NNAG National Neurosciences Advisory Group

Lessons learnt from the COVID-19 pandemic Priorities in care for people with neurological conditions after the pandemic

A report by the National Neurosciences Advisory Group (NNAG)

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I have had my neurological appointments cancelled until next year, and in the meantime my neurological condition is worsening. I have experienced much mental distress. I experience intense neuropathic pain – it's like someone pouring hot water onto my foot, and it prevents me from sleeping. I have tried everything to help manage the unbearable pain, but it is incredibly difficult to treat.

I have been going to a pain clinic for nearly 20 years, but this shut down when COVID-19 hit. I have also been shielding, which means the risk of me travelling to hospital on public transport was too great a risk. I have not been offered any remote appointments. My walking clinic has been cancelled too – this has to be done face to face anyway so they can assess how you are walking properly.

So many of the things I enjoy, like visiting art galleries, have closed – it means I don't have a break. I try to keep active, and go on walks, but my life has been turned upside down. I am confident that if Government knew what life has been like for so many people with neurological conditions during COVID-19, they would be taking it more seriously.

Martha, who lives with Complex Regional Pain Syndrome, Reflex Sympathetic Dystrophy (RSD) and Causalgia

Acknowledgements

We offer our sincere gratitude to the individuals and organisations who supported and contributed to this report. We wish to acknowledge the tremendous contribution and effort of the clinical and non-clinical workforce, and third sector organisations, who work tirelessly to improve the lives of people living with neurological conditions before, during and beyond this pandemic. And, most importantly, we are indebted to the thousands of people living with neurological conditions and their families who shared their experiences and views. Thank you.

Foreword

COVID-19 has undoubtedly had a profound effect on people with neurological conditions and their services. As support from the NHS and social care has been restricted, health and care professionals across the country have found new ways of maintaining some contact with people with neurological conditions remotely. Patient groups have found new ways of facilitating peer to peer support and providing a listening ear to people with neurological conditions when they need it most. COVID-19 has accelerated remote models of care, as well as new ways of referring people for specialist support and providing advice and guidance to primary care. It is absolutely critical that we learn these lessons of the pandemic where we can, and work as a community to build back better as a result.

It is in this spirit that we present this report, which summarises key evidence from individuals and organisations from across the neuroscience community about what the impact of the pandemic has been on them. This report presents first-hand testimony from people with neurological conditions, professional bodies and patient groups from across the country about what needs to happen now as we move forward.

We are committed to taking these recommendations forward and encouraging others to play their part as well. In particular, NNAG and the Neurological Intelligence Collaborative (NIC) will work together to define optimum neurological pathways of care across a range of neurological conditions, as well as define the outcome measures associated with these and how data on outcomes might be collected and analysed. We will work to ensure new ways of working are reflected in these pathways. And, we will ensure that equity of access to care is at the heart of this work, as well as relevant workstreams led by NHS England and NHS Improvement, and other health bodies.

Looking to the future, neuroscience services face significant challenges and opportunities – evolving treatment options for a wide range of neurological conditions, including dementia, mean that we need to build and invest in services that are fit for the future, enabling access to innovation as this becomes available. We are yet to understand fully the long term impacts of COVID-19 on the individual, but effective treatment and support for post COVID-19 syndrome does require neuroscience input – be this to pick up neurological complications, manage an acute neurological disease or assess changes to cognitive and behavioural function and help people to recover. Many gaps existed in the neurological workforce prior to COVID-19 – if we are to meet these challenges, we must ensure we have the right health and care workforce available, across neurosciences, to deliver treatment and support now and in the future.

Fundamentally, now is the moment for the neurological community to work together to achieve better treatment, care and support – the level of collaboration across the community has been astounding during these unprecedented times. This must continue if we are to reach our collective vision of ensuring every person with a neurological condition gets the right treatment, care and support.

Adrian Williams and Georgina Carr
Co-Chairs of the National Neurosciences Advisory Group (NNAG)

Executive Summary

The COVID-19 pandemic poses an unprecedented challenge to the delivery of NHS health and social care services. People with neurological conditions, approximately 1 in 6 of the population, have been profoundly impacted across their care and daily life since the onset of the pandemic.

Our report found that since the onset of England's first lockdown in March 2020 people with neurological conditions have been directly impacted across all areas of life, from access to food, ability to work, social interactions and support, and accessing essential health and social care services. Many have been shielding or self-isolating because of the virus, increasing anxieties, loneliness and isolation, at times exacerbated by unclear and inconsistent messaging and advice. This has led to increased pressure on family members, carers and the charities and patient organisations providing support services.

The pandemic and resulting rapid reallocation of already over-stretched resources away from neurology, is highlighting and exacerbating existing gaps and unwarranted variation in care for people with neurological conditions. This looks set to worsen as the pandemic continues to unfold. A growing number of long-covid patients now require neurological, neurorehabilitation and neuropsychiatric and/or neuropsychological care to manage symptoms and functioning. Going forward we anticipate an increased demand on neuroscience services to ensure the needs of this new cohort of patients are met; pathways, funding, timeliness of intervention and workforce capacity must all be taken into consideration.

In particular, we found:

- There is a risk that those who were less able to access timely care are less likely to access it now due to a lack of formal and informal support, and isolation from those closest to them.
- There has been disruption to a wide range of services for people with neurological conditions, including neurology, neuroradiology, neurophysiology, neurosurgery, neuropsychiatry and neuropsychology, rehabilitation and therapy services. Although many have redoubled their efforts to try to bring services in line with provision pre-pandemic, gaps in support and capacity remain.
- In some areas, already long waiting lists have increased. At the same time, referrals to neurology services have dipped in many areas, suggesting people with suspected or existing neurological conditions may not be coming forward when they experience new symptoms.
- There has been widespread adoption of remote consultations, new triage and advice and guidance models but further research and evaluation is needed to understand the impact on patient outcomes and experience and establish consensus on good practice.
- For some groups of neurological patients virtual consultations has meant the welcome access to a consultant or specialist nurse, perhaps reducing the costs and logistics of travelling distances for follow up appointments faced pre-pandemic. However, virtual assessments are not clinically appropriate in all cases, some symptoms and deterioration

of health cannot be picked up virtually. There is also a risk that they can lead to lower threshold in referral to diagnostic services. Of course, not every person with a neurological condition had access to the technology required for remote consultations, or know how to use it.

- People may not have access to a safe space for their remote medical appointments either. Digital and health inequalities risk being exacerbated by too widespread a roll out of remote consultations, and must be accounted for in planning.
- The health and social care workforce have responded and adapted at pace. Supporting the psychological needs of the workforce, prioritising their safety, and addressing disruption to neurology training and education are critically important both in the immediate and longer term.
- The lack of uniform and mandatory coding and data systems to support critical decision making hindered the efforts to identify clinically vulnerable and clinically extremely vulnerable neurological patients in the first wave of the pandemic.
- The pandemic has exposed and exacerbated longstanding barriers to social care that people with neurological conditions and their families face.
- The neurological and neuropsychiatric manifestations of COVID-19, while still emerging, are likely to further increase demand on services, both in hospitals and the community.
- Neurological research has been significantly disrupted - this is compounded by financial pressures on medical research charities - and risks compromising future innovation and advancement of treatment options for people with neurological conditions.

The impact of the pandemic has been variable. It has shone a harsh light on existing health inequalities, which were of course prevalent in access to services for people with neurological conditions prior to the pandemic. The impact on services has often been influenced by prevalence of the virus in the region, digital maturity of the service and capacity to redeploy staff, amongst other factors. Impact of the pandemic on people with neurological conditions is likely to have been influenced by access to services, access to informal support networks, levels of deprivation, as well as sociodemographic factors known to have a relationship with incidence and severity of COVID-19 (for example age and ethnicity).

In compiling this report the NNAG has received evidence from across the neuroscience community. People with neurological conditions, patient organisations, professional bodies and service leads have all shared their findings and experience in order to understand and learn the lessons in the response required. This report addresses some of the most prominent, urgent and overlapping issues affecting people with neurological conditions, the health and social care workforce, services for people with neurological conditions, the future of neurological research, and the lessons we can learn as we look ahead to the future.

Some of the issues touched on in this report pre-date the pandemic. COVID-19 has highlighted the now even more pressing and urgent need to act. In recent years encouraging steps have been taken to address gaps and unwarranted variation in care, including NHS England and NHS Improvement’s Neurosciences Transformation Programme, the Getting it Right First Time (GIRFT) programme and the RightCare neurosciences toolkits. Collaborative efforts to support the progress in the care for people with neurological conditions are key going forward.

Our Recommendations

In the short term (within 3 months):

1. NHS England and NHS Improvement, commissioners, healthcare professionals, professional bodies, patient groups and people affected by neurological conditions should work together to ensure the needs of people with neurological conditions are central to any decisions made about the recovery of NHS services.

NHS England and NHS Improvement nationally:

2. All restoration and neurological service improvement initiatives, for example the NHS England and NHS Improvement neuroscience transformation programme and the neurology (GIRFT) programme should actively engage and support people affected by neurological conditions to be involved in the development of this work.

3. Develop a fair, appropriate method to effectively commission the remote delivery of treatment and care across the clinical pathway, that reduces the likelihood of widening digital inequalities and is rooted in driving good clinical outcomes.

4. Patient choice must be central to decisions concerning the wider use of telemedicine and digital tools to ensure that no one is excluded as a result of the greater use of digital technology in delivering care.

5. As part of the outpatient transformation programme, healthcare professionals, professional bodies, patient groups and people affected by neurological conditions should work together to define the principles and processes involved in successful remote consultations, with patient choice at the heart; and successful triage and advice and guidance, promoting optimum outcomes, quality care and consistency in approach nationally, where possible.

6. Where changes and improvements are made to block contracts and tariffs, ensure this is communicated with clarity to local commissioners and providers, and the potential impediment these pose to the development of business cases and services development, to ensure the sustainability of services going forward.

Integrated care systems

7. Local pathways for people with neurological conditions and suspected neurological conditions should include properly resourced triaging, with the expertise that are needed at the right stage in the pathway to ensure that patients receive the appropriate care and treatment needed.

8. Within one month of NHS England and NHS Improvement returning to incident level 3, all neuroscience services should have the resources including staff and space, to return to pre-COVID-19 levels.

Clinicians and providers

9. In order to address the backlog of appointments caused by the COVID-19 pandemic waiting lists for specialist care should be risk stratified and prioritised on clinical grounds. This must be underpinned by robust digital IT systems which capture real time data to support decision making.

10. Outcomes following the use of telemedicine must be measured and, ideally, the quality weighed against the gold standard of face to face care.

The UK Government

11. Must clarify if and how recent spending commitments to support UK research will contribute towards neurological research and support the charity research sector in particular.

In the longer term:

NHS England and NHS Improvement nationally:

11. NHS England and NHS Improvement should lead a national plan for neurology in collaboration with NNAG and its members. The plan should seek to address longstanding and immediate issues identified across services including workforce shortages, lack of integration of mental health and neurology services, unwarranted variation in access to health and care services, premature deaths associated with a neurological condition and tackle longstanding health inequalities facing people with neurological conditions. The plan should also include the necessary funding to enable transformation of services and promote the active involvement of people with neurological conditions in the planning and delivery of care.

12. NHS England and NHS Improvement should develop and invest in a national rehabilitation plan. The plan should address access to rehabilitation for people with neurological conditions along their whole care pathway. This should be backed up by increased support allocated to the delivery of services and address shortfalls in workforce and data systems to support delivery.

13. NHS Digital and NHS England and NHS Improvement and Improvement should work in collaboration with the NIC, the data arm of the NNAG, to develop a clinically led pragmatic system of clinical classification of outpatient episodes which can be supported by NHS systems locally. Building on this, the community should develop a neurological dashboard to aid service planning and development, which collates information about the outcomes and experience associated with good clinical care.

Research funders

14. Support an evaluation of the safety effectiveness of remote delivery of neurological treatment and care on health outcomes. The scope should cover the breadth of neuroscience services.

Health Education England

15. Recognising the long term need to ensure our neuroscience workforce are supported and retained, extend the use of “wellbeing hubs” for the clinical and non-clinical workforce beyond the pandemic.

16. Work with the NNAG, NHS England and NHS Improvement and relevant professional bodies and charities including the ABN and Neurological Alliance to address the ongoing competencies, curriculum, training and recruitment requirements of the breath of health and social care professionals involved in the care and support of people with neurological conditions, recognising the impact that the COVID-19 pandemic has had on neurology training and education.

Local commissioners

17. Integrated Care Systems (ICSs) and Sustainability and Transformation Partnerships (STPs) should recognise, prioritise and adequately resource services for people with neurological conditions, evidencing that the unmet needs of patients and poor patient experience is addressed going forward. The integration of mental health and neurological care should be prioritised as commissioning arrangements change.

Department of Health and Social Care

18. Work with the Care and Support Alliance, Association of Directors of Adult Social Services and others to better understand and ensure resources are in place to meet long standing unmet need in the social care system. We urge the Department to bring forward such proposals in 2021.

About the report

Since the onset of the COVID-19 pandemic the NNAG has been working with NHS England and NHS Improvement, patient organisations, professional bodies and partners to monitor, report and respond to the impact of the pandemic on services and people living with neurological conditions. In August 2020 the NNAG put out a call for evidence for further literature and findings in relation to the risks, impact and opportunities posed to the care of people with neurological conditions. The purpose of this report is to identify and broadly summarise the key themes across the evidence, utilising the collective insight and intelligence of NNAG to identify "lessons learnt" from the COVID-19 pandemic, and to put forward recommendations reflecting the diverse needs of people with neurological conditions.

The report is intended to be a valuable resource to the Department of Health and Social Care, NHS England and NHS Improvement, and any individual or organisation responsible for restoring and transforming care for people with neurological conditions both during and moving forward from the pandemic.

A full list of organisations/individuals that submitted written evidence, and evidence categories, can be found in Appendix 1.

About neurological conditions

There are now an estimated 16.5 million cases of neurological conditions in England, at least 1 in 6 people live with one or more neurological condition(s). There are over 600 types of neurological conditions. These include conditions of the brain, spine and/or nerves; some which are comparatively common such as migraine, multiple sclerosis and Parkinson's, and others which are rare. Neurological conditions can be sudden, fluctuating, progressive and/or lifelong and have a range of different causes including genetic factors, traumatic injury and infection, although the causes of some neurological conditions are still not well understood. Anyone can be affected by a neurological condition, no matter their age. Neurological conditions can result in significant challenges to a person's mobility and/or cognitive function and/or cause considerable pain, having a significant impact on their quality of life and wellbeing. In some cases, neurological conditions can lead to premature, avoidable death.

Although the predominant clinical presentation of COVID-19 is with respiratory disease, neurological manifestations are being recognised increasingly. The most recent evidence suggests COVID-19 patients may also present with a cerebrovascular event, including ischemic stroke, intracerebral haemorrhage, and central nervous system vasculitis. Some have also presented with altered mental status, including unspecified encephalopathy and encephalitis.

About the National Neuroscience Advisory Group

The National Neurosciences Advisory Group (NNAG) is a collaboration of professional bodies, patient groups, national and local policy and commissioning leads. We exist to improve treatment, care and support for people with neurological conditions. As the only national, multi-disciplinary expert group working to improve treatment, care and support for people with neurological conditions, NNAG plays a central role in helping to understand the impact, as well as rebuild, during and after the COVID-19 crisis. NNAG focuses on services in England, although many of the lessons from the COVID-19 pandemic apply across the UK too.

Introduction

The COVID-19 pandemic has posed an unprecedented challenge to the delivery of health and social care services.

Prior to the pandemic people with neurological conditions in England faced significant unwarranted variation in treatment, care and support across health and social care services. This included unwarranted variation in spend on neurology, treatment and support approach and outcomes, and patient experience. The experience of people with neurological conditions of their care is also comparatively worse than other condition areas.

Despite increasing prevalence and cost to the health service[i], neurological conditions and services are not a clinical priority for NHS England and NHS Improvement. In policy terms the specialty is hidden within the wider long-term conditions policy agenda and it lacks levers for improvement, meaning there are few specific incentives to improve neurological care within NHS accountability frameworks.[ii] The NHS long-term plan, RightCare neurology toolkits, Getting it Right First Time (GIRFT) programme and the NHS England and NHS Improvement Neurosciences Transformation Programme have all provided encouraging opportunities to work towards improving neurological care in recent years.

Since the onset of the pandemic people with neurological conditions have experienced the impact across all areas of life from access to food, ability to work, social interactions and support, accessing social care and receiving health care for their neurological condition. People with neurological conditions are amongst the most impacted by the virus, with many self-isolating, 'shielding', and experiencing high levels of anxiety and loneliness.[iii]

There has been a wealth of resources, articles and guidance produced by professional bodies and patient organisations and aimed at individuals, health professionals, commissioners and policy produced since the onset of the pandemic. Yet whilst NNAG welcomed the recent Westminster health and care select Committee report we were concerned to see the lack of mention of the millions of people affected by neurological conditions and the loss of essential, time critical services such as rehabilitation to help people function independently.[iv]

This report highlights the impact and risks of the pandemic on the fragile and overstretched systems supporting people living with a neurological condition in England and sets out the priorities to address these in the immediate and longer term.

The impact of the pandemic on people with neurological conditions and their care

This section of the report identifies the key themes reported to NNAG. It is by no means an exhaustive list nor is it intended to be a complete and final account of the impact of COVID-19 on the lives and care for people affected by neurological conditions, which is still ongoing. We provide a summary, highlighting some of the most pressing, and in some instance's longstanding, issues impacting the care of people with neurological conditions.

Neurological Care

Background:

Neurology services provide care for the diagnosis, treatment and care of all conditions that affect the brain, spinal cord, peripheral nervous system and muscles. Neurological care covers both acute and chronic presentations. Services are delivered in the community, hospitals and specialist neuroscience centres dependent on local availability and delivery model. People with neurological conditions will require access to different parts of the care pathway, dependent on their individual needs, and at different stages of their condition.

Experience of care for people with neurological conditions is significantly variable across the country, [v] as is spend on services.[vi] In the Neurological Alliance's recent Patient Experience Survey of over 10,000 people with neurological conditions, almost half of those responding (46%) reported that their condition impacted on their quality of life to a great extent.[vii] The survey also found that respondents who live in the most deprived areas experience the longest waits for specialist services, as compared to those living in less deprived areas.[viii] COVID-19 itself has of course also shone a harsh light on health inequalities in England, therefore inequalities in access to care may have widened further. The number of deaths in England as a result of having a neurological condition rose steadily in the decade to 2014 according to Public Health England, rising from around 23,000 deaths (23,051) in 2001 to around 32,000 (31,925) deaths in 2014, an increase of almost 40% over that period.[ix]

Impact of the pandemic:

During the initial stages of the pandemic there was a rapid re-organisation of services and redirection of NHS resources towards fighting COVID-19. Clinics and services had to change the way they operated and many still remain at reduced capacity. In some areas this is significantly impacting on the ability of services to meet the needs of people with neurological conditions now, as well as plan for the future. Some patients have found themselves unable to access specialist support, had appointments cancelled, and felt anxious and confused about accessing NHS services. A survey of more than 1600 people with neurological conditions conducted in June 2020 found that more than 7 in 10 respondents had experienced a delay in treatment or support.

The majority of the delays were reported to be a routine appointment with their neurologist.[x]

In the initial stages of the pandemic cancellation or delay of almost all routine appointments with consultants and specialist nurses were reported.[xi] Some people with neurological conditions reported that they were not offered a telephone or online appointment during this time, indicating the variation in services' ability to respond and adapt to the crisis. There were also reports of restricted access to medication – in some cases this was because prescriptions from GPs were harder to get.

Services, professional bodies and patient organisations responded quickly to the unfolding impact of COVID-19 on care for people with neurological conditions. Expert and essential guidance has been produced including the Association of British Neurologists (ABN) 's collated COVID-19 advice and guidance for health professionals, and a plethora of information and resources from charities and patient groups. Innovative and creative solutions in the delivery of services and care are being carried out to conform with social distancing restrictions, personal protective equipment (PPE) and safety requirements.[xii]

In particular, the use of remote, virtual, consultations in outpatient neurology care has increased substantially. Triage services have been expanded and enhanced, as has the provision of advice and guidance to primary care on best management of neurological conditions.

Virtual and remote consultations:

- Virtual and telephone appointments were, for the most part, reported as providing much needed timely access to care in a time of lockdown and social distancing.
- The uptake of virtual consultations has been reported as positive during this time.
- Undoubtedly, people with neurological conditions were by and large supportive of at least some contact from their specialist, even if this was by phone or videoconference.
- There is also evidence to suggest variability in the suitability of remote consultations for people with neurological conditions. The evidence received was also mixed on patient reported satisfaction with virtual consultations. There are also real concerns around health inequalities and safeguarding measures.
- Digital literacy, internet and phone provision, information and support and access to a safe space to allow for a private conversation with their clinician are some of the factors that are likely to influence patient experience of remote consultations.
- From the clinical perspective virtual consultations are not appropriate for assessment in all cases. Concerns have been reported about the quality of assessments when patients are not seen face to face. When seeing a new patient, the rapport between health professional and patient/carer is critical; this is far more difficult remotely

The nuances of an individual's condition cannot be seen remotely, for example how they walk into the consultation room, how they interact with the local environment. For some conditions, such as movement disorders, the use of virtual consultations is inappropriate. Assessing details of the examination, such as eye movements, fine tremor, gait, or changes in tone are impossible. This applies to a number of specialties and it could be argued that for most neurological conditions, the initial consultation should be face to face.

- Effective triage has been an essential tool across the pathway to ensure people with neurological conditions receive the appropriate support at this time. However, there is currently no consistent way to triage patients and it is critically dependent on the quality of the referral information received. Guidance on this is being produced by the ABN following a detailed survey of practices.

Redeployment of the workforce:

- The redeployment of health professionals out of neurological services to cope with the COVID-19 crisis had a significant impact on the capacity of services to provide care for people with neurological conditions during the height of the pandemic in Spring 2020.
- The impact is likely to be variable across the country. Factors including rate of local COVID-19 cases and pre-existing workforce capacity and vacancies will affect variation.

Patient behaviour:

- A reduction in referrals to outpatient appointments and reluctance from some patients to engage with existing services has been reported. This has largely been attributed to fear of the risk of COVID-19 infection and mixed messaging in the initial stages if the pandemic.

Waiting lists:

- There is now a significant backlog of appointments as services are restored. There is an estimated backlog of 227,000 neurology and 58,000 neurosurgery appointments, even before a second wave of COVID-19.[xiii]
- The backlog of appointments and resilience of services to respond is likely to vary across the country. It will be influenced by a number of factors including workforce capacity and physical space to adhere with social distancing guidelines for face to face appointments.
- Given the nature of neurological conditions, many people's symptoms will have significantly deteriorated since the onset of the pandemic. For example, over a third (34%) of people with MS said they felt their MS symptoms had got worse, with many saying their ability to walk had deteriorated (during the first lockdown)[xiv] As such, prioritisation of waiting lists is hugely challenging. Non acute patients that may have been considered "low priority" several months ago may now be falling through the gaps as services struggle to catch up.

Referral to diagnostic services:

- Virtual consultations in neurology services can mean a lower threshold for referral for neuroimaging and neurophysiology services. Some services have seen an increase in referrals for diagnostic testing during the pandemic.
- The limitations of virtual consultations may compound challenges in effective triaging in these services with implications for both patient outcomes, experience and capacity of services
- There is a likelihood of a 'lag' in referrals once a proportion of neurology patients not initially physically examined during the pandemic are subsequently seen face to face resulting in referral for studies at that stage. This will be subject to variation between services in deferent geographical regions.
- In some cases, neurophysiologists reported examinations taking about 50% longer due to the need for extra cleaning and PPE change between patients.
- Some clinical neurophysiology departments are in areas such as basements and outbuildings. This puts further pressure on services as the need to social distance and adhere to cleaning and safety requirements, both in clinics and waiting rooms, presents challenges.

Neurosurgery:

- During the first wave a reduction in both elective and non-elective neurosurgical procedures was observed. Non-elective volumes increased back to more normal numbers by June 2020.
- Most urgent elective activity was maintained in most units in the UK eg neuro-oncology surgery for malignancy by maintaining Covid-19 free pathways and in some units, use of the independent sector.
- Non-time-critical elective care was compromised most. This still recovered well but not completely (i.e. to pre-pandemic levels) between the first and second wave.
- The Society of British Neurological Surgeons (SBNS) alongside the Royal College of Surgeons (England) created a guide to levels of clinical priority for use during and after the pandemic, using codes P1-6.[xv]
- In it, a number of neurosurgical procedures were considered appropriate to delay for more than three months (P4), including movement disorder implants, epilepsy surgery and some slow growing brain tumours. This may have worsened anxiety amongst people with neurological conditions who could benefit from such procedures.
- The functioning of multi-disciplinary teams (MDTs) changed, with many moving to fully video conferencing very successfully and without compromising care.

- The challenges around the national neurosurgical waiting list present before covid have been exacerbated. Thankfully NHS England and Improvement working with SBNS have a project in place to work through these challenges.

- Networks in each region have been created to share best practice and provide mutual aid.

- The restoration and recovery will aim to focus on re-matching demand with capacity by supporting shared decision making, improving productivity and efficiency, reducing length of stay and critical care utilisation, increasing flow, improving rehabilitation access and increasing resources where necessary to deliver more activity.

- All units have designated Covid-19 mitigated pathways to allow elective surgery to continue.

- All on an elective waiting list are being reviewed and people with neurological conditions given an opportunity to delay their care, postpone it or discuss their concerns with their clinical team if their condition has worsened.

Parkinson's UK surveyed more than 1700 people affected by Parkinson's in April-May 2020 during the most severe part of lockdown to find out the effects of the COVID-19 situation on the Parkinson's community. 34% of people with Parkinson's had appointments with their Parkinson's nurse cancelled and of these, 52% were not offered a phone or online appointment. Similarly, 34% had appointments with their Parkinson's Consultant cancelled and of these, 68% were not offered a phone or online appointment. 29% of respondents had a GP appointment cancelled. 15% of respondents decided to cancel their own appointments as they were anxious about the risk of catching coronavirus if they entered a hospital.

The impact of the coronavirus restrictions on people affected by Parkinson's, Lancaster University, June 2020 [xvi]

At the MND Care Centre at King's, from October 2018 to September 2019 they received 206 new MND referrals. From October 2019 to September 2020 this dropped to 135 (a drop of 35%). This pattern was seen in other specialist MND centres with typical drops of 30 to 50%. The drop is due to people not being seen by GPs or, if they are, they are not receiving the investigations that would normally result in a referral to neurology. King's was able to maintain its diagnostic service despite redeployments, virtual clinics, and the additional workload from the pandemic.

At King's, the number of neurology, palliative care and CNS appointments were relatively similar to the previous year. However, there were over 200 fewer therapy contacts due to 4 months without therapy clinics This reflects the huge impact of the pandemic on the delivery of the multidisciplinary team service due to redeployment of staff.

Evidence submitted by Professor Ammar Al-Chalabi (King's) and Professor Chris McDermott (University of Sheffield)

A survey of 12 MND Care Centres during the first lockdown found the following:

- The mean increase in waiting times for referral was 58 days
- The mean gastrostomy delay was 6.43 weeks
- 8 centres (two thirds) reported compromised end of life care for people with MND
- 52 people with MND were given their diagnosis over the phone

Survey of 12 MND Centres conducted by the Motor Neurone Disease Association (MNDA)

The MS Society and MS Trust surveyed 181 MS Health Care Professionals (HCPs) in June 2020 about the impact of Covid-19 on MS services in the UK. 70% of MS professionals responding to the survey did not think the MS service they work in or with was able to meet the needs of people with MS to the extent it was pre-Covid-19. Respondents identified the key challenges in returning to pre-Covid-19 capacity as the backlog of patients (75%), lack of physical space to deliver care safely (66%), patients being reluctant to attend appointments/hospital (60%) and lack of staff (37%). 24% of respondents said more than half of the workforce in their MS service was still redeployed away from MS care. Of those who were redeployed, 29% said they did not feel their time was being well used.

Findings of a survey of MS healthcare professionals on the impact of Covid-19 on MS services in the UK. MS Society, MS Trust July 2020[xvii]

"Wards and investigations and surgery closed. I have seen 4 deaths already in very short time. We are used to seeing excess mortality in normal times, but preliminary reports seem to suggest rising premature mortality in people with epilepsy"

Professor Ley Sander, Academic Neurologist, UCL, London (Evidence submitted by SUDEP Action)

NeuroResponse set up the @home phlebotomy service to ensure that people with MS on a disease modifying drug can continue to have their blood monitors for any possible side effects during lockdown. The @home service is up and running, results are getting back to the specialist teams and they are very pleased with the safety net we offer to them and their patients. Patients love the @ home service and have provided positive feedback, including: "L.... was very kind and considerate. She was also professional and explained the procedure to me which I really appreciated. She was wearing full PPE which made me feel very safe."

Feedback on a home phlebotomy service for MS patients set up during the pandemic[xviii] (Evidence submitted by NeuroResponse)

"There is general concern about the reduction in income being seen by Hospices, one hospice has had to take out a commercial loan to keep going. A number of hospices do not have the required level of PPE or the training to admit patients on NIV or needing suction. Where it has not been possible to address the issue for the most part community-based support has been provided."

Evidence submitted by Motor Neurone Disease Association.

COVID-19 has had an impact on patients requiring surgery for malignant brain tumours—with 10.7% having a change of management due to COVID-19, most commonly by not having surgery and many having no active treatment at all"

Impact of COVID-19 pandemic on surgical neuro-oncology multi-disciplinary team decision making: a national survey[xix]

Mental Health

Background:

In common with other long-term conditions, coping with the impact of the diagnosis and symptoms of a neurological condition can lead to depression and anxiety. However, the interplay between neurological conditions and co-morbid mental health conditions is often far more complex than this. Changes in the brain can directly affect emotions and cognitive functioning; psychiatric symptoms can exacerbate neurological symptoms, and neurological medications can have side effects that include mental health problems. In some cases, a patient presenting with psychiatric symptoms may have an underlying neurological condition and, conversely, neurological symptoms may not reflect a neurological disorder but a functional disorder secondary to emotional difficulties.[xx]

The NNAG recently reported a troubling outlook for people with co-morbid mental health and neurological conditions including a lack of joined up care, the absence of care planning, an inability to access mainstream mental health services and a lack of training and guidance for both IAPT professionals and non-mental health professionals to support the needs of people with neurological conditions.[xxi] Prior to the pandemic, 4 in 10 respondents to the National Neurological Patient Experience Survey said their mental health needs were not being met at all.

Impact of the pandemic:

Surveys and reports submitted to the NNAG from the third sector detail the devastating impact of the pandemic and lockdown on people with neurological conditions: Lockdown and uncertainties concerning wellbeing, access to health care, treatment management and other social factors, brought on by COVID-19 have had a detrimental impact on the mental health and wellbeing of people with neurological conditions. Increased depression, anxiety, suicidal thoughts and social isolation were widely reported. For many this was coupled with a loss of appropriate and timely support services, restrictions in access to supermarkets, community services and rehabilitations, an impact on employment and income, and increased pressure and stress on family members and care givers.

Access to appropriate mental health services:

- Pre-existing gaps and unwarranted variation in care for people with neurological conditions and co-morbid mental health needs has been exacerbated by the pandemic.
- Access to neuropsychological services was extremely difficult prior to the pandemic, but this has become even harder as a result of COVID-19, with some services now reporting a three year wait for access to support.
- Complex in-patient, specialised neuropsychiatry services have, in some areas, stopped as a result of the pandemic.

Rise in anxiety and depression:

- Many people with neurological conditions have experienced depression and anxiety as a result of isolation, loneliness and disruptions to care. There is emerging evidence to suggest the mental health impact on people with neurological conditions is greater than that on the general population.

Neuropsychological and neuropsychiatric impacts of COVID-19:

- The neuropsychological and neuropsychiatric impacts of COVID-19 itself are not yet fully understood. However, case studies have revealed neurological problems in severely affected COVID-19 patients in particular, that may require support from neuropsychiatry. These include cognitive deficits, hallucinations, as well as things like delusions and paranoia in patients with no previous history of mental health issues. Further research is required to understand the cause, nature and scale of impact of neurological issues associated with COVID-19 and the appropriate services required.

“Emerging research suggests that autistic people have experienced heightened anxiety and more mental health difficulties during lockdown; this increase is larger than in neurotypical people. Data from the National Child Mortality Database suggests a possible rise in self-harm and suicidality during lockdown, autistic people and those with ADHD are known to be at increased risk.”

Impact of COVID-19 on autistic people. Action Briefing (2020) - Autistica

Two thirds of survey respondents with a brain injury reported a negative impact on their psychological wellbeing: 64% reported an increase in anxiety. 60% reported a negative impact on their mental health; and 53% reported a worsening of depression

The impact of lockdown on brain injury survivors and their families - Headway – the brain injury association[xxii]

Therapy and Rehabilitation Services

Background:

Rehabilitation services, both in hospital and in the community, play a key role in the recovery, support, symptom management and function of people with a range of newly diagnosed and ongoing neurological conditions. From physiotherapy, speech and language therapy, occupational therapy, continence specialists and taking part in physical exercise, rehabilitation is about maintaining physical, psychosocial and emotional health and wellbeing.[xxiii] Consistent, high-quality rehabilitation is essential to speed recovery, maximise restoration of function and achieve the best possible quality of life for people with neurological conditions across the entire pathway. There is acknowledgement within the NHS that there is strong evidence that continued, coordinated multidisciplinary rehabilitation in the community improves long-term outcomes and can help to reduce hospital re-admissions.[xxiv]

Prior to the pandemic the provision of rehabilitation and therapy services for people with neurological conditions has fallen short of what is needed to achieve recovery, support, symptom management and function. There is inequity of access to therapy and rehabilitation pathways, and limited integration between traditional silos of therapy delivery. Fragmented care pathways, insufficient data collection, and workforce challenges across all professional groups further contribute to the challenges facing neurorehabilitation in the community. Most treatments are delivered by therapists in the community or outpatients – usually overseen by a Band 7 or Consultant Therapist (Band 8), working closely with local commissioners and primary care. If there are no community neurorehabilitation services, the local population is likely to receive up to six week intermediate care in the community in response to a GP referral to avoid a hospital admission, i.e. with limited (or no) specialist neurorehab input.

Responsibility for funding rehabilitation is split between national and local NHS bodies, depending on the level of complexity, need and specialist support required. However, there are no specific requirements for local NHS bodies to fund community rehabilitation services.[xxv]

Impact of the pandemic:

The COVID-19 pandemic has magnified challenges facing rehabilitation services. Access to rehabilitation services has been particularly badly affected. The redeployment of community-based therapists and influx of new referrals to neuro-rehab units have further compounded this. NHS data acquired by the Neurological Alliance, shows there were 20,695 (28 per cent) fewer outpatient appointments with a rehabilitation consultant across all neurological conditions between March and June 2020 compared to the same period last year.

The impact of removing a person’s opportunity to progress towards achieving physical therapy goals can have a significant impact on their physical, psychosocial and mental health. Some neurological conditions can deteriorate rapidly without specialised rehabilitation. Struggling to get the rehabilitation they need will leave some neurological patients with their mobility, cognition, communication and motor skills permanently affected, reducing quality of life and independence. For others this can have life changing consequences.[xxvi]

Early discharge from in patient units:

- In the first wave of the pandemic in-patient rehabilitation beds were lost to free up capacity for new cases due to COVID-19.
- Many patients were discharged prematurely and without adequate care packages at a time of reduced capacity on community services and redeployment of community therapists.
- Short term in-patient rehabilitation contracts have now been introduced to cope with the COVID-19 crisis.
- At the onset of the second lockdown NNAG has received evidence that some trusts have repeated the direction to free up in-patient beds.

Redeployment:

- The redeployment of community-based therapists, with no planned restart of services has led to gaps in care in some areas.

Cancellations of community rehabilitation services:

- Community rehabilitation appointments have been cancelled, delayed or limited during the pandemic, many of these are time critical services for patients with neurological conditions.
- Many people with life changing brain injuries have had their rehabilitation programmes cut back or cancelled with no indication of when these may resume.[xxvii]
- Therapies that help people with progressive neurological conditions such as Parkinson’s and MS to manage their pain on a daily basis, or to stay mobile and independent, such as ‘hands on’ physiotherapy and physical activity, have been cancelled, sometimes because they are held at facilities in the community which have closed.[xxviii]

Virtual appointments:

- Virtual rehabilitation appointments have been provided in some areas with positive feedback on physical and mental health as well as reduced isolation.[xxix] However, digital inequality is a real problem for people with neurological conditions.
- In some cases, virtual consultations are inappropriate. The cognitive ability of the individual and the type of intervention are factors which can impact on the effectiveness of virtual services.

Waiting lists and capacity:

- In-person consultations take longer due to social distancing and cleaning procedures. As a consequence, less patients can be seen in person which is contributing to the backlog of appointments and increased waiting times for people with neurological conditions.

Increase in demand:

- The COVID-19 pandemic is causing an increase demand on neurological therapy and rehabilitation services. This looks set to continue in the short and longer term.
- There is a pre-existing need for rehabilitation and therapy services from major trauma, stroke, neurosciences and spinal networks which will continue
- Additionally, people with neurological conditions who discharged early or who did not present during the pandemic must have their rehabilitation needs met in the short and longer term.
- COVID-19 patients will continue to require rehabilitation services to address cardio-respiratory and neurological needs resulting from the virus and long COVID syndrome needs.

The impact of lockdown measures on self-management:

- The closure of public gyms, community-based gyms and exercise classes as a result of the pandemic further impacts on the ability of people with neurological conditions to self-manage

"Over half (57%) of those who sustained their brain injury in the past two years and 42% of all respondents reported that their rehabilitation had been negatively impacted by lockdown."

The impact of lockdown on brain injury survivors and their families - Headway – the brain injury association, 2020

"34% of people with Parkinson's said that reduced access to exercise had a big impact on their lives. Many were frustrated that established physical self-care routines had been disrupted and they were worried about the impact on their symptoms, and the long-term effects on their health."

The impact of the coronavirus restrictions on people affected by Parkinson's, Lancaster University, June 2020[xxx]

Over a third (34%) of people told us they felt their MS symptoms had got worse during lockdown, with many saying their ability to walk had deteriorated, they were experiencing increased fatigue and pain, and were struggling with low mood. When it came to speaking to a rehabilitation professional during this time, 7 in 10 (69%) of those who needed it said they were unable to. Of those whose symptoms had worsened, over half (51%) felt a reduction in, or changes to specialist support had contributed to their symptoms getting worse.

Too much to lose. The importance of improving access to community rehabilitation for people with MS - MS Society 2020[xxxi]

Responses show that for 74.2% levels of activity decreased, affecting function mildly (5.7%) moderately (25.7%), severely (28.6%) very severely (14.2%), this in turn adversely affected movement and balance, increasing falls and dependence on caregiver.

Covid-19: Impact of Reduced Exercise on MS: Survey Report, St Helens MS Branch: July 2020

85% of respondents reported that the virtual centre helped them to focus on, maintain and/or improve their muscle strength during the COVID-19 lockdown. 58% of respondents reported that accessing the online activities/classes online and receiving phone calls from staff members helped them feel less isolated during lockdown 46% of respondents reported that the virtual centre allowed them to stay in control of their wellbeing and maintain positive self-esteem. The members who reported this also confirmed it helped them to feel more independent during the COVID-19 lockdown period

Virtual service review. Evidence submitted by the Neuro Therapy Centre, Chester

Berkshire Community based Neurorehabilation developed a tool that facilitated decision making with regard to risks and benefits of face-to-face contact to stroke and patients with neurological conditions. Risks were documented and considered alongside patient needs and goals and appropriate use of remote and telerehabilitation approaches. The tool has been adopted by other services across the country enabling clinicians to feel more confident and maximising opportunities for therapy delivery.

Evidence submitted by the Clinical Policy Unit, NHS England and Improvement[xxxii]

Regions have also been proactive in creating training opportunities to empower others. The South Yorkshire and Bassetlaw Integrated Care System's hosted network and Greater Manchester stroke operational delivery network have delivered webinars to 100+ people to share current delivery and use of remote rehabiliation in the region and share best practice.

Evidence submitted by the Clinical Policy Unit, NHS England and Improvement

Social Care

Background:

In recent years social care has been high on the political agenda. Yet working age people with neurological conditions have continued to be neglected in the social care system and in plans to reform it. In 2018/19 over a third of people with neurological conditions who were in receipt of social care reported that it was not meeting their needs. The same survey, conducted by the Neurological Alliance found that 45% of respondents with a neurological condition receive care from an unpaid carer such as a friend or family member.[xxxiii]

Impact of the pandemic:

The pandemic has exposed and exacerbated longstanding barriers to social care that people with neurological conditions and their families face. Challenges accessing and navigating social care have been intensified as stress and pressure on unpaid carers increased and continues to increase under lockdown restrictions. For patients with cognitive impairments the impact of isolation and reduced visits from family, friends and care givers risks rapid decline in wellbeing and functioning. Insufficient personal protective equipment (PPE) in the early stages of the pandemic, and a lack of testing for staff and care home residents has and continues to risk the safety of staff and people with neurological conditions.

Residential care:

- Difficulty accessing regular COVID-19 testing for both care staff and residents has exacerbated anxieties amongst residents, family members and friends during the pandemic.
- Family and friend visits to care homes have been limited if not stopped completely, causing significant anxiety for residents and those closest to them. In some cases, deterioration of a resident's condition (for example, dementia) has been directly attributed to this.
- Negative press of care homes and infection rates has also impacted referral levels and increased anxiety for residents and visitors despite the variation in infection rates across care homes.
- In some residential homes there has been a greater use of technology which has helped to reduce isolation of residents.

Discharge:

- There has been confusion and a lack of clarity around the emergency discharge procedures and the care costs people with neurological conditions would have to pay during the pandemic

Access to care in the community:

- Access to care in the community has been significantly reduced from pre-pandemic levels.
- The risk of infection of COVID-19 has led to an increase in cancellations of care visits. Insufficient levels of PPE contributed to this in the early stages of the pandemic.

“For the first three months of the pandemic, we struggled to access consistent and sufficient supplies of PPE for our staff. Whilst this issue has now been resolved, our services are still struggling to access regular COVID-19 testing for both our care staff and residents. The government are prioritising testing for residential care homes for older people, and for people with dementia, however we also have vulnerable people in our care. We cannot safely allow regular visits from families and friends until we have regular testing in place.”

Evidence received from Sue Ryder

“There are ad hoc reports of continuing healthcare (CHC) and Disabled Facilities Grant (DFG) decisions being delayed, difficulties being experienced in contacting social workers and insufficient carers being available. There is one report of CHC applications being fast tracked. In at least one area there has been a drive to rationalise the provision of care and reports of wheelchair and mobility aids services not performing or ceasing to trade.”

Evidence received from Motor Neurone Disease Association

“Our report found that 48% of the people with Parkinson’s receiving social care and support at home received less care during the pandemic. This left people unable to manage safely in their own homes. For instance, a person with Parkinson’s had their care package, which helped them manage their daily medication stopped. Medication is crucial for people with the condition to control their symptoms.”

The impact of the coronavirus restrictions on people affected by Parkinson’s, Lancaster University, June 2020. Evidence submitted by Parkinson’s UK[xxxiv]

Identifying the clinically vulnerable and clinically extremely vulnerable

Background:

Issues with clinical coding in neurology are not new. The majority of clinical neurology activity takes place in the outpatient setting, but despite this, clinical coding of outpatient episodes is not mandatory. As a result, trusts do not code routinely and so there is very limited information on disease specific activity at an outpatient level.

Impact of the pandemic:

Early in the COVID-19 pandemic response the Chief Medical Officer for England commissioned the National Health Service (NHS) Digital to identify vulnerable people at 'high risk' of complications from COVID-19, who should be 'shielded' for at least 12 weeks (shielded patient list (SPL)).[xxxv]

Inadequacies in NHS local and national neurological datasets compounded the challenge of identifying whether patients with particular neurological diagnoses were 'extremely vulnerable' based on certain specific clinical features and/or disease severity. A huge amount of manual work had to subsequently be completed by teams of clinicians, at a time of reduced capacity in many areas, to identify who would be deemed extremely vulnerable based on the guidance given by the Association of British Neurologists (ABN). The multitude of information systems, lack of consistency in file systems, names and formats, etc. further hampered efforts at local level to automate any aspect of the process.[xxxvi]

Confusion and a lack of clarity on shielding requirements meant that some vulnerable people with neurological conditions were unable to access additional appropriate support in the initial stages of the pandemic, and were left without the appropriate information or resources at a time of crisis.
The Commons Health and Social Care Committee summarised that "some patients were left feeling confused by the information they received, and frustrated by the lack of clarity of what practical changes they would need to take in order to adhere to the shielding guidance. Changes to shielding guidance also did not respond to some patients' anxiety or remove confusion."[xxxvii] For some people with neurological conditions that lack of clarity has led to loss of access to support structures, and even employment, and the deterioration in the physical and mental health.

The lack of clarity surrounding the identification of people with neurological conditions who should be shielding in the first wave of the pandemic has led to increased anxiety, isolation, confusion regarding shielding arrangements, concerns, access to government support, support to access supermarkets and medication deliveries, and the impact on employment and an exacerbation of health inequalities for the most vulnerable.

> “We surveyed more than 1600 people with neurological conditions in June 2020. The survey revealed that 49% of people had found the Government’s advice on shielding to be unclear, 31% had had difficulty accessing their normal food supplies and 23% had experienced difficulty in obtaining their regular medication.”

Restarting services for people with neurological conditions after the COVID-19 pandemic and planning for the longer term, Neurological Alliance [xxxviii]

Workforce

Background

Prior to the pandemic workforce shortages existed across the health and social care services for people with neurological conditions.

The ABN have identified an emerging workforce crisis. The UK has a far lower number of neurologists per 100,000 population than the majority of Europe,[xxxix] with a long recognised shortfall in neurologists. This issue is being exacerbated by the combination of an increase in newly appointed consultants working part-time, and an increased number of early retirements. There are already long-standing vacancies in some areas of the country and simply not enough new neurologists are being trained to stem emerging workforce problems.[xl]

A significant proportion of UK neurologists showed signs of burnout prior to the pandemic in 2019. Equally, it must be stressed that redeployments away from neurology services have helped to maintain processes of care for patients in similar specialities, such as stroke.

Nursing shortages in neurology are also well recognised. For example, an estimated additional 61 to 105 new specialist MS nurses are needed to bring average caseloads down to an acceptable level.[xli] Demand for epilepsy nurses is estimated to be three times above the current availability.

The estimated turnover rate of directly employed staff working in the adult social care sector was 30.4%, equivalent to approximately 430,000 leavers over the year. However, most of these leavers don't leave the sector. Around 67% of jobs were recruited from other roles within the sector. It is estimated that 7.3% of the roles in adult social care were vacant in 2019/20, equal to approximately 112,000 vacancies at any one time.

The average number of sickness days was 4.7 in 2019/20, this equates to approximately 6.72 million days lost to sickness over the 12-month period.[xlii]

Impact of the pandemic:

The COVD-19 pandemic has impacted the workforce across services for people with neurological conditions. Rapid reorganisation, redeployment of staff, changes to working practices and safety requirements have been introduced across services. There will be some variation on the impact of these changes, and the impact on stress levels and mental health of the workforce resulting from the pandemic. These are likely to be influenced by existing workforce levels, local variations in infection rates, and redeployment rates amongst other factors.

Psychological impact on the workforce:

- In the early stages of the pandemic reports of increased camaraderie and teamwork were cited as the workforce adapted as required to changes brought on by the pandemic.

- Redeployment to COVID-19 wards, facing a working routine outside of normal practice, and increased pressures to reduce waiting lists are amongst factors risking the stress and mental health levels of the workforce.
- In any second wave, there is likely to be more work fatigue, more burn out – the workforce has been exhausted by the past 9 months and providing the same extraordinary level of work on a second occasion will be difficult to accomplish. The mental health of staff is vulnerable at this time and should be actively protected.

Redeployment:

- The majority of specialist registrars, and approximately a third of consultant neurologists surveyed by the ABN in June 2020 had been redeployed.
- It has been estimated that there was mass redeployment of the more than 2,000 neurology specialist nurses across the country.[xliii]
- Many community-based therapists were redeployed away from rehabilitation services.

Change of duties:

- Reduction in capacity has meant a change in duties and/or additional duties. For example, during the pandemic, junior doctor responsibilities were taken on by consultants on the wards; in some trusts, neurologists started to work in stroke, and in acute DGHs, often the neurologists were deployed to the local trust and had responsibility for general medical cases, with varying levels of supervision.

Staff members shielding and working remotely:

- In some disciplines remote working is achievable, allowing the workforce to work from home providing the necessary technology and equipment is in place. In other areas of the pathway this is not possible and/or their roles require them to attend in person with additional PPE and cleaning measures in place.
- As such some members of the workforce have a higher risk of exposure to COVID-19 due to the nature of their work.
- Some staff members are shielding due to increased risk to COVID-19 due to age or health related factors.
- In teams that work closely together, such as neurorehabilitation teams, the contraction of COVID-19 in one staff member will lead to the temporary loss of a significant proportion of the team as they isolate. This further impacts on capacity and waiting lists.
- Evidence submitted by the British Society for Clinical Neurophysiology noted a high proportion of BAME and elderly consultants in the profession. Some colleagues are shielding or working from home due to the virus which reduces the capacity to meet the increase in demand during the pandemic.

Safety:

- In social care the early stages of the pandemic saw an inability to access adequate PPE. Since resolved, services are still struggling to access regular COVID-19 testing.

Education and training:

- Education and training have been disrupted due to the pandemic.
- Current undergraduate medicine students have had greatly reduced exposure to neurological patients, neurological clinical assessments and examinations this year which has potential implications for the future.
- Neurology training has also been disrupted, for example due to redeployment and less exposure to face to face practice.
- The impact on education and training is likely to be variable. Online training methods have potential to improve access to some areas of neurology training.
- The ABN and other professional bodies are well placed to monitor and advise on the emerging impact of training and education of the workforce going forward.

Informal carers

Background

Informal carers across the country were already providing an incredible amount of care unpaid for family or friends before the pandemic. For example, prior to the pandemic, the MS Society found that over half of those supporting someone with MS don't have the practical, emotional or financial support they need. This is despite the fact that 41% of people spent 35 hours or more a week providing support – the equivalent of a full-time job.

Impact of the pandemic:

The closure or changes in support and services for people with neurological conditions, coupled with the impact of lockdown, changing rules and restrictions, the and risk of COVID-19 infection, has placed increased and intense pressures on family members, friends and unpaid carers.

Residential care:

- The restrictions of visits to care homes has caused huge levels of stress and anxiety amongst friends and family of people with neurological conditions. This is also, of course, having an impact on the mental and physical health of many of these unpaid carers for people with neurological conditions.

Reduced breaks from caring:

- Lockdown restrictions, and increased needs of people with neurological conditions mean that there are fewer opportunities for carers to take a break from caring.
- Many informal carers have also reported a deterioration in the condition of the person they care for.
- There is a concern about the risk of infection from paid carers entering the house, so they stopped care. This has placed additional pressure on informal carers.

Impact on mental and physical health:

- Many informal carers have reported that their own mental and physical health has deteriorated during lockdown.

Bereavement support:

- Charities reported an increased demand for support, including bereavement support in particular. The bereaved are negotiating challenging post-death services yet there are further barriers due to COVID-19 as investigations & coronial services change. Those bereaved by neurological conditions are also saying they feel excluded from public narrative about sudden grief, which is dominated by COVID-19 19 grief.

The impact on family members, friends and carers, particularly spouses or partners, has been considerable. The findings of our survey showed that 68% took on more caring responsibilities, and this figure rose to 74% if you lived with the person with Parkinson's. 42% of family members of carers said the coronavirus restrictions negatively affected their mental health and 34% said it impacted their physical health.

The impact of the coronavirus restrictions on people affected by Parkinson's, Lancaster University, June 2020[xliv]

Lockdown was reported to have a significant impact on relationships with family and friends for people with brain injury and their relatives. Whilst around 40% of respondents reported no change in relationships and up to 20% reported positive changes, 37% reported a negative effect on relationships with friends, 24% with partners and 30% with family as a whole. Again, these changes should be seen in the context of relationships that may already have been experiencing significant strain due to the effects of brain injury and the pressures of caring. A 2018 Headway study showed that 69% of brain injury survivors experienced loss of friendships and 44% reported breakdowns in their family relationships even without the additional impact of the recent lockdown.

Headway - the brain injury association

Carers UK surveyed more than 5900 current and former carers in October 2020. More than half (58%) of carers have seen their physical health impacted by caring through the pandemic, while 64% said their mental health has worsened. Projections based on polling indicate that unpaid carers across the UK have provided £135 billion of care since the start of the pandemic in March. That's £530 million of care every day.

Carers UK, Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic[xlv]

Research

Background

Research into the cause and treatment of neurological conditions has accelerated rapidly in the past decade. There has been a revolution in treatment options for some neurological conditions as a result. More than 660 studies into neurological disorders are underway in the UK.

In 2018 the UK government invested £82.5 million for dementia (£97 for each of the 850,000 with dementia), £34 million for Parkinson's disease (£234 for each of the 145,000 with Parkinson's disease) and £12.8 million for epilepsy (£21 for each of the 600,000 with epilepsy)[xlvi]. There is however evidence to suggest that neurological research is traditionally underfunded compared to other areas, such as oncology or cardiovascular.

Impact of the pandemic:

There was a shift in Government research funding on COVID-19, possibly at the expense of other disease areas including neurological conditions. Medical charities invested £1.9 billion in medical research in the UK in 2019, and half of publicly funded medical research nationally.[xlvii] Charity research funders have experienced huge downturns in their income, which has led to the suspension of their research grant funding.

Impact on the advancement of knowledge:

- There have been significant delays to neurological trials, slowing down our ability to understand the causes of, and possible treatments, for neurological conditions.

Impact on research infrastructure:

- Some research trainees were redeployed during the first wave of the pandemic.
- A slowdown in recruitment to trials may have a longer-term impact on NIHR funding as funding is often based on number of recruits.

Impact on participation:

- Clinical trials often provide an opportunity for more quality care, and people with neurological conditions have been denied this opportunity due to disruptions to research.

Impact on the charity research sector:

- The Association of Medical Research Charities (AMRC) estimate that the medical research charity sector experienced a 38% loss in their fundraising income during the first phase of the pandemic.
- 70% of clinical trials and studies funded by AMRC charities were stopped, paused or delayed.
- On average, AMRC charities cut or cancelled 18% of their spend on research in universities.
- The sector estimates it will take 4.5 years to recover.

Looking ahead: priorities for the future

This section of the report identifies priority areas to be addressed both in the immediate and long term. Many of the issues addressed here are not new but have been highlighted or magnified by the pandemic.

Risks to resilience of the system due to workforce:

- There was already a shortage in the health and care workforce across neuroscience services, and this has been exacerbated by the pandemic. Longstanding issues and gaps in health and social care services for people with neurological conditions needs to be addressed to ensure the resilience of services going forward.
- A range of options to recruit, retain and support the neurological workforce must be considered. These include enhanced use of clinical networks to share skills and expertise, and fellowship schemes to allow neurology registrars to develop subspecialty expertise in shortage areas.
- Individuals and teams will have been impacted both personally and professionally by the pandemic in different ways. This needs to be taken into consideration, and the wellbeing of the workforce prioritised going forward.
- Disruption to neurology training and undergraduate medical education has potential knock on implications for the future of neurological care. Steps should be taken on both a local and national level to address this as part of action to address the wider workforce crisis in neurology.

Protecting patient choice:

- Patient choice has been considerably compromised during the pandemic. Whilst this has been to some extent unavoidable at points it is important to highlight this as a risk going forward. People with neurological conditions, and suspected neurological conditions, should know, as much as possible, what to expect – when is an appointment likely, how is this to be delivered, and what do they need to prepare. If an option exists between face to face and remote, and the two are equal in their clinical appropriateness, patient choice should dictate where the appointment takes place.

Data and evidence

- Recent events have exposed the lack of resilience of the data systems to support crucial decisions.[xlviii]
- Until a uniform and mandatory neurology outpatient coding system is in place the lack of neurology outpatient coding will continue to compromise the resilience and effectiveness of the system.

Clinical prioritisation of waiting lists:

- For some people with neurological conditions, their symptoms and functioning will have significantly deteriorated over the course of the pandemic. There are now increased waiting list times in many areas and services, some backlogs are estimated to take 2 years to address. Careful consideration needs to be given as to the prioritisation of these waiting lists. This requires robust digital IT but also ongoing clinical review to ensure changes in status are not missed and are acted on appropriately. This has to be a dynamic decision with each person with a neurological condition, especially in progressive disorders.

Effective triage across the pathway:

- Effective triage across services, with the expertise that are needed at the right place in the pathway will prevent people with neurological conditions from ending up in the wrong place. Yet there is no national consensus on triage risking unwarranted variation in quality and experience of care.

Virtual consultations:

- Without a thorough investigation and evaluation of virtual and remote consultations during the pandemic we lack the national view needed to determine appropriate use in the care of people with neurological conditions. Such an evaluation should include analysis of the the experience, patient outcomes and process outcomes associated with remote consultations. The differences and similarities between phone and videoconference delivery ought to be considered. This evaluation could take place as part of the outpatient transformation programme, through local audit processes, and through utilisation of patient experience programmes such as the Neurological Alliance patient experience survey. We need a better understanding of patient outcomes since the onset of the pandemic.
- Reimbursement of virtual consultations by the national tariff system is needed to allow services to plan for the future.

Mental health services

- Longstanding issues, including the need for parity of access to mental health services for people with neurological conditions, coupled with lack of capacity in services, increased waiting lists and increase in demand pose risks in the short, medium and long term.
- The introduction of ICS's provides an opportunity to address and organise access to mental health services for people with neurological conditions. The integration of mental health care should be prioritised as commissioning arrangements change.
- There will be an increase in demand on services due to the neurological and neuropsychiatric manifestations of COVID-19. Services must be properly resourced and systems, such as effective and appropriate screening for mental health needs, and the collection of data to support service delivery and improvements in place.

Social care

- The impact on adult social care in light of this pandemic cannot be underestimated. With long-term structural issues already affecting a social care system creaking at the seams, the additional pressures COVID-19 has brought could be life threatening for some.[xlix]

- The impact of COVID-19 on local authority budgets threatens the future of services including adult social care and the support that people with neurological conditions desperately need.

Therapy and Rehabilitation services:

- Longstanding issues in community and specialist rehabilitation and therapy services needs to be urgently addressed to prevent the further deterioration of patient whose care has been compromised over the pandemic, and to meet the increase in demand due.

- Short-term rehabilitation contracts introduced to cope with the COVID-19 crisis with lower service specifications should not be rolled over or become permanent. The point of discharge should be determined by goal attainment rather than focusing on a fixed duration of admission.

- Patients discharged prematurely due to COVID-19 need to be regularly/ urgently reviewed to ensure that their mobility and speech and language skills are not deteriorating.

- Provision must be made for in-patient rehabilitation beds in order for people with acute and longer-term neurological conditions to continue to receive the neurorehabilitation they urgently need alongside the needs of new COVID-19 patients.

- Community rehabilitation teams should be properly resourced, at least restored to pre-pandemic capacity as soon as possible.

Research

- Government investment is needed to ensure that the research sector recover from COVID-19.

- Investment, which includes recognition of the essential role of medical research charities is essential to limit the long-term impact of disruption and delays to neurological research on the care and treatment of people with neurological conditions.

Conclusion

Pre-existing gaps and variation coupled with the short- and long-term impact of the COVID-19 pandemic on an overstretched NHS and social care system have created a "perfect storm" for the care of people with neurological conditions. This looks set to exacerbate health inequalities, threaten health outcomes and the quality of life for millions of people living with neurological conditions in England.

Evidence on the neurological and neuropsychiatric manifestations and complications of COVID-19 infections is still emerging. This is likely to accelerate as the pandemic develops and clinical syndromes are detected, characterised, their mechanisms investigated and the understanding of patients' needs and treatment develops.[l],[li]

The pre-existing variations in services and care for people with neurological conditions, together with varying levels and rates of COVID-19 across the country, mean that both the response and resilience of neurological services to respond to the crisis has differed. Neuroscience services must be properly resourced, with adequate workforce levels and underlying data and technology systems to ensure they are resilient enough to meet rising demand in the short and longer term.

Without the capacity and necessary infrastructure, including robust data systems, flexible local pathways and support for the workforce, to restart services to a pre-COVID-19 level patient outcome will worsen. Meanwhile neurological charities and third sector organisations that provide a crucial lifeline for people and their families are facing unprecedented shortfalls to their income alongside rising demand from their beneficiaries to plug the gaps in health and social care.[lii]

The workforce responded at pace to adapt and tailor services to people with neurological conditions where capacity allowed. This has led to innovation in the delivery of care which, in the case of telemedicine, has the potential to improve access to care for many of the millions of people living with neurological conditions.

However, it must recognised that these changes were put in place at pace and further work needs to be done to evaluate and understand how we can better meet the needs of people with neurological conditions at a time of social distancing and with reduced capacity in services. Rapid changes to service delivery implemented during the pandemic should be seen as minimum service provision and not considered the norm. Thorough evaluation and consensus on appropriate use of virtual consultations, triage systems and addressing longstanding issues with neurology outpatient coding should be prioritised.

This report has identified areas of immediate priority to addressing the gaps in, and risks for the care for people with neurological conditions. The many references and publicly available resources from the neuroscience's community give further context and detailed guidance needed to address these priority areas.

The NNAG is set up and well placed to work with NHS England and NHS Improvement and local ICSs and STPs to ensure that the needs of people with neurological conditions are met, and help meet the objectives of the NHS long-term plan during and after this pandemic

It cannot be stressed enough that in these rapidly changing times, and as evidence and guidance about the impact of COVID-19 on people and services continues to emerge, the evidence and recommendations listed here are not, nor are they intended to be, exhaustive. However, they should be given the priority deserved to risk worsening the status quo for people with neurological conditions.

Appendix: Responses to our call for evidence

List of organisations and individuals:

- MS Society
- The Neurological Alliance
- Autistica
- NeuroResponse
- SUDEP Action
- Headway – the brain injury association
- Association of British Neurologists
- Motor Neurone Disease Association
- Royal College of Nursing
- Parkinson’s UK
- Epilepsy Action
- Sue Ryder
- Professor Hedley Emsley, Consultant Neurologist and Professor of Clinical Neuroscience, Lancaster University & Lancashire Teaching Hospitals NHS Foundation Trust
- Professor Peter Hutchinson, Professor of Neurosurgery at the University of Cambridge and Director of Clinical Research at the Royal College of Surgeons of England.
- The Neuro Therapy Centre, Chester
- The British Society for Clinical Neurophysiology

Evidence submitted fell into the following categories

1. Guidance on restarting services
2. Impact surveys and policy reports
3. Published articles and case studies
4. Research studies
5. Unpublished reports and preliminary findings from services, research and patient groups

The evidence submissions were reviewed to identify the common themes understanding the impact, risks and potential opportunities arising from the COVID-19 crisis. The emerging themes were considered within the context of NNAGs work to identify and provide thought leadership since the start of the the pandemic. This included horizon scanning activities, NNAG and NNAG led meetings, pathway development and reporting to the NNAG/NNAG members. The initial summary of findings were presented to the NNAG core group.

Subsequent interviews and follow ups have been conducted with NNAG members and stakeholders to help shape and review the report’s recommendations.

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