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| **Neurological Framework Newsletter**Issue 2, October 2021 |

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| **Introduction**Welcome to issue 2 of Scottish Government’s Neurological Framework Newsletter. The aim of the newsletter is to keep partners updated on progress in the delivery of [Neurological care and support: framework for action 2020-2025 - gov.scot (www.gov.scot)](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=000c6176ba&e=0c849360d6) The Framework’s vision is that everyone with a neurological condition will be able to access the care and support they need to live well on their own terms. If you would like to discuss any of the developments highlighted here, ask for colleagues to be added or removed from this mailing list, or contribute to a future newsletter, please contact the Scottish Government Neurological Conditions Team at Clinical\_Priorities@gov.scot |

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| **News****Quality Assurance of Standards for Neurological Care**Healthcare Improvement Scotland (HIS) has agreed to lead quality assurance of progress on implementing the [General standards for neurological care and support (healthcareimprovementscotland.org)](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=620f331335&e=0c849360d6). This meets commitment 11 of the Framework, *We will promote and support the implementation of the Health and Social Care Standards 2018 and Healthcare Improvement Scotland General Standards for Neurological Care and Support 2019* The commission will be designed so that health and social care organisations, including the third sector, can undertake a self-assessment against the standards, supported by peer review. An assessment toolkit will be developed and work will be done over the next year to prepare organisations to deliver this. Initial work is taking place to recruit staff to support the work and a reference group will be established to design the work once this is in place. |

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| **Neurological Framework Round Three Funding**To date, £1.4 million has been spent to support implementation of the Framework.  For 2022-23, we are planning to move to a more targeted approach for funding so we can address commitments in the framework that have received less funding to date or require more specific focus. It is currently anticipated that for 2022-2023 a proportion of the funding will be focused on supporting delivery of Commitment 9: *We will support Integration Authorities and the NHS to improve services and support, with a commitment to evaluate and test generic/ neurology community based multi-disciplinary team models and to test innovative ways of delivering health and social care, including new roles and new arrangements for co-ordinating care and support for people with neurological conditions.* We are also scoping funds required for capturing accurate population data for people with neurological conditions (Commitment 12). Additionally, we are currently reviewing funding provided to Round 1 and 2 projects and what further support may be required to ensure projects reach their full potential. Details of our funding approach are being finalised and will be announced in the next few weeks. There is also further one-off funding that may be available to us as part of wider Scottish Government support to protect our health and social care services this winter. We would welcome any ideas from the neurological community of any short term projects, delivering this financial year, aligned to the principles set out by the Cabinet Secretary for Health and Social Care earlier this week ([link](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=2bbf11a06a&e=0c849360d6)). |

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| **My Neuro Survey**The Neurological Alliance of Scotland has commissioned healthcare consultancy Quality Health, to undertake “My Neuro Survey” which gathers patient reported experience data. We are finalising arrangements for distribution of the survey to clinics in NHS Scotland. This includes a briefing for clinic staff to support patients to complete the survey. The survey includes a version specifically for use in paediatrics. There are a number of reasons to get involved:* Receive an individual report of your service’s results
* Deliver a rich source of data on your patients‘ experience
* Influence the future quality of treatment, care and support
* Shape the methodology of this important survey – all at no cost to your service
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| **New guides for carers**The Neurological Alliance of Scotland has created three new resources for carers of people with neurological conditions.  The guides set out what to expect when people are new to caring, what to expect from Advocacy services, and explain Anticipatory Care Planning. These new resources can be downloaded from the Neurological Alliance's website at [What is a neurological condition? | Neurological Alliance of Scotland (scottishneurological.org.uk)](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=2e99ece64f&e=0c849360d6) |

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| **Learning Sessions**The following sessions have been facilitated recently in order to support neurology professionals with various aspects of delivering better care and support. **Anticipatory Care Planning**Healthcare Improvement Scotland hosted a webinar on Anticipatory Care Planning (ACP) for professionals who work with people with neurological conditions. The session aimed at building confidence in using ACP and to encourage people to think about how it can be used for general care planning. The session was attended by nearly 300 people and heard from Judith Newton, National Nursing Lead for MND/Consultant Nurse; Moira Flett, MS & MND Specialist Nurse, NHS Orkney; Rosalind Gray, Occupational Therapist, Head of Therapies at Nightingale Hammerson; and Adeline Tan, Improvement Advisor, HIS. A recording of the session will be available shortly from the HIS iHub website: [Anticipatory Care Planning Toolkit](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=065f25c3fa&e=0c849360d6) To build on the session we are creating a ‘neuro ACP’ webpage on the IHub site, which will include video presentations on Anticipatory Care Planning in neuro conditions, case studies, tips and insights, blog pieces, and tools to assist health professionals in creating ACPs. **Modernising Patient Pathways (MPPP) – Neurology Network**The first meeting of the MPPP clinical network for neurology took place on 1 September. Topics on the agenda included the successful Patient Initiated Review implementation in NHS Greater Glasgow and Clyde, using GP/patient information leaflets to get the best from Active Clinical Referral Triage, multi-speciality pathways for syncope, and group intervention for functional neurological disorder (FND). All of these approaches have demonstrated improvements to the patient experience and contribute to running services more efficiently Further information is available from jamie.cochrane@gov.scot **Virtual / Face to Face consultations for Allied Health Professionals and Neuropsychologists**A short webinar was held on 16 September on best practice and experience in seeing neurology patients using remote technology. The session heard from Callum Duncan, Consultant Neurologist NHS Grampian; Maggie Whyte, Consultant Neuropsychologist NHS Grampian; Jayne Dorans, Speech and Language Therapist, NHS Ayrshire and Arran, and was chaired by Stephanie Fraser Chair of the National Advisory Committee for Neurological Conditions.The link to the recording is here: [https://youtu.be/cOpdhlVsyM8](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=9ca5e1e703&e=0c849360d6)  Guidance is being developed on good practice for virtual consultations for medical staff and we are looking to develop resources for Allied Health Professionals and neuropsychologists.**MND Learning Resource**Royal College of Nursing has published a learning resource on Motor Neurone Disease (MND). Participants taking the course will have:* improved understanding of what MND is, and the red flags for its diagnosis
* increased awareness of symptom management and available treatments
* an appreciation of the importance of coordination and a multi-disciplinary approach to achieving good care for people living with MND
* explored the importance of advance planning and timely support for changing symptoms
* considered the impact of a diagnosis of MND on a person and their family and carers and know where to go for further information

[MND Resource | Royal College of Nursing (rcn.org.uk)](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=a132abfeb2&e=0c849360d6) |

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| **Funded Innovation Projects** In this section we highlight progress of some of the projects that have been funded through the innovation fund that has been set up to support the Framework. Five of the projects from Round 1 have concluded and we will feature them in the next issue of this newsletter. This issue focusses on Parkinson’s Connect and Neurosymptoms for FND. **Neurosymptoms FND - Guide site and app launched July 2021**In 2009, Prof Jon Stone a neurologist in Edinburgh established neurosymptoms.org, the first online source of information for people with Functional Neurological Disorder (FND). This disabling but hidden condition is the second most common reason for a neurology outpatient visit. The innovation fund allowed a huge upgrade to the existing aged site and the creation, by popular demand, of an app – neurosymptoms FND guide. The work was done in collaboration with Pooja Jain an entrepreneur sponsored by the University of Edinburgh and her team at Cognihealth. They gathered input from patient charities, patients and clinicians with a survey of over 400 respondents to inform the work. The new site and app is much more accessible and readable, with better ways for clinicians to recommend certain sections, an FAQ section and a new search function. The launch campaign in July 2021 was seen by over 150,000 people. So far monthly visits have been in excess of 50,000 around the world and over 4000 people have downloaded the new app. The improvements have been praised by patients and clinicians. Prof Tony David, Director of the Institute of Mental Health, UCL, London described the site as ‘*genuinely transformative for thousands of patients’*.[Functional Neurological Disorder (FND) – A Patient's Guide to FND (neurosymptoms.org)](https://scot.us6.list-manage.com/track/click?u=0470bf210fd0021ae85ae4b21&id=ee985694cf&e=0c849360d6)  |

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| **Parkinson’s Connect**Parkinson’s Connect was established by Parkinson’s UK and has been shortlisted for a UK wide third sector award. Parkinson's Connect will provide best-in-class, proactive and tailored support for people affected by Parkinson’s from the moment they are diagnosed with the condition and throughout life. The service combines access to expert advisers alongside self-management tools and personalised information, all shaped using modern digital and service design approaches. A key benefit of Parkinson's Connect is that it is integrated with the NHS so people with the condition get a consistent and joined up care experience. The service is designed to tackle two major problems:* People diagnosed with Parkinson's receive little information or guidance about how to manage their condition - leading to worsening symptoms and increased stress, anxiety and fear
* Parkinson's is the fastest growing neurological condition and current health services are already under strain, leaving people with limited access to support from healthcare professionals.

Parkinson's Connect is set up to reach people at diagnosis through a sector-first referral to Parkinson's UK directly from NHS teams, and then continues to offer proactive support throughout life with the condition. The project uses a lean service design methodology to make sure all aspects are rooted in the needs of people living with Parkinson’s. Further details from Claire McNeill, cmcneill@parkinsons.org.uk |

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