is.
- Following up on the unique patient identifier as this is an essential element in terms of data and integrated care.
- Service providers to collate information on waiting lists as a way of exposing the gaps and used in an advocacy context and reported on in annual reports.
- Learning from current Integration Programme for Older People and see how that could translate to brain injury.
- Information and education for GPs on brain injury.
- TCD and Acquired Brain Injury Ireland to publish the policy analysis paper as a key policy advocacy tool.

## Final remarks

Barbara O'Connell, Chief Executive concluded the roundtable with some final remarks. She highlighted that this unique opportunity of coming together to talk collectively about the issues we face in the brain injury community is both empowering and critical. The need to work collaboratively has never been greater. We need to ensure that we have our voice heard and that we as stakeholders play an active part in the policy making process. Today's roundtable has highlighted the many policy and service challenges we face, and Acquired Brain Injury Ireland is ready to play its part and we will continue to work collectively and collaboratively with all in this room to improve the lives of people with ABI and their families.

**Appendix 1  
Roundtable Participants**

<b>Title</b>	<b>Name</b>		<b>Title</b>	<b>Organisation</b>
	Barbara	O'Connell	Chief Executive	Acquired Brain Injury Ireland
Dr.	Karen	Foley	National Service Manager	Acquired Brain Injury Ireland
Dr.	Brian	Waldron	Neuro-psychologist	Acquired Brain Injury Ireland
	Gráinne	McGettrick	Policy and Research Manager	Acquired Brain Injury Ireland
Dr.	Sara	Burke	Policy Analyst	TCD
Dr.	Sarah	Barry	Assistant Professor	TCD
	Edina	O'Driscoll	Programme Manager MCRN Demonstrator	HSE
Prof.	Mark	Delargy	Rehabilitation Medicine Consultant	NRH/Beaumont
Dr.	Jacinta	McElligott	Rehabilitation Medicine Consultant, Clinical lead	National Rehabilitation Hospital
	Ciara	O'Rourke	Clinical Nurse Specialist	Beaumont Hospital
	Conor	Leonard	Operations Manager	Donnybrook Hospital
	Elaine	Whelan	Speech and Language Therapist	CRT Limerick
	Sonya	Gallagher	Head of Rehabilitation Services	Headway Ireland
	Niamh	Cahill	Expert by experience	
Prof.	Anthony	Staines	Professor of Health Systems	DCU
	Dervilla	Danaher	Physiotherapy Manager	Mater Hospital
Dr.	Dominic	Trepel	Assistant Professor, Health Economist	Global Brain Health Institute, TCD
	Monika	Pilch	PhD scholar	TCD
	Manjula	Manikandan	Neuro-physiotherapist PhD scholar	RCSI
Dr.	Valerie	Toomey	Programme Manager (Brain Injury)	National Rehabilitation Hospital
	Fran	Malone	Family carer	
	Chris	Macey	Advocacy Manager	Irish Heart Foundation
	Richard	Stables	Information Manager	Headway Ireland
	Dee	Da Silva	Executive Assistant	Acquired Brain Injury Ireland



	<b>Caroline</b>	<b>Cullen</b>	<b>Communications Manager</b>	<b>Acquired Brain Injury Ireland</b>
	<b>Jane</b>	<b>Clarke</b>	<b>Independent Facilitator</b>	
<b>Apologies</b>				
<b>Prof.</b>	<b>John</b>	<b>Ryan</b>	<b>Emergency Medicine Consultant</b>	<b>St. Vincent's University Hospital</b>
<b>Prof.</b>	<b>Joe</b>	<b>Harbison</b>	<b>Geriatrician</b>	<b>St. James Hospital/TCD</b>
<b>Prof.</b>	<b>Ronan</b>	<b>Collins</b>	<b>Clinical lead, Stroke Programme</b>	<b>Tallaght University Hospital</b>
	<b>Joan</b>	<b>McCormack</b>	<b>Programme Manager, Stroke Programme</b>	<b>HSE/RCSI</b>
	<b>Catherine</b>	<b>Slattery</b>	<b>Director of Rehabilitation</b>	<b>Peamont Hospital</b>
<b>Dr.</b>	<b>Cathal</b>	<b>Morgan</b>	<b>Head of Operations, Disability Services</b>	<b>HSE</b>
	<b>Marion</b>	<b>Meany</b>	<b>Head of Disability Strategy and Planning</b>	<b>HSE</b>
	<b>Kieran</b>	<b>Loughran</b>	<b>CEO</b>	<b>Headway Ireland</b>
	<b>Dervla</b>	<b>Kenny</b>	<b>Programme Manager Rehabilitation Medicine</b>	<b>HSE</b>
	<b>Gabriele</b>	<b>Gardenal</b>	<b>PhD Scholar</b>	<b>TCD</b>
<b>Dr.</b>	<b>Niall</b>	<b>Pender</b>	<b>Neuro-psychologist</b>	<b>Beaumont Hospital</b>



## Appendix 2 Agenda

### Stakeholder Policy Roundtable

**How Irish health policy is responding to the rehabilitation needs of people with acquired brain injury.**

**18.02.2019**

<b>Time</b>	<b>Item</b>	<b>Speaker/Lead</b>
<b>9.00am</b>	<b>Arrival, tea and coffee</b>	
09:30	Welcome and introductions	Grainne McGettrick, Acquired Brain Injury Ireland
09:40	Introductions	Facilitator: Jane Clarke
10:00	<b>Input 1: Context setting and overview of the policy landscape</b>	Grainne McGettrick, Acquired Brain Injury Ireland Dr. Sara Burke, TCD
10:20	Roundtable discussion	Facilitator: Jane Clarke
10:50	Summary of the main points from the discussion	Facilitator: Jane Clarke
<b>11:00</b>	<b>COFFEE BREAK</b>	
11:15	<b>Input 2: Can systems thinking address a fragmented brain injury pathway?</b>	Dr. Sarah Barry, TCD Dr. Karen Foley, Acquired Brain Injury Ireland
11:35	Roundtable discussion, plenary	Facilitator: Jane Clarke
12:05	Summary and agreement of the main points Next steps	Facilitator: Jane Clarke
12.25	Final remarks	Barbara O'Connell, CEO Acquired Brain Injury Ireland
12.30pm	Ends	

**This event will begin and end on time and Chatham House Rules will apply**