

LOOKING BEYOND COVID-19: EMBRACING DIGITAL SOLUTIONS FOR NEUROLOGICAL CARE

JULY 2021

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WITH THANKS TO OUR FUNDERS



INTRODUCTION



Welcome to our report which examines the experience of online service provision within neurological care services in response to COVID19. This publication brings together a series of investigations and discussions with a range of stakeholders: from service users to providers and incorporating research findings and insights from across healthcare in Ireland as we strive to understand this new digital landscape: its opportunities and its challenges.

March 2020 saw the beginning of a rapid and unprecedented move to deliver online services and supports across neurological care services. Within a very short timeframe, people with neurological conditions were accessing hospital appointments, physiotherapy sessions, support groups and information through their laptop or smartphone with the entire range of services, both in hospital and community, having to adapt rapidly to the digital environment.

A year on from the first lockdown announcement, in March 2021, NAI organised a webinar “Beyond COVID19: Promoting Digital Responses to the Needs of People with Neurological Conditions” featuring a round table discussion involving stakeholders from across neurological care together with health service leads in information technology and digital transformation.

This report summarises the discussion from this webinar, together with the findings from surveys and interviews conveying the perspectives of service users and providers across both hospital and community services.



The report also incorporates a series of profile pieces from NAI member organisations, outlining their individual digital responses to COVID19. A similar approach has been used in the recently published report by the National Economic and Social Council¹ to highlight the speed and depth of the response to COVID19 by the voluntary sector. The examples in this report show voluntary organisations within neurological care at the forefront of understanding and responding to the potential of digital technology to reach out to their clients.

This publication represents a first step by the NAI in seeking to reflect on the learning from the online experience and understand the potential implications for future service delivery to meet the needs of people with neurological conditions. We hope that the findings and discussions outlined in this document will be of interest to all our stakeholders and will contribute to the emerging debate on the future of online healthcare in Ireland.

Magdalen Rogers
NAI Executive Director

Tom Scott
NAI Chair

¹ Building a New Relationship Between Voluntary Organisations and the State in the Health and Social Care Sectors: Paper from the Dialogue Forum with Voluntary Organisations (June 2021) National Economic and Social Forum

FOREWORD



I am delighted to contribute the foreword to this Neurological Alliance of Ireland report: Looking Beyond COVID19: Embracing Digital Solutions to Neurological Care. COVID19 saw a rapid and unprecedented move to utilising digital technology to deliver services within health and social care settings. Service providers and service users were catapulted into what was for many a new and challenging space. Neurological care has always been at the forefront of pioneering the use of technology in healthcare in Ireland. This report, together with the NAI webinar in March of this year, highlights for me that this drive to innovate and embrace change is increasingly becoming embedded across all providers of neurological care in Ireland. At its centre is a network of patient organisations which have developed specialist responses to the needs of people living with neurological conditions in the community.

There is a clear opportunity for the HSE to learn from and engage with providers across neurological care in learning from their experience and incorporating their expertise as we seek to integrate telemedicine and digital health into future service provision. One of the particular strengths that comes across in this document is the extent to which neurological providers have reached out to and listened to service users: pre-empting the two-way conversations that needs to take place to involve patients as equal partners in the co-design of all healthcare approaches, including the use of digital technologies.

I congratulate the NAI for putting together this very valuable and informative report and look forward to working with them into the future.

Prof Martin Curley

Director of Digital Transformation and Open Innovation Health Services Executive

SUMMARY

SURVEY FINDINGS

75% of service users surveyed would use online services into the future

74% of service users would like a combination of face to face and online services going forward

26% of service users reported poor broadband as a barrier to accessing online services

60% NAI member organisations providing an average of 60% services online compared to 8% pre-COVID

53% NAI members estimating they are reaching an average of 53% of their client base through their online service provision (estimates across providers ranged from 10% to 90%)

SUMMARY OBSERVATIONS AND RECOMMENDATIONS

There needs to be a national, co-ordinated approach to the provision of online healthcare, recognising the resources required in terms of equipment, expertise and dedicated staffing to provide these services.

There is a requirement for systematic research both within neurological care services and wider healthcare to evaluate outcomes from online healthcare provision and the type of care that is suitable to be provided online.

This report captures the extensive work carried out by individual NAI member organisations, only in designing online services to meet the needs of their clients but also providing considerable support and outreach to enable them to avail of these services. The extraordinary response of the voluntary sector to the challenges of COVID19 gives added impetus to the need to build a new relationship with Section 39 organisations based on true acknowledgement and practical recognition of their role within health and social care services.

The service user must be central to the debate on online healthcare going forward. People should be enabled to have real choices about how their care is delivered and should not be disenfranchised by the use of digital technology in providing services.

SECTION 1: STAKEHOLDERS PERSPECTIVES

FROM SERVICE USERS AND SERVICE PROVIDERS

NAI carried out a series of investigations in late 2020, aimed at capturing the experience of service users as well as service providers from both hospital based and community based (not for profit) neurological care services.

PART 1: SERVICE USER PERSPECTIVES

Over one hundred service users completed an online survey in late Autumn 2020. The findings highlight the extent to which respondents had increased their use of online supports, with 39% reporting that they received services or supports for their neurological condition “always or usually” compared to 17% before the pandemic. Almost half of those surveyed (46%) reported that they were now receiving most of their services online with over 50% of respondents reporting that their use of online services had increased significantly since the onset of COVID19. The type of services accessed online varied from support groups (65% of respondents reported accessing these online) to appointments with their neurologist (35%) and online webinars for information or advice about their condition (35%).

A majority of respondents (75%) saw themselves using online supports and services into the future, after COVID19. Only a small percentage reported that they would like to receive all their services online (6%) with the vast majority preferring a combination of face to face and online services (74%).

The survey findings also provide an insight into service users preferences for the type of services that are provided online and face to face. For example while 76% would rather access an information seminar online, 87% would prefer a face to face appointment with their neurologist.

A vital caveat is that this survey fails to capture the views and experiences of service users who, either by choice or due to other reasons such as lack of access to or ability to navigate technology, did not avail of online services and supports during the pandemic. This report highlights throughout that the needs and preferences of these service users must be reflected in the design and delivery of services going forward and their voice must be heard in any future debates on the delivery of neurological care services and wider healthcare.

Table 1.1 Currently accessing services or supports for your neurological condition online (i.e. via your computer, laptop or smartphone)

Accessing services or supports for neurological condition online	Percentage (%)
Yes	61%
No	39%

Table 1.2 Frequency with which respondents have received services or supports for their neurological condition over the past month via your computer, laptop or smartphone

Received services or supports via computer, laptop or smartphone over past month	Percentage (%)
Always	14%
Usually	25%
Sometimes	32%
Rarely	18%
Never	11%

“Online access so much less stressful than travelling to hospital and waiting in a room for hours before appointment only for said appointment to last less than 5mins, haven taken the day off work to do so”

“Ideally would like combination of online services and face to face service”

“Less cost/time travelling between appointments”

“It can be helpful and time saving but I also feel the need for face to face contact”

Table 1.3 Extent to which service users were accessing services or supports online for their neurological condition before the onset of COVID-19

Received services or supports via computer, laptop or smartphone over past month	Percentage (%)
Always	14%
Usually	25%
Sometimes	32%
Rarely	18%
Never	11%

Table 1.4 Extent to which service users are currently getting their services online rather than face to face

Accessing services online rather than face to face	Percentage (%)
I now access most services for my neurological condition online	46%
I access some services online but mostly face to face	22%
I am finding it very difficult to access services at all whether online or face to face	17%
About equal online and face to face	15%

Table 1.5: Use of online services and supports for their neurological condition since the onset of COVID-19

Change in use of online services and supports since COVID-19	Percentage (%)
It has increased significantly	51%
It has increased somewhat	21%
It has stayed the same	23%
I used online services for the first few months of COVID but now my use has decreased	5%

Table 1.6: Type of online services and supports accessed over the past month (option to choose more than one service)

Type of online service/ support	Percentage (%)
Appointment with my neurologist	35%
Appointment with a nurse specialist	10%
Appointment with my GP	27%
Support Group Online	65%
Physiotherapy session online	24%
Meeting with my key worker or case manager online	4%
Online webinar for advice or information on my neurological condition	35%

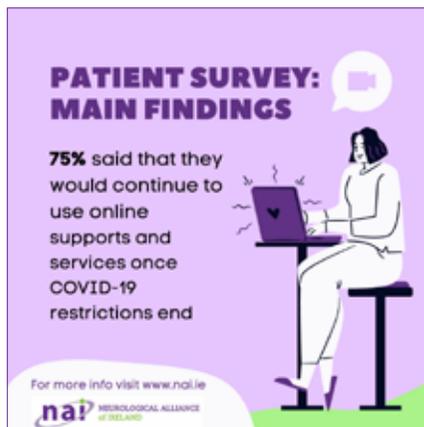


Table 1.7: Barriers in accessing online services and supports.

Barrier	Percentage (%)
Poor broadband coverage	26%
Difficulty getting access to a computer or laptop	11%
Difficulty understanding how to use technology	18%
Preferring face to face communication	32%
Concerns over privacy	13%

Table 1.8: Extent to which service users see themselves accessing online supports and services in the future after COVID-19

Using online supports and services in the future after COVID-19	Percentage (%)
Yes	75%
Not Sure	20%
No	5%

Table 1.9 Service User Preferences for Future Care

Response	Percentage (%)
I would like to have the choice of a combination of face to face and online services and supports going forward	74%
I would prefer to get most of my services and supports online	6%
I would prefer to get all my services and supports face to face rather than online	20%

Table 2.0 Type of services users would prefer to receive online or face to face

	Face to Face	Online through my computer or laptop
Appointment with my neurologist	87%	13%
Appointment with my specialist nurse	60%	40%
Appointment with my GP	86%	14%
Support Group for People with My Condition	34%	66%
Physiotherapy session	68%	32%
Meeting with my key worker or case manager	57%	43%
Information Seminar for people with my condition	24%	76%



PART 2: PERSPECTIVES FROM NOT FOR PROFIT PROVIDERS

Not for profit organisations provide the critical infrastructure of long-term community based neurological care in Ireland. The pandemic saw an exponential rise in demand for many of their services as many statutory supports were closed or curtailed with staff redeployed to COVID-19 roles within the health services.

Thirteen not for profit providers of neurological care services completed the NAI survey in late Autumn 2020, approaching nearly half of the total membership of the umbrella. The responses reflect the extent to which organisations had responded to the need for online service provision with 60% of current services being delivered online at the time of the survey compared to 8% pre-pandemic. Organisations recognised the challenge of reaching out to all service users estimating that, on average, half of their clients were accessing services online. Client preference for face to face interactions, as well as issues with broadband access and use of technology among service users represented the most significant barriers to delivering online services within these organisations.

NAI recognise that the survey findings do not capture the unique approaches adopted within individual organisations as they transformed their service models to rapidly embrace the need for online supports and other outreach services. This section of our report therefore includes a series of individual profile pieces from NAI member groups reflecting their own experiences and the tailored approaches developed within each of their organizations' as they responded rapidly and flexibly to the needs of their clients.

Table 2.1 Provision of online services by the organisation

Currently providing supports service online	Percentage (%)
Yes we are currently providing online services to our clients	93%
No we are not currently in a position to provide any online services to our clients	7%
We do not currently provide online services but we are currently developing our capacity to do so	0%

Table 2.2: Pre COVID and Current Online Service Provision

	Average percentage (%) across organisations
Estimated percentage of your organisations total services/programmes delivered during lockdown	67%
Estimated percentage of your organisations services currently being delivered online	60%
Estimated percentage of your organisations services that were delivered online pre COVID19	8%
Estimated percentage of your total clients that are availing of online services to any extent	53%
Estimated percentage of your organisations services that will continue to be delivered online over next SIX MONTHS	62%

**Table 2.3: Type of Services/Supports Provided Online
(Opportunity to Tick More than One Response)**

Type of service/support delivered online	Average Percentage (%) across organisations
One to One Helpline/Advice/Information	44%
Support Group	89%
One to One Meetings with key worker/case manager	56%
Physiotherapy or exercise classes	22%
Rehabilitative training sessions	44%
Webinars featuring health professionals and other specialists	78%

Table 2.4 Barriers to delivering services online from a service provider perspective (Ranked 1-7)

Barrier to delivering services online	1	2	3	4	5	6	7	N/A
Staff expertise and experience in using technology	0%	14%	14%	29%	0%	0%	29%	14%
Access to equipment for staff, laptops etc.	0%	0%	25%	25%	13%	0%	25%	12%
Local broadband access for staff working from home/remotely	0%	0%	33%	22%	22%	11%	0%	12%
Difficult to provide online services that are suitable for our client group: we need to be face to face	12%	33%	0%	22%	0%	22%	11%	0%
Many of our clients are not online due to age profile/broadband access or other reasons	25%	25%	13%	0%	13%	13%	0%	11%
Current funding is not structured to enable us to deliver services online	13%	0%	13%	0%	25%	38%	0%	11%
Clients prefer face to face interactions and prefer not to use online service options	50%	25%	0%	0%	13%	0%	12%	0%

Table 2.5 Needs in order to continue to deliver services online (Ranked 1-7)

Needs in order to deliver services online	1	2	3	4	5	6	N/A
Training for staff in the use of technology	13%	25%	13%	0%	25%	13%	11%
Access to equipment: laptops etc for staff	13%	13%	11%	25%	13%	25%	0%
Improved broadband access for staff working from home/remotely	0%	22%	0%	22%	33%	23%	0%
Improved broadband access more generally: to enable our clients to access online services	22%	11%	56%	0%	11%	0%	0%
Changes in how current funding is structured in order to enable our organisation to deliver online services	11%	12%	0%	44%	0%	22%	11%
Specialist expertise available to our organisation in order to develop online programmes/address privacy issues etc	33%	11%	22%	12%	22%	0%	0%

Table 2.6 Potential Barriers for Service Users in Accessing Online Services (From a Provider Perspective) Ranked 1-6

Barrier to clients accessing online services	1	2	3	4	5	6	N/A
Poor access to the internet (broadband)	12%	22%	11%	22%	22%	11%	0%
Difficulty getting access to a computer or laptop	25%	25%	25%	25%	0%	0%	0%
Difficulty understanding how to use technology	25%	38%	25%	0%	12%	0%	0%
Specific effects of their neurological condition e.g. cognitive/memory/sensory impairment	22%	0%	11%	44%	11%	12%	0%
Our clients prefer face to face communication and do not like using online services	13%	13%	25%	13%	36%	0%	0%
Concerns over privacy	0%	0%	0%	0%	22%	67%	11%



PROFILES OF THE DIGITAL RESPONSE AMONG NAI MEMBER ORGANISATIONS

Enable Ireland (Virtual Adult Service)

On March 20th 2020, we had to close our Adult Service Centres as a response to Covid-19. These centres provided vital supports to the adults with disabilities who go there, in many cases, every day. For many adult with disabilities, the centres were their connection to their community and provided opportunity to participate in training, personal development and socialise with friends. Without the centres, many adults were facing weeks of isolation and loneliness.

Very quickly, staff in Enable Ireland Adult Services got together with volunteers from Microsoft Ireland to see how they could virtually reopening Enable Ireland adult services. In a few short weeks, using technology they have opened up a virtual community centre for these adults. Enabling them to engage with activities at their local service centre from the comfort and safety of their own home.

The service initially piloted in Dublin in April 2020 for adults accessing Enable Ireland's day, residential and respite services. It was hugely successful and extended to the rest of the country where Enable Ireland provide Adult Services, including Tipperary, Clare, Limerick, Cork and Kerry. One year on, over 170 adult service owners access the virtual service and over 160 hours of services are delivered via the platform every week. While our day centres and hubs around the country are open, we continue to provide a mix of face to face and virtual supports for adults with disabilities.

The programme of activities are selected and in many cases run by adult service owners themselves and reflect their interests.

Daily and weekly timetables of activities include everything from yoga, art, Zumba, bingo, physiotherapy, quizzes, theater and cooking. The creativity knows no end!

The reaction from adult service owners has been overwhelmingly positive - "it makes the day go so much quicker. You can see the joy it brings to everyone when you are on-line, it's brilliant. I am getting to meet people from other centers for the first time. I am doing activities I wouldn't usually do. Even when this (pandemic) ends this virtual service should continue as part of our service." Adult Service Owner Dublin

"I love checking the time table to see what's on. We have lots of fabulous sessions like cooking, quiz, sports and Special Events. But I would have to say Bingo would be my favourite. It has helped me so much to stay connected to everyone." Adult Service Owner Cork

"The Virtual Adult Service has been brilliant. It's helped to keep me going this last year. We've built a community and you can really get to know people. I feel like I've a bigger group of contacts now because of it. It's opened up new opportunities to me, like hosting my own chat show." Adult Service Owner Limerick

Family members are equally positive about the virtual community

"Now my daughter is back in the hub one day a week and she continues to join the Virtual Service two or three days a week. It is great to have the mix of both. She's up in the morning waiting for it to come on. All the adults are asked what they want to do on it. It's really designed for them and what they are interested in."



Headway Ireland: (Remote Service Provision During COVID-19)

Background

By February 2020, it was becoming clear we would need to plan for the closure of our centres. It was vital that all staff could work from home as we needed to continue our services to clients remotely and continue to operate. We ran tests with staff to ensure that they have access to all the platforms they needed to continue to do their job from home. They each stayed at home for a half day to check all their access and their connectivity.

Headway set up a Covid Response Information Site on SharePoint so all staff could access any new information at the same time. This was used as a central portal for information on resources for staff to inform clients about online services, communication friendly/different languages information on Covid, wellbeing, information for carers etc.

Sound base to start from

After we closed our doors to face to face services on 18th March, it was obvious that we needed to support clients remotely as much as possible through a combination of approaches. This included maximising the use “low” technology (such as phone, post etc) as well as “high” tech. So, the aim was to develop a range of methods of reaching various client groups. Although the phone and postal approaches were familiar, this of course, necessitated the development of some completely new service delivery methods using unfamiliar technology.

Our choice of technology platforms for our online remote service delivery was informed by the fact that we already had the functionality built into the existing license structure and were, generally speaking, a smart reuse of existing technology rather than investment in new technology.

We already had MS Teams via our Office 365 subscription without having to upgrade. In addition, we used the Learnupon LMS system for our clients as part of the existing license that we use for the staff policy and procedure training.

We used PowerPoint for courseware development, as the skill was already widely known within the organisation. We used a free authoring tool, ispring, to develop early versions as proof of concept before investing in a full licence.

We took advantage of the wide use of smartphones for the creation of basic video and audio material.

In addition, we were very mindful of GDPR and data privacy concerns and implemented various things such as extra education for staff working from home, a rollout of two factor authentication for secure sign on and control over use of insecure systems.

Services Delivered Remotely

Online Courses

We developed a range of online e-learning courses for clients, in a wide range of subject areas relevant to brain injury, some of which were completed with a very short timeframe with low tech equipment. Development continued throughout, and since the start of the pandemic, we have had over 200 Learners consume nearly 1000 hours of material. One of the side benefits of this project has been the interdisciplinary and inter-regional working which took place in the development teams.



Online Peer Group Sessions

We organised a range of online live peer group sessions delivered via Teams for clients and also for family member support. We used these groups to deliver over 10,000 hours of service to clients in their own homes. The online groups have also been key in a blended learning strategy, where we can encourage independent, asynchronous e-learning alongside synchronous online groups. It took a lot of support for some clients to be able to connect as all the support was done online or over the phone. Initially, the groups were kept very small but then increased in size when everyone was comfortable with the process.

Online Therapy/ Psychology Sessions

Therapy/counselling services continued through the use of online or telephone therapy for clients. We also rolled out the use of the HSE system, Attend Anywhere to our psychology team which enabled a more user-friendly experience for clients doing individual work.

Online case administration

Staff developed the facility for clients who were able to use email to fill in forms online for the purpose of outcome measures and other administrative paperwork, e.g. emergency contact information, and in some cases referral forms.

The Future

Feedback on our remote service offerings has been sought at regular intervals, and it is clear to us that there are many clients who want to continue to avail of services at least in part online (In an early survey, two thirds of clients indicated an interest to engage in future services online).

It is also clear that there remains a lot of learning for us arising out of our experience in the pandemic, not least in how to develop the most appropriate blend of online and face-to-face services and how best to support clients to engage with the service using technology.



Migraine Association of Ireland

COVID-19 government restrictions began just after St. Patrick's Day 2020 resulting in all MAI public face to face work and staff immediately moving to work from home. All existing face to face appointments at Migraine Clinics nationwide were suspended and no new appointments were taken. Migraine nurses were transferred to frontline duty. The SláinteCare Programme aimed at developing the Headache Care Pathway model in various hospitals was suspended. Along with the general distress felt by people with the rapidly changing situation, it became clear that people living with migraine had increased stress due to concerns about their medications, access to medication and lack of access to specialist services.

An Instagram survey confirmed that 72% of people's symptoms had got worse since lockdown. Our survey bore out the global experience, as evidenced by reports from 'The Migraine Trust' and 'Migraine World Summit'. Another survey carried out by NAI produced similar findings and reported 26% of neurology patients had significant challenges in accessing ongoing care. The statistics showed significant impact on family life, relationships, finances and the majority highlighted 'Voluntary Organisations' as their main source of information on Covid-19 and its implications.

MAI's Information Line saw a dramatic increase in contact both by phone and email. As stress is one of the main triggers for migraine, MAI set up a range of responses by recruiting expert speakers to develop online programmes to address emerging needs on Zoom and Facebook Live. Video replays were uploaded to our YouTube channel. In addition, we set

up a 'FAQ' section on our website to cover the main areas of concern expressed by our callers via advice from migraine specialists from Beaumont Migraine Clinic.

We became very active on social media which has resulted in a huge increase in numbers of people in contact. Working closely with migraine specialists, we developed new and innovative ways to give support to people who were impacted by migraine during the pandemic.

While issues around the COVID-19 were negative, there was a very positive outcome for MAI in the communication field resulting in a surge of radio interviews (RTE and Virgin Media) nationwide and locally. We saw a significant increase in online event attendance and on our social media engagement skyrocketed.

Looking beyond COVID-19, our key focus is to advocate for better access to care in Ireland working closely with European Migraine Headache Association (EMHA) and specialists worldwide. We will promote this through online events, seminars, surveys, social media, and website content as well as press opportunities. We will continue to run online events which have proved highly successful during the pandemic.



Epilepsy Ireland

This last year has been a steep learning curve for so many when it comes to online services. Thinking back to February 2020, the prospect of holding a virtual event would have been alien but now our team are holding weekly events on all matters of important subjects for people with epilepsy and their families.

With the onset of the pandemic, like many other organisations there was undoubtedly an initial worry amongst our team about how our services would adapt online and of course, how the people we support would feel about this. Epilepsy Ireland are a community-based organisation and at the heart of what we do is that public facing and personal approach whereby our team of Community Resource Officers are there for those living with epilepsy.



Aside from the face-to-face aspect of our service, we are pleased to report that 99% of our services have been adapted for online delivery and we have continued to provide vital supports for people with epilepsy and their families since the early stages of the pandemic. This has included group support meetings; one to one support meetings; Living Well with Epilepsy 'Toolkit' sessions whereby our Community Resource Officer educates a new diagnosis about the condition; administration of emergency medication training for healthcare professionals; demonstration on the use of emergency medication for parent's/family members, the continuation of our Training for Success course in IT Sligo; amongst so much more.

Our team adapted quickly to the new environment, as did our service-users and there has certainly been many lessons learned through our experience of online services. This can perhaps be best seen through our Virtual Epilepsy Education sessions supported by Sláintecare and other national online events we held during the pandemic.

Our Virtual Epilepsy Education Sessions allowed people with epilepsy and their families hear directly from leading neurologists such as Dr. Liz O'Mahony, Prof. Norman Delanty, Prof. Colin Doherty, Dr. Bláthnaid McCoy and Dr. Danny Costello to name but a few. Through this virtual environment, they were able to provide their expertise to a large audience and that same audience were able to put forward general questions about their epilepsy. We reached a huge number of people with epilepsy with these events and provided them with vital insights and expertise – in the comfort of their own home.

It is hard to imagine how these events would have worked in "normal" times with time pressure and travel involved for the consultants involved; travel involved for attendees and indeed; potential costs and limitations of venues. In addition, with these virtual events we had entire households in attendance while in physical meetings – using the example of parents of children with epilepsy – it is possible that only one parent could be able to attend a physical event due to childcare and other commitments.

With these Virtual Epilepsy Education Sessions, 88% of attendees reported an increase in their knowledge about their condition and were more aware of the things that can trigger seizures and how to prevent these while 81% reported that they were better equipped with the information needed to manage their medication and stated they were more confident about their knowledge of risks and safety regarding their epilepsy.

While we look forward to getting back into communities and meeting people face to face once more, we have learnt a lot over the past year about how we can support even more people living with epilepsy across Ireland.



Neurology Support Centre Sligo

After many months of planning and refurbishments, in March 2020 we were finally ready to open the doors of our premises at Molloway House in Sligo. Then COVID hit, and like so many others, our well-laid plans went out the window.

Our services are aimed at people with neurological conditions and their families. Our intention is to be a welcoming place where our users can come for information and advice; counselling; holistic therapies; transport; peer support groups and even just a social get-together. We are not a clinical centre, rather we are aimed at making a difference in the day-to-day life of our users, whether it is a walk on the beach in our beach wheelchair, a reflexology treatment to relax and rejuvenate, or a peer support group to meet old friends and new.

However, with COVID obviously we couldn't offer face-to-face services, so we decided to focus initially on one or two aspects.

Support and Advice

We were able to keep the phone lines open during Covid, and so offer advice and support to people with various neurological queries or worries. We received quite a few queries from people with less common conditions. While there are many wonderful neurological charities specific to conditions such as MS, Epilepsy, etc., those with rarer conditions generally do not have a national or regional organisation to turn to for help. This is an area we are keen to pursue in the future, as these people can feel very alone and isolated as most people they encounter day-to-day have not even heard of their condition, and it is quite demoralising and distressing for them.

We have been able to put people with similar conditions in contact with each other, which has been greatly appreciated, and we will continue to encourage mutual support through social media groups for example.

Counselling

At the end of 2020, we launched Mpath, our dedicated support system. There are several elements of the service:

Mpath offers a 24/7 help and support line to those with a neurological condition, and their families and carers. A dedicated healthcare professional will answer all calls professionally and confidentially. If desired, this can be followed up with a series of counselling / psychotherapy sessions.

Support is available for depression, anxiety, bereavement, addictions and stress, and there are also experts available to advise on legal and financial issues.

Mpath also offers an online platform which contains e-learning modules on wellbeing areas such as sleep, nutrition, exercise, etc.

We have been delighted to have been able to offer these services over the past many months, and we will continue to offer them into the future even after we have been able to welcome people into the Centre in person.

The Irish Heart Foundations: Online digital supports for Stroke Survivors since COVID-19 and beyond

Previous to Covid-19 The Irish Heart Foundation ran 21 Stroke Support Groups nationwide that met face to face weekly for exercise therapy and a social chat, with various information sessions, and outings.

At the outbreak of the pandemic, we had to shut down our face to face meetings and move all our supports to online platforms. We set up a traffic light system for our members and we prioritised the most vulnerable to get regular phone calls from our experienced Stroke Coordinators and Volunteers who were able to ensure they were well supported.

For those that had home supports in place, they joined our WhatsApp groups and online zoom sessions. We also increased the content and interaction on our closed stroke and carer Facebook groups, building a virtual community where people could get peer to peer support, information and encouragement.

We quickly developed a weekly online zoom virtual timetable for our members with our groups operating Monday to Thursday with an hour and a half of exercise therapy followed by a social chat.

Also provided is a “social and information club” every Monday that delivers a varied range of fun activities. We also provide information talks from healthcare professionals on different aspect of living with a stroke.

All of our online groups and sessions are moderated and run by our team of Stroke Coordinators. For members who were unable to get online, as well as regular phone calls, we created a monthly newsletter which has kept them connected. We were also allocated funding for devices from an “RTE does Comic Relief” grant and this allowed us to fund tablets and Wi-Fi for our members who needed them, to support them to get online.

For our younger stroke survivors, we provided twice weekly meet ups for an exercise class and social chat via zoom, as well as monthly information session geared towards their unique needs. Past online talks for this group include speakers from The HSE Living well programme, Occupational Health, A Physiotherapist, Stroke Nurses, The National learning Network and ABII Step Ahead Programme, to name but a few.

We also have a closed Facebook group called “Life after Stroke” where we also deliver yoga, mindfulness, tai chi, music therapy session for members together with themed monthly information and support. We also provide a closed Facebook group for carers, that provides them with a safe space for support and information.

Further supports offered to all members include counselling, a personal exercise programme and peer to peer support and also our nurse support line, to ensure that all our members have access to expert advice on any aspect of their condition.

The Stroke check-in service

At the end of March 2020, the HSE’s National Stroke Programme asked for our help to support Stroke patients who were being discharged early from hospital to accommodate patients with COVID-19.



In response to this urgent need, The IHF set up a virtual support service called “The Stroke Check in Service” (SCIS). The aim of this service was to put a virtual “arm around people’s shoulder”, and provide practical information and advice, as well as helping to ensure that discharged patients have everything they need to help to live as fulfilling a life as possible. Patients referred to the SCIS would get an initial phone call from an IHF support line nurse to check in with them and establish their needs. Other ways the nurse support line helps is by clarifying the information patients have received from their medical teams, medication queries, and provide information on topics such as diet, exercise, and self-management.

The patient is then linked with one of our Stroke Group Co-ordinators or Volunteers who provide weekly phone calls offering information and advice, signposting and following up on queries. Patients work with the service for a 12-week period depending on needs and have options to move onto our existing group supports post service. Other service options include a Siel Bleu designed individual exercise programme, counselling and peer to peer support.

Since April 2020 over 500 stroke patients & carers have been referred into the SCIS service. In total, 4313 calls have been made and our network has doubled in size.

Our virtual services have proved to be so essential and have allowed us to reach people we were unable to reach before, that we will ensure they endure and expand long after covid fades.



Slánú Stroke Rehab

Slánú Stroke Rehab is a not-for-profit service that specialises in helping stroke survivors to retrain their brain to get function back in their stroke-affected hand and arm. This involves intensive, personalised therapy and coaching that harnesses the brain's own natural ability to reorganise and rewire (neuroplasticity).

Over that weekend in mid-March 2020 Slánú Stroke Rehab 'pivoted' to online upper limb stroke rehabilitation. The days of in-person individual, paired and group training were suspended and we seamlessly continued to support our clients via a computer screen.

With our guidance and encouragement our clients quickly became adept at getting onto the virtual call to continue their training and maintain the high level of intensity that is essential for improvement. They muted/unmuted, turned videos on and off, went into breakout rooms and shared screens! They were able to reposition their device (laptop or tablet) on the kitchen table or on the countertop while they practised a range of activities that challenged their affected arm and hand. They confidently showed off any new tasks they had tried out in their own environment. Family members were able to be there with them and also family members or friends were able to join the call remotely to follow their progress.... and offer noisy encouragement!

Our clients were able to be in control of their training session in their own environment and take breaks when necessary, in their own home. For those for whom fatigue is an issue there were particular advantages, e.g. not having to travel, able to schedule multiple shorter sessions, able to time training exactly to when they were at their best at short notice etc.

Some clients pointed out that they were able to concentrate better as they focused on the screen and were able, for example, to watch our demonstrations in a more focused way. We were able to record some parts of the session for them to watch back later and also review together any videos of their own independent practice that they shared with us between sessions.

We arranged virtual group training with all the clients on the screen together and training in unison and when needed we are able to pop out with a client into a breakout room for a quick one-on-one before returning to the group to continue (just as you would do in the 'real' situation). That way the participants were able to benefit from the group dynamic (encouragement and maybe a bit of competition!) in addition to individual attention for a particular element.

Our clients ranged in age from 34 to 81 and the majority of them enjoyed the new experience – some of them found it too challenging and chose to train at home with some offline contact with us.

We have reflected on the experience with our clients and we have concluded that the online/virtual 'mode' would be useful for selected components of the training regime and in fact would be more effective. We have agreed that a 'hybrid' way of working will be the future!

Kudos to all our clients for giving it a go (even it did not suit some of them in the end).



Spinal Injuries Ireland

Since March 2020 In light of Covid pandemic, face to face interactions with Service User were replaced with virtual interactions. Service provision is directed by the Business Continuity Plan. In line with Government policy on COVID – 19 pandemic, SII services adapted to deliver core services virtually, over the phone, Zoom and Microsoft Teams.

The Service Community Outreach (COO) team have maintained a strong online presence. They have maintained contact with existing Service Users and family in line with SII Mission and Vision. Significant investment in the Website with more ways to connect and interact with SII and improve our digital footprint. Online Forum for Service Users is available for peer-to-peer discussion and interaction, moderated by SII peer volunteers and COO.

The development of the online education programme, online peer to peer programme, new website and community forum enabled new ways to deliver this new virtual service and promote these events with the public and Service Users.

Online activities have given Service Users better access to all online education programmes as they did not have to travel and could attend in person or watch the recorded session. Access to expert speakers was easier on-line and we have a broader range of speakers from around the country, NI and UK, with no travel, and far less cost for hosting the events.

My Life and Wellbeing During Covid 19 - Virtual Conference

We were devastated to have to cancel our conference in April, so we decided to host a virtual conference instead in October 19th – 23rd, sponsored by Coloplast. There were 13 sessions over the week with a different theme each day. Almost 250 people engaging with the conference over the week.

There was some distress with access to services to hospitals and health care professionals for those with ongoing medical conditions and access uncertainty about access to vaccination. Access to professional counselling was available for those who need needed this support

Christopher and Dana Reeve Foundation Strategic Alliance

SII announce formal affiliation between the Christopher & Dana Reeve Foundation (Reeve Foundation) and Spinal Injuries Ireland (SII) that will enable collaboration to improve quality of life for individuals and families impacted by SCI. This affiliation will allow the sharing of best practices and Reeve's National Paralysis Resource Center (PRC) services/educational content, as well as create global fundraising opportunities. Both organizations will leverage the affiliation for greater awareness and visibility of our community, inclusion, etc. and of our respective brands.



Acquired Brain Injury Ireland: Remote Rehabilitation During COVID-19

In March 2020, almost overnight all services and support functions had to pivot and adapt to the COVID-19 pandemic. Staff management and national office supports had to respond in an agile and committed manner to continue to support our service users.

Initially residential services were among the only services to continue in a face to face manner while all essential community services, day services, case management and clinical assessments and interventions moved to remote delivery or were paused.

In order to ensure safe service provision in the pandemic, ABI Ireland established a new COVID Executive Management Team who met daily initially to consider issues arising from the services. A raft of policies, procedures and training were developed, communicated, and rolled out to all services and these remained live documents under continuing review to this day. All staff who could work from home were equipped to do so. A comprehensive screening process was developed to ensure that any staff member / service user who became symptomatic or a close contact was screened and needed authorization to return to work/service to ensure safer environments.

As time progressed and public health guidance was updated, all services were enabled to move to an individualized risk based approach and were able to continue in a safe manner. This essentially meant that a blended approach to rehabilitation occurred, with some rehabilitation happening face to face and some happening remotely. All staff and service users had to get

used to a new way of working, being creative about how they connected with others, and re adjusting to a new normal and a new language. Staff and services faced uncertainty, stress and worry in the face of trying to continue services with a lot of unknowns.

In February 2021, ABI Ireland reached out to its service users to survey their experience of using technology and availing of rehabilitation remotely during the COVID-19 pandemic.

- When asked about the devices used to access rehabilitation remotely, 70% spoke of using their smartphone, 49% used a tablet, 47% used the laptop, 13% used a desktop, and 7% used a digital assistant.
- 92% of survey participants had access to Wi-Fi while 2% did not.
- 74% of our service users found technology helpful for rehabilitation, while 61% found it easy to make the switch on line.
- When asked about the advantages of using technology to access rehabilitation, 64% said that not having to travel was a significant advantage, 58% spoke of being able to stay at home as an advantage and 28% spoke about being able to concentrate better.
- However, when asked about the drawbacks of using technology to access rehabilitation remotely, 61% spoke of not being able to meet other people, 28% spoke of being isolated, and 23% experienced connectivity problems. Survey respondents felt remote rehabilitation could not completely replace face to face.



- This survey also demonstrated that the service users felt more training for both staff and service users on how to use technology was needed, including suggestions for an information booklet on how to get started on technology.
- 79% of those surveyed reported that they would consider using technology to access rehabilitation into the future.



Muscular Dystrophy Ireland

MDI's vision is of an Ireland that enables people with neuromuscular conditions to fully participate in society and reach their full potential. We offer support to people with muscular dystrophy and their families by:

- Providing information and support to people with neuromuscular conditions and their families through a range of services, including our Family Support Programme, Counselling and Bereavement Service, Personal Assistance Service, Youth Service Programme, Information, Transport, Equipment Loans and Home from Home Apartment.
- Advocating for services and entitlements for members; and educating and informing society about the conditions.
- Supporting researchers and clinicians to carry out quality research into neuromuscular conditions.

Like so many organisations across the country, MDI had to be creative and adapt the way we work so that we can continue to provide core services to members and support the muscular dystrophy community to keep connected while staying apart. At the start of the pandemic, we asked members how we could best support them. Then, guided by what members told us, we adapted our services. We have been providing supports to our members by Zoom, as well as by phone, text, and email. Throughout, we put safety at the core of all activities and operated in line with public health advice.

Virtual activities for adults

MDI moved to providing a lot of one-to-one support by phone as well as substituting virtual meetings for our usual home visits and meetings with members, their families and professionals.

Members told us that social isolation and managing their anxiety were the issues they found the most challenging during the pandemic and so we developed initiatives to support people to maintain their emotional well-being.

- We have been holding regular regional get-togethers on Zoom for adult members, known as 'tea rooms' and 'coffee mornings'. These are facilitated by an MDI Family Support Worker and members are finding them great.
- We ran two self-care and mindfulness workshops in November 2020. Following extremely positive feedback, we offered two eight-week courses on self-care and mindfulness, one aimed at members with muscular dystrophy/neuromuscular conditions and the other tailored to members who are carers/parents of a person with muscular dystrophy/neuromuscular conditions. Everyone said they would attend this course again. Here is what one participant told us about how they experienced the course:

"I was very happy to be able to meet other members of MDI. It would have been impossible without Zoom because meeting in person and socialising for me is very hard. I learned how to cope better with my condition and I would like to have the opportunity to have more courses like that in the future".

Due to their success, we began a second set of courses in May 2021.

- In April 2021, MDI set up a virtual peer support group aimed at members with muscular dystrophy/neuromuscular conditions. It ran for eight weeks and was facilitated by a qualified counsellor. It was an overwhelming success – all participants said they would attend this course again.



- We have also been running a variety of social events for adult members such as murder-mystery events, quizzes and bingo.

We have also organised informative webinars based on members' interests, including several from Citizen Information on entitlements and benefits for disabled people and a webinar from the Disabled Drivers' Association of Ireland on wheelchair accessible vehicles.

Virtual activities for younger members

MDI have four Youth Support Workers located around the country who work directly with children and young people with muscular dystrophy/neuromuscular conditions and their families. MDI's Youth Service Programme aims to support young members to grow, develop and achieve their full potential through building confidence, self-esteem, resilience and empowerment. Before the pandemic, our youth work activities included a variety of day trips, youth club activities and workshops as well as one-to-one, goal-focused work. During the pandemic, we have been running virtual youth clubs for two age groups every fortnight – under-18s and young adults aged 18 to 25. We have also been running a range of virtual activities, including: a spy academy workshop, quizzes, musical bingo, thematic fun, crafts, games and competitions for Christmas, St Patrick's Day, Easter and Halloween. Here is what one participant said they liked most about these activities:

“They were amazing. They are so much fun and it's really nice to meet up with other people. I have met new people while taking part in these events and also got to interact with members who I already knew.”MDI looks forward to making virtual activities part of our ongoing services to members alongside face-to-face supports.



Multiple Sclerosis Society of Ireland

MS Ireland moved its regional services online in response to the COVID pandemic. Our regional services include case work (1:1 Support to people with MS and family members) health promoting physical activity which includes physiotherapy and yoga programmes, peer support events such as “coffee mornings” or “time to chat”, other programmes such as mindfulness, and a series of information webinars/lectures all of which moved to an online format. The element of the service we will focus on for this paper is health promoting physical activity. In 2020 we delivered health promoting physical activity programmes to over 1000 participants and the aim of this summary is to provide further detail of that process and outcomes. Our organization adopted Zoom as our videoconferencing platform, due to its ease of use for our participants, and Teams as our organizational and communications platform. One of our physiotherapists, Dr Susan Coote had been working in tele-health since July 2019 and was able to quickly develop policies, procedures and guidance documents. Underpinning that development was a community of practice “Exercise and MS” hosted on Teams, in which our independent contractors, and other specialist MS physiotherapists could exchange ideas, brainstorm solutions, and receive training in order to optimise the transition online.

Pre-pandemic MS Ireland delivered health promoting physiotherapy exercise programmes at regional level, where people with MS living in a geographical region came together to exercise in a community venue. Known as “Getting the Balance Right” these programmes were based on research conducted with the University of Limerick and have strong evidence

for their ability to improve both mental and physical health outcomes and for valuable peer learning and social support. These classes continued online, and satisfaction was extremely high. Satisfaction surveys and pre and post assessments showed improvement in symptoms, and 60% agreed that they would prefer to continue online even when in person classes become possible again.

In parallel MS Ireland was leading a SlainteCare Integration Fund project “Active Neuro” which also moved online. Active Neuro stemmed from our challenge of implementing evidence based MS physiotherapy led exercise programmes in primary care teams and the HSE. A barrier was insufficient numbers at local primary care team level and the solution was to deliver health promoting exercise programmes for people with a mix of neurological conditions. We firstly mapped the stakeholders and their offerings, we held very positive stakeholder and public consultations – all of whom were positive about working “stronger together”. In 2020 we delivered programmes to 159 people, education and training to PCCC Physiotherapists and Sports partnership tutors, and received extremely positive feedback from participants. Participants indicated that 97.5% would attend online exercise programmes in the future, 60% - preferred online exercise programmes to in-person programmes, and 100% reported that online classes were an effective way to exercise.

Our attendance rates of 79.3% can be considered excellent and similarly the proportion of participants completing our programmes is higher than our in person programmes at 76.7%. Outcomes for fatigue, strength, and participation were excellent demonstrating maintenance or improvement in this

older population with progressive conditions. There was a significant reduction in A&E and inpatient services utilization, reducing from 14 to 9 people (36% reduction) and from 86 to 35 days (59.3% reduction). We reduced falls per person from 5.33 to 2.89 resulting in reduced injury, healthcare utilization and fear and activity curtailment.

Stemming from Active Neuro, we are now building on that knowledge that online programmes are effective and that the barriers of transport, time and accessibility are reduced and that essentially the issue of local implementation is now less relevant. Move Smart MS is funded by Rethink Ireland the social innovation fund and delivers specialised, symptom specific programmes tailored to level of ability and to stage of MS diagnosis. Initial feedback from participants is extremely positive, and they appreciate the combination of education, coaching and peer support with physiotherapy led exercise for specific symptoms. Further analysis of the outcomes of these programmes will be available later in 2021.



Spina Bifida Hydrocephalus Ireland (SBHI) – the move to online service provision

The reality of the COVID-19 pandemic, which took hold in Ireland from March 2020 onwards, meant that we became acutely aware of the need to adapt our service. With this in mind, we have become increasingly expert in the area of online events and training. SBHI offers a range of supports to our service users. Our professional teams enable SBHI to support individuals who have spina bifida and/or hydrocephalus (SB/H), as well as the families, friends, and professionals who are present throughout their lives. Over the past sixteen months our services have been offered online.

The Respite and Recreation Team has run over 130 online sessions, covering a wide range of subjects – yoga, cooking, social chats, exercise, photography, jobs club, brain training, Spanish, puppet show, personal development, creative writing – to name but a few! We have received a lot of positive feedback, here is one that stands out: “Since the pandemic started, these sessions have been a fantastic help for me. I really enjoy all the activities, I have learned a lot and the sessions have brightened up my life.”

The Education and Training Team works to ensure that all contemporary knowledge related to learning, training and SB/H is shared and understood. The training and resources are all provided to service users, organisations and educational establishments using various social and learning platforms and are advertised using social media. One participant said of training recently - “I enjoyed listening to the information and having the chance to meet others on zoom. The workshop was very informative.”

The aim of the Research and Campaigns role is to meet the needs of service users and the organisation through research and campaigns that drive SBHI’s advocacy agenda to ensure that individuals with spina bifida and/or hydrocephalus have access to better services. All research, campaigns and advocacy support are currently being delivered online.

The Open Opportunity Programme provides a quality person-centred Day Service to individuals living with SB/H. During the Pandemic the service operated a hybrid model via online sessions and outdoor visits and support. These weekly visits really had a hugely positive impact on all service users’ mental health during that very isolating and lonely time. Feedback we got included the following: “When I was isolated in my room in the home, the online sessions and Skype calls got me through”.

The aim of the Family Support Service is to work with our members, their families, and carers, by providing guidance and information in an environment which is conducive to their needs. When our services moved online, we supported members to connect with us virtually as well as through regular phone and email contact. More recently we have also begun the reintroduction of Virtual Coffee Mornings as a means of bringing those we support together safely within their local communities and offering an opportunity for individuals to meet and grow their own networks and connections. One parent said: “It was really nice to meet other parents again after a long lockdown with covid. It was very helpful to also receive training from Coloplast nurses and ask some burning questions with the family support team. It was a great opportunity to de-stress with those who understand. I look forward to going again in the future”.



The Health Development Project's main aim is to increase positive health awareness, understanding, and experience amongst adults living with spina bifida and/or hydrocephalus. Key complex health issues for individuals with these conditions have been identified and webinars have been held to educate service users and their families/carers, giving greater access to individuals across Ireland to attend.

The aim of the SBHI Peer Support Service is to foster an environment whereby individuals living with SB/H share their experiences with others seeking advice. Following the onset of COVID-19, SBHI set up a COVID-19 private support group for its service users through Facebook. On foot of this success, SBHI set up its Peer Support Service online in September 2020. The online service is now known as 'Better Together'. The Facebook-based service is a peer-lead, online group which also provides one-to-one emotional and practical support service via messenger to those living with spina bifida and/or hydrocephalus in Ireland.

As outlined above, SBHI has provided support to our service users in a very comprehensive way throughout the last sixteen months so that those who are vulnerable in our society continue to get the help, information and interaction they need in a very difficult time for all.



Freedom Tech

FreedomTech is collaboration between the Disability Federation of Ireland and Enable Ireland. We work to ensure that everyone with a disability, including older people, have access to affordable, up to date and appropriate technology that suits their needs. Assistive technology refers to “the application of organised knowledge and skills related to assistive products, including systems and services. Assistive products are any external product brackets including devices, equipment, instruments or software) ...the primary purpose of which is to maintain or improve an individual’s functioning and independence, and thereby promote their well-being” (WHO 2020). It is worth noting that an unquantifiable number of people who accessed online services needed accessible or assistive technology to do so.

FreedomTech runs a community of practice called the Community Hub for Assistive Technology (CHAT) open to everyone with an interest in learning and engaging in an inquiry into how we can collectively learn our way forward and improve policy and practice. We are AT users, service providers, technologists and industry and academics.

We held 5 online CHATs over April and May 2020 with participation from between 40 to 120 participants depending on the topic. The first CHAT focused on the challenges and opportunities of developing virtual services. We were joined by Professor Mac MacLachlan, National Clinical Lead for Disability Services, HSE and Co-Director of the All Institute, Maynooth University who outlined the importance of access to technology and assistive technology at this time. Breakout room discussions then focused on identifying the greatest unmet need and potential areas for joint working and sharing knowledge across eight themes: Education, Therapy and

Assessment, Day Service Provision, Independent Living, Access to AT, Reaching those not on line, Digital Skills and Ethics and Safeguarding Technology. We held 5 subsequent online CHATs on themes that emerged: day service delivery, therapy and assessment processes, independent living and reaching those not on line . In October we returned to look at education.

These conversations provided a valuable discussion space across different kinds of services and professions who were all grappling with similar issues around access to broadband, hardware and software as well as the digital upskilling that was required to get both for staff and those accessing services online. An emerging theme was the extent to which each service or organisation was working in silos and participants appreciated the shared space in which to learn and resource each other. This was particularly important as the ground shifted under people’s feet and guidance around GDPR, security and consent were live issues. Further detail on the discussions can be accessed at www.freedomtech.ie.

Our 2021 CHAT gatherings have continued to draw a wide range of participants:

Topics have included:

How to use different platforms to best effect

Shared tips and tricks on using Zoom, Teams and WebEx and Attend Anywhere as well as a panel discussion between Mike Walsh, HSE, Peter Kearns Irish Independent Living Movement and Joan O’Donnell Doctoral researcher, and FreedomTech. <https://freedomtech.ie/chat-community-hub-for-accessible-technology/chat-accessible-video-conferencing/>



How technology helps us

Padhraic Dormer was in discussion with Laura Dempsey, Owen Mc Girr, Emma Mc Grane and Alan Melvin who shared their personal experiences of using and developing accessible technology over the last year. <https://freedomtech.ie/chat-community-hub-for-accessible-technology/chat-how-accessible-technology-helps-me/>.

Sustainability of Online Supports and Services

Minister Anne Rabbitte gave a recorded message, emphasizing the importance of assistive technology in developing landscape of services. Further discussion on how to create sustainable models, resources and funding for virtual services was discussed with Alex Mason HSE, Hubert McCormack and Elaine Mc Donnell MDI Ireland, Des Kenny, Irish Independent Living Movement with respondents Alison Hartnett, National Federation of Voluntary Bodies and Allen Dunne, Disability Federation of Ireland: <https://freedomtech.ie/sustainability-of-online-supports-and-services/>.

The success of online engagement has accelerated the need to develop a coherent AT policy that can work systemically across all areas of the person's life and in tandem with virtual services. Funding must follow the person. This is particularly important as people accessing service have greater choice around when, where and how to participate in different online offerings. FreedomTech has advocated for an AT passport within the context of an AT ecosystem that cuts across all different aspects of the person's life. A systemic response includes procurement, funding, assessment, training, and support and is set within the frame of digital literacy and digital access, thus enhancing the life choices of disabled people to choose between in person and virtual engagement into the future.



PART 3: PERSPECTIVES FROM HOSPITAL BASED NEUROLOGY AND NEUROREHABILITATION SERVICES

Prof Colin Doherty, Consultant Neurologist St James Hospital, Dublin and Principal Investigator FutureNeuro Research Centre.

Pre-Covid about 20 per cent of the epilepsy clinics in St James's were delivered via telemedicine, facilitated by the existence of the National Epilepsy Electronic Patient Record (EEPR), with a lot of work already in this area before the pandemic hit.

Prof Doherty said the service plans to move towards 50-60% of clinics being held virtually; as it suits epilepsy.

The initial cohort of patients using the epilepsy telehealth service pre-pandemic tended to be younger, more tech savvy, and some lived long distances from the clinic. However, when Covid-19 hit all patients were offered the option of the telehealth service, and Prof Doherty reported that older patients adapted very well to the technology, with very good feedback, especially related to the convenience of the service and not having to travel. There was actually more resistance from the clinician side, he noted, suggesting that for the patient there were potentially significant benefits of not having to travel long distances/deal with traffic, take time off work, arrange childcare, etc. for an appointment, compared to the clinician being present in their clinic anyway.

NAI commissioned a series of interviews with hospital-based neurological care services, asking them to share their experiences as well as their viewpoints on online approaches to service provision and the potential to incorporate it into future models of service delivery.

He said the current long established outpatient model of care used in Ireland is no longer fit for purpose and that the pandemic has offered the chance to look at changing healthcare delivery to better suit the current needs of patients and service providers, which would also better align with the objectives of the Sláintecare healthcare policy.

“What do patients actually want? They are quite happy to sit at home at the kitchen table and do a phone/video call for disease surveillance and when they need to be seen, they want to be able to see a specialist - they don't want to have to turn up at an emergency department and wait on a trolley for 24 hours. We need a more responsive model of care, which is what I have been trying to develop for many years.”

Prof Doherty pointed out that remote care has been a long-time feature of healthcare services in countries like Australia and New Zealand, with plenty of evidence available on how to best deliver it.

In addition, Prof Doherty said that an integrated hybrid care approach should also allow clinicians to see patients in person at short notice when they actually need urgent care, as opposed to a rigid three- or six-monthly appointment. “Delivering care at

the right time, in the right place and being able to see patients when they actually need us. That is the key mix with telehealth-also having the capacity to see a patient quickly.”

He also raised the point that there is a large carbon footprint in having patients travel long distances to hospital clinics, especially when they are attending a national service potentially at the other end of the country, coupled with the fact that the overwhelming majority of patients in his service travel by private car, and that this is something that should be taken into account too when looking at the pros and cons of remote healthcare provision.

Prof Doherty contributed to a scientific article on this topic² (Love in a Time of COVID: Clinician and patient experience using telemedicine for chronic epilepsy management, published in *Epilepsy and Behavior* December 2020) which had some pertinent findings.

From 24 March to 24 June 2020, 1,164 epilepsy patients were seen in 1693 encounters of which 729 (63%) patients were seen in 748 scheduled virtual encounters. A total of 118 clinician impressions were captured through an online survey and 75 patients or carers completed a telephone survey.

Key findings:

- There was no backlog of appointments or loss of care continuity forced by the pandemic.
- Clinicians expressed strong levels of satisfaction, but some doubted the suitability of new patients to the service or candidates for surgery receiving care via telemedicine.
- Patients reported positive experiences surrounding telephone appointments comparing them favourably to face-to-face encounters.
- The availability of a shared EEPR demonstrated no loss of care contact for patients with epilepsy.
- The survey showed that telemedicine is seen as an effective and satisfactory method of delivering chronic outpatient care.
- Older patients adapted very well to the technology. Positive environmental impact too - 90% of the patients usually travel by car.
- There was more resistance from clinicians rather than patients.

² Love in a Time of COVID: Clinician and patient experience in using telemedicine for chronic epilepsy management. *Epilepsy and Behaviour*: epub 2020 Dec 17



Prof Tim Lynch: Consultant Neurologist at the Mater Misericordiae University Hospital and Clinical Director of the Dublin Neurological Institute at the Mater Misericordiae University Hospital

Prof Lynch noted that neurology services in Ireland were already overwhelmed, with an inadequate service in the north west (Sligo covering Donegal) before the pandemic, thus rapid adoption of telemedicine was vital to keep services going.

To assess the quality of the telehealth services provided during the pandemic, research by Prof Lynch's team was conducted, consisting of audit questionnaires of neurologists, registrars and patients (500) across Parkinson's movement, MS, epilepsy, headache, and general neurology clinics in his services, on their views of the service provided.

In general the clinicians (60%) thought the telehealth service being provided was suitable, whereas less so from the patients (36%). Patients still wanted a face to face service. There were some technology problems, especially in older patients.

Clinicians wanted face-to-face for first consultations in particular – this was especially the case with Parkinson's, MS, rarer and more complex disorders.

Clinicians found telemedicine easier with return patients – there was already a relationship there, and with well controlled patients.

Telehealth clinics can be more efficient in relation to ongoing care in in-person outpatient clinics.

Patients liked the travel avoidance, and not having to arrange childcare, etc.

Overall, the use of virtual clinics during the pandemic was of great benefit, worked, was essential, and 'was better than nothing'.

Activity went up over 20% in 2020 despite pandemic; but didn't make much difference in waiting lists – as there is ever growing demand, Prof Lynch noted.

The switch to telemedicine during the pandemic is a real opportunity for positive change in healthcare service delivery he concluded.



Dr Amanda Carty, Programme Manager, Brain Injury Unit, National Rehabilitation Hospital (NRH)

The NRH provides comprehensive inpatient and outpatient services to patients who, as a result of an accident, illness or injury, have acquired a physical or cognitive disability and who require specialist medical rehabilitation.

Ms Carty outlined the rapid implementation of telehealth at the NRH during the emergence of Covid-19, giving insight into the difficulties services that did not already have telehealth experience pre the pandemic. Initially the hospital had significant difficulties getting hold of the necessary tech equipment as a voluntary service; there were global shortages of headsets, and having to purchase laptops and other equipment as well as using different software telehealth solutions and trying to get staff trained up and patients used to the new technology was quite challenging.

“Once the HSE adopted its Attend Anywhere software things improved significantly - it was much preferred by patients and staff, easier to use and attendances improved. In a very significant achievement, the NRH brain injury unit managed to provide the same amount of outpatient appointments in 2020 as in 2019 despite the pandemic and the aforementioned challenges in switching to telehealth provision”.

While the success of telehealth services can vary according to patient needs, access to technology and the type of care being provided, Ms Carty said it was proving very efficient in specialties like occupational therapy and speech therapy.

Like Prof Doherty and Prof Lynch she noted telehealth services were very convenient for patients who previously had to travel long distances to this national centre.

Patients however missed the peer and group support of physical meetings and socialisation, which is very important for many of these patients given how their conditions can impact their mobility and ability to socialise, work, travel, etc. Online groups do provide some support and are useful, but again she emphasised that patient choice and the individual needs of the patients need to be key in designing telehealth services.

Ms Carty said her unit is planning to conduct research on patient outcomes and patient experience.

She said that a hybrid model is what should be provided in the future, post-pandemic: Patient-centred, offering choice, and facilitating the virtual checking in on patients. There are also plans to expand telehealth services to pre-admission patients for assessment, preparation and outreach, which would help benefit their inpatient care, as well as the introduction of post-discharge follow-up through telehealth - again aimed at providing a more integrated comprehensive care approach.

Telemedicine in Ireland and the COVID-19 Pandemic

The arrival of Covid-19 in Ireland with its associated risks and restrictions on in-person patient care resulted in a rapid increase in the usage of telehealth almost overnight. Research carried out in October 2020 by Behaviour and Attitudes on behalf of doctors' regulatory body, the Medical Council, showed there has been a five-fold increase in the use of telemedicine since March 2020. By October 2020, 21% of the population had used a telemedicine service, up from 4% of the population in March 2020.

Attend Anywhere is the web-based platform for patients to access pre-arranged video consultation appointments, which has been adopted for use by the HSE during the pandemic. It can be used on any computer, tablet or smart phone, and the HSE reports that it is very pleased with its success to date, and intends to keep using it after the pandemic.

Between May 2020 and January this year, it was reported that over 100,000 virtual patient consultations had taken place through Attend Anywhere, lasting over 55,000 hours with over 8,500 clinical staff registered to use the platform. Since then usage has continued to increase, and it is being utilised across a range of medical specialities, with patients less likely to not turn up for an appointment compared to in person appointments.

In April 2021, the Medical Council published the report of its Working Group on Telemedicine³ that highlights the challenges and the benefits of telemedicine during the Covid-19 pandemic.

The report includes insight into the effectiveness of telemedicine in other jurisdictions such as New Zealand, Australia, Canada and the United Kingdom,

where telemedicine has greatly enhanced healthcare for those living in remote areas or in need of outside hours support among others.

The report recognises the importance of supporting this emerging area of healthcare in Ireland to ensure that its associated benefits can be maximised to enhance the standard of care for Irish patients, while also ensuring that an appropriate regulatory environment is created to continue to ensure patients are protected.

Commenting on the report, Dr Rob Hendry, Medical Director at Medical Protection Society (MPS) said the report, along with its recommendations, is a positive step in supporting the medical profession to navigate the minefield of remote consulting during the Covid-19 pandemic and beyond. Throughout the pandemic, he said that MPS has received frequent enquiries on telemedicine.

“While it is right that the report acknowledges that telemedicine can improve access to healthcare for some communities, a significant number of doctors have told us about their concerns around the potential impact on vulnerable patients. Access to telemedicine could be impacted by factors such as digital literacy, disability, language, location or internet connection.

“Doctors must feel properly supported and should not be left to deal with any unintended repercussions from an increased use of telemedicine. A long-term strategic approach is needed when considering the role of virtual care beyond the pandemic. This should be based on the experiences of patients, an ongoing evaluation of the barriers to accessing telemedicine for vulnerable patient groups, and the concerns raised by doctors.”

³ Report of the Medical Council Working Group on Telemedicine (April 2021) Irish Medical Council

SECTION 2: REPORT FROM NEUROLOGICAL ALLIANCE OF IRELAND ROUND TABLE DISCUSSION

On March 25th 2021, the Neurological Alliance of Ireland organised a webinar as part of events for National Brain Awareness Week.

“Beyond COVID19: Promoting digital responses to the needs of people with neurological conditions” highlighted the key findings from the surveys and interviews highlighted earlier in this report, as well presentation from MS Ireland and the HSE. This section focuses on the panel discussion from this webinar, outlining the contributions from the individual panelists and summarising the key points from the debate.

Panel Chair: Dr Colin Doherty Consultant Neurologist and Principal Investigator FutureNeuro research centre.



Mr Gary Boyle,
Patient Advocate and person
with Parkinson's



Dr Derrick Mitchell,
CEO, Irish Platform for Patient
Organisations, Science &
Industry (IPPOSI)



Mr Aidan Larkin,
Services Development
Manager, Multiple Sclerosis
Society of Ireland



Ms Julie Bellew,
IT Deputy Delivery Director:
Community Health: Health
Services Executive



Prof Martin Curley,
HSE Director of Digital
Transformation and Open
Innovation HSE.

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Panel Chair,
Dr Colin Doherty Consultant Neurologist and Principal Investigator FutureNeuro research centre.

Questions Posed to the Panel (Note that this Section Incorporates Responses from Panelists Contributed in Advance of the Webinar in Response to these Questions)

1. What in your view are the opportunities represented by telemedicine/online approaches to service provision beyond the Covid19 pandemic?
2. What are the challenges/caveats in your view in delivering care online: including any specific issues you have come across in your own experience?
3. Outline from your perspective any potential obstacles that must be addressed in adopting a wider health system approach to the delivery of care online

During the panel discussion, Prof Doherty noted that his particular service was better prepared than many for pivoting to telehealth provision during the pandemic, but that there had already been an increasing appetite for a different approach to healthcare provision, using technology, pre-Covid-19. He outlined details of the eHealth Lighthouse Epilepsy EPR project, and said it was all about making the patient a member of the healthcare team; being involved in updating, validating and accessing their own healthcare information/record, reporting on their progress and outcomes; essentially taking on an active role in managing their health.

“Key is the rise of the informed patient and bringing them on board and asking them what do they actually want [from their healthcare services] as opposed to just assuming what they need, and to be more involved in the design of services,” said Prof Doherty.

Promoting Digital Responses to the Needs of People with Neurological Conditions

QUESTIONS FOR PANEL MEMBERS

- 1 What in your view are the opportunities represented by telemedicine/online approaches to service provision beyond the COVID-19 pandemic?
- 2 What are the challenges/caveats in your view in delivering care online: including any specific issues you have come across in your own experience?
- 3 Outline from your perspective any potential obstacles that must be addressed in adopting a wider health system approach to the delivery of care online.

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Promoting Digital Responses to the Needs of People with Neurological Conditions

<u>Panel Chair</u>	<u>Panel Members</u>
→ Dr. Colin Doherty Consultant Neurologist, St. James Hospital Principal Investigator, FutureNeuro Research Centre	→ Mr. Gary Boyle, Patient Advocate → Dr. Derek Mitchell, CEO, Irish Platform for Patient Organisations, Science & Industry (IPPOSI) → Mr. Aidan Larkin, National Services Development Manager, MS Society of Ireland → Ms. Julie Bellew, IT Deputy Delivery Director, Community Health, HSE → Professor Martin Curley, HSE: Director of Digital Transformation and Open Innovation, HSE

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Asked about the opportunities of telehealth post pandemic, Mr Curley said the ability to remotely monitor people at home with mild symptoms of Covid-19 and other diseases (COPD, severe asthma) to avoid or reduce hospitalisation is being piloted by the HSE with external companies, and this has exciting potential.

Mr Boyle, as a telehealth service user, said it had been great to be able to connect remotely with his consultant for urgent care during the pandemic, and it is reassuring to have that capability there now. He also spoke about being able to access movement therapy, including Irish dancing, online when Covid-19 forced in-person classes to stop, which has been vital in maintaining his mobility.

“While people with Parkinson’s tend to be older, and there is less computer literacy in this cohort traditionally, within weeks of services having to move to virtual provision (telephone, WhatsApp, etc) there was rapid adoption and uptake. We now have double the amount of people attending compared to where we started. That shows me that people can take on board change, and have a change of heart when they are faced with the alternative of having nothing. It is something that has really been embraced. I’m really excited about this opportunity and think we have something now that can change the game completely... while recognising that remote services will never totally replace face-to-face care.”

Prof Doherty and Mr Boyle spoke about the need to recognise the burden on patients in receiving routine in-person care, for example outpatient appointments, and the travel and waiting time involved for a short meeting.

Mr Mitchell highlighted the work IPPOSI had done on electronic healthcare records and telehealth pre-pandemic and how the chaos created by Covid-19 had made people see the benefits of remote care (ePrescribing as well as video consultations) more clearly, with many lessons and innovations that can be applied to future services.

He said it was clear that many of the outcomes clinicians wanted to see for their patients were achievable through remote care provision, which as well as being convenient for patients allows them the opportunity to be more active participants in the care process.

He echoed calls for ensuring patient input into the design of such services and said clinician reluctance has to be addressed through further engagement, information and education. He also stressed the importance of continuing to develop and actually roll-out electronic patient records in Ireland, which would further enhance telehealth services and the healthcare experience for patients.

“People are starting to see the benefits of remote consultations and e-prescribing. The lessons learned from the pandemic should serve to encourage more virtual care in the future, but not only via remote consultations and e-prescriptions, but also the provision of virtual case management or certain follow-up rehabilitation / therapy sessions. As such, health and social services which are seeking to convert part of their services into quality remote services must continue to receive adequate funding. However, despite its benefits, remote care should only be used under specific circumstances. For many patients, nothing can replace certain procedures and the human contact

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– in particular when meeting a new care professional, when receiving a diagnosis, when sensitive or highly impactful information is announced, or when important decisions on their care are to be made”.

Aidan Larkin noted that MS Ireland were already planning for the future, incorporating the learning from the pandemic experience. “The opportunity of adopting/developing the service models as ‘an as well as’ model as opposed to ‘an instead of’ model when delivered well offers great opportunities with many accidental benefits e.g. scheduling timely appointments, reduced travel, convenience, childcare costs, built environment barriers thus reducing cost and many of the stresses of attending appointments. Within the MS space we have demonstrated that information, physio, peer support, symptom management programmes and counselling can be delivered with a high degree of success remotely”.

Mr Mitchell and Mr Doyle also noted the importance of providing adequate broadband and more education for patients on using new technology.

Ms Bellew pointed out that there is now a significant amount of educational, training and ongoing support resources available through the HSE for telehealth provision, which is being further developed, and that family, community (libraries, local health centres, etc) and advocacy/healthcare charity services (Alone, Age Action, etc) can also help patients with regards to learning about and accessing telehealth services.

“I feel there are massive opportunities. There has been a generational leap in terms of the use of tech within service delivery. As citizens we have seen first-hand the role tools like video can have as new additional ways of receiving care, be that from our own families, communities, organisations or with respect to clinical care. Remote monitoring and on-line therapies are also delivering real change. These technologies are truly patient centred care”.

OVERVIEW AND CONCLUSIONS

In putting together this report, our aim in the Neurological Alliance was to document the response across neurological care to the challenges of service provision during COVID19, as well as to reflect on the experience and draw some potential lessons for retaining and integrating this technology into future models of service provision.

Our research with service users showed that online service provision had many valuable aspects. It was vital in keeping many services going during the pandemic, providing a critical opportunity for service users to continue to receive care when face to face services were closed or curtailed. Many service users expressed satisfaction with the convenience of accessing services online, they no longer had to travel and face long waiting times as well as being able to access information and advice, that they would have had to travel in order to avail of pre-Covid. Anecdotally, service users reported a difference in their experience of care, feeling more relaxed and empowered in their home setting to ask questions and take in more information.

However, there are clear caveats and challenges associated with online service provision. Many service users will not engage with online services, either through choice or through barriers such as broadband access or access to and ability to utilise technology. There is a need for systematic research, both within neurological care and more widely in health and social care services, to understand and evaluate outcomes from online services and the type of care that is suitable for online provision. This report documents examples of research taking place to inform the design and delivery of online services: from the evaluation of service user participation and outcomes from

the epilepsy patient portal to the service user surveys carried out within individual NAI member organisations.

A consensus is emerging that there needs to be a national, co-ordinated approach to the provision of online healthcare, recognising the additional resources required in terms of equipment, expertise and dedicated staffing to provide these services. A long-term strategic approach is needed, which provides the guidance and support required to all providers, both statutory and voluntary.

At the centre of future direction is this area must be meeting the needs of the service user. People with neurological conditions should be enabled to have real choices about how their care is delivered and equally people should not be disenfranchised by the use of digital technology in providing services. Digital healthcare will be a key “test case” for how we engage service users in the design and delivery of neurological care and wider healthcare.

One of the aims of this report was to capture the unique response to online service provision across NAI member groups. Each organisation was faced with similar challenges but each responded in individual ways working closely with service users not only in designing services but also providing considerable support and outreach to enable them to avail of these services. NAI member groups were keen to respond quickly to the need, conscious that many of their clients were left isolated with few supports due to the closure and curtailment of many statutory health and social care services and the redeployment of healthcare staff.

OVERVIEW AND CONCLUSIONS

This report lends further support to the growing recognition that COVID19 should represent a catalyst for change in the State relationship with the voluntary sector in health and social care provision. The examples highlighted in this report show the depth of innovation within voluntary sector neurological organisations as they rapidly embraced technology to reach out in unique ways to their clients. They are already moving forward in integrating these approaches into future models of service delivery, demonstrating once again the flexibility and responsiveness of these organisations in developing new services and approaches to the needs of people with neurological conditions.

This publication leaves us with many unanswered questions. In some ways it is too soon to envisage to what extent online services and supports will be retained and integrated into future models of service delivery. On the other hand, many service users have had a positive experience of online services and are keen to know what their future care looks like as we move out of restrictions and towards a more normal environment for the delivery of healthcare.

There was a universal acknowledgement among all the stakeholders involved in our consultations that there is “no going back” and that it is likely some aspects of online service provision could and should be retained into the future.

We in the Neurological Alliance of Ireland look forward to a continued role in informing discussions around the future of online healthcare in meeting the needs of people with neurological conditions, recognising that significant challenges as well as opportunities lie ahead.

It is appropriate to end this report with the voice of the service user:

“Telemedicine can present a very valuable alternative to the arduous annual adventure of travelling long distances just to see a Consultant/HCP for a short, 15min. review. This technology is a clear breakthrough in Health Care provision, delivering us the potential to ‘take the pressure off’ our current health system - not by replacing it, but by enhancing it and making the system work smarter”

Gary Boyle Patient Advocate

List of NAI members

Acquired Brain injury Ireland
Alzheimer Society of Ireland
An Saol
Aphasia Ireland
Ataxia Foundation Ireland
Aware
Bloomfield Health Services
Cheshire Ireland
Chronic Pain Ireland
Dystonia Ireland
Enable Ireland
Epilepsy Ireland
Headway
Huntington's Disease Association of Ireland
Irish Heart Foundation
Irish Hospice Foundation
Irish Motor Neurone Disease Association
Migraine Association of Ireland
Move4Parkinsons
Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland
National Council for the Blind
Neurofibromatosis Association of Ireland
Neurology Support Centre
North West MS Therapy Centre
Parkinson's Association of Ireland
Peamount Healthcare
Polio Survivors Ireland
PSPA Ireland
Slanu Stroke Rehab
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group

Associate Members

Brain Tumour Ireland
Syringomyelia Chiara Malformation Support Group



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