NHS Strategy Consultation

1. What do we want to see in the 10-year health plan and why?

We believe that there are huge issues within the current NHS set up and within service delivery which are leading to significant issues for our members. Most of these focus around access, diagnosis, geographical differences, health inequalities, and significant variations in the type of support people receive across primary and secondary care, as well as after discharge as part of recovery and ongoing health and health related needs. We have tried to capture within our response what is important to both our members, and to us as a patient advocacy group and health charity.

In terms of structuring our response as per the consultation document, we have broken down our response to this question under the headings associated with the rest of the consultation questions.

Move more care from hospitals to communities

We completely agree that we should be moving services away from building-based services, and to be more community-based. In order to do this, we would like to see more diagnostic support and treatment available to people within the community. This could be through the use of mobile facilities, or using existing clinics and GP surgery facilities. Bringing secondary care services and outpatient support into the community, so that it is delivered to people closer to home would be a significant improvement.

One of the big issues for our members is around not having a named lead clinician, or in some cases, not having a local clinician at all with specialist insight into Guillain-Barré Syndrome and other related inflammatory neuropathies. While we have seen others asking for lead clinicians within hospitals, in line with a move away from hospitals, and into communities, we would like to see named lead clinicians for geographical areas. The size of this area should reflect local needs, and specialists shouldn't be too generic. Access should be place based, with clinicians coming to people rather than people going to hospital (for ongoing support).

Our members want to see more diagnostic support and treatment that is delivered closer to home, as well as being significantly improved from existing standards. This should include community based services, diagnostics, treatments and ongoing condition management. Our view is that ongoing support can be delivered through community outpatient services, with access to clinicians delivered in the community, follow up appointments carried out locally and support delivered in different ways near to where people live and work. We would like to see more specialist nurses operating within communities. We understand that economies of scope and scale are important to providing efficient and effective services, so while GBS/CIDP specific nurses would be amazing, we know that this isn't likely. However, by bringing cohorts together then needs can be met. For our members local Neurological Nurses would be an effective way of meeting local needs.

We also believe that it is vital to see significant improvement within preventative and proactive services. In particular we would like to see:

- **Local community rehabilitation services.** The introduction of local smaller rehab centres in communities, along with community services that outreach into people's own homes. It is vital that this isn't time limited, but linked to needs and recovery outcomes
- **Specialist Community Neurological Physiotherapy**. Access to neuro physio via primary care
- **Community Specialist Nursing (neuro nurses**). As laid out above and mirroring the universal MS Nurses services, and the Neuromuscular nurses based within some specialist secondary services, but placed in the community. These could be delivered via video conferencing for some communities
- **Occupational Therapy, and aids and adaptations.** Full scale OT assessments and support, alongside reasonable budgets to provide aids and adaptations, quickly and appropriately. This will support rehab at home, and reduce delayed discharges
- **Ongoing support (CHC/ASC/Community).** In order to provide appropriate services, ongoing support may be required. This means effective and appropriate continuing healthcare, access to Adult Social Care (we realise this is out of scope) and better links to community sector providers and support

We would like to see investment and development of self-management, allowing more people to manage their own recovery, condition and wellbeing. This will mean greater investment in community provision (especially in the community and voluntary sector), more education, and access to technology.

The majority of our members are negatively impacted by physical health issues. However, an equal number are impacted by emotional health issues as well. These can create stand-alone issues, or exacerbate physical health issues. Many people have gone through trauma as a result of intensive care, treatment, or being diagnosed with a life altering condition. We believe that emotional health support (especially trauma informed support) must be part of ongoing community support, adding to and working with physical health interventions.

Finally, we feel that it is vital that both primary and secondary care services, as well as emerging community health services, are educated and encouraged to signpost people to community and voluntary sector services. Many people are unaware of the support that is provided within the community sector, and many clinicians either don't know or don't share. As a result, organisations like ours are unable to maximise our impact and reach the people who would benefit from our support. Better links between the NHS and the community sector, and a mutual respect (rather than the community sector being seen as a poor cousin) would be beneficial to people, and meeting needs.

Better use of technology

We feel that there is a real opportunity to support people through the user of technology. This obviously comes with a number of challenges, but there is a real opportunity to support treatment, rehabilitation, recovery, and ongoing condition management through technology. This would include improved delivery of medication and treatment within the community (for us this includes IVIG and alternatives), the use of kit to support rehabilitation in lieu of specialist neurological physiotherapy (this could also include online access to physio, and tools and resources that can support and monitor recovery and ongoing management).

One big issue for people is around reporting progress, issues, and alerts. There is obviously opportunity to use various pieces of kit for monitoring and reporting. This could link specialists anywhere in the country to individual patients, with remote accessing and interventions provided as required.

Many people with the conditions we support do not have access to a specialist neurologist or nurse specialist, and certainly not regular access. Providing support through video conferencing would mean (with additional resources of course) everyone could get access to specialist input. Having people access online means that outpatient access would become much simpler and convenient, and would remove the cost and inconvenience of people going to an outpatient department, often many miles from their home.

We are all aware that the NHS record system is far from perfect with issues still in place between primary and secondary care in terms of access and sharing. This leads to incomplete records, delays, and patients often having to reshare their own histories again and again. We hope that this will be fixed within the next iteration of technological rollout, and that digital notes will actually be put in place, including with access by the individuals themselves.

Included in this, we hope to see implementation of a digital 'passport' for each individual based around their individual needs. This would follow people around the health (and social care) system and enable a much more person-centred approach to meeting someone's needs. This could include information about the person, their wants and needs, likes and dislikes, personal history, and links to their circles of support.

We feel that people should be empowered to self-manage their own condition, but in order to do so they need access to the appropriate tools and resources. These could be both in terms of appropriate online information, and advice, access to support when they need it, and equipment that can help with specific jobs and functions. As technology improves, the ability to self-manage improves, but people don't know what they don't know, and don't always have access (either through lack of knowledge or lack of resources) to things that could improve their lives and reduce their call on the NHS.

As AI improves (along with our ability to use it effectively and safely) there are some real opportunities to use it as an effective tool to support key NHS functions, as well as to improve our understanding and management of conditions. Within GBS/CIDP there is the opportunity to look at AI as a tool for improving diagnostic rates and the timeliness of diagnosis. Most GPs and A&E doctors are unaware of these conditions or lack experience with them, and as a result often mis-diagnose, or send people home when they should be treated (leading to potential long-term issues). The use of AI as a support tool for diagnosis or improving diagnostic assessment would be welcomed. We also believe that AI could be used for symptom tracking, and understanding the likelihood and impact of various symptoms and residuals. This is something that should be looked at as a way of reducing impact.

Telecare and Telehealth systems have been in place for many years, but we still haven't maximised the impact of these, and many remain built around the systems first rolled out nearly two decades ago. These should be updated and improved with access coming at an earlier opportunity, and looked at as part of discharge planning.

Finally, it is vital that NHS data is improved dramatically. Information on specific conditions is incredibly poor, with Read codes in place but not used in primary care, and secondary health data not fully recording acute incidences. This lack of information means that no one can plot data trends, identify issues, or highlight inequalities across systems. This makes it incredibly hard to provide support, or commission specialist services and interventions. The limited data that is available is also not accessible to anyone outside the NHS. It is vital that community sector groups like ours are able to gain access to anonymised NHS data so that we can target our resources effectively. Information like the Neurological Dashboard should be available to everyone as standard, and higher level anonymised data should be shared so that we can work with it to map need, incidence, prevalence, response, and impact. You never know, we might even be able to do a better job with the data than the NHS!!

Spotting illnesses and tackling the cause of ill health

In terms of prevention and tackling the causes of ill health, this can be very difficult for GBS/CIDP/MMN/ and associated conditions. Whilst staying healthy is a general good preventative measure for these conditions, there are no specific preventative measures for these rare but impactful autoimmune conditions. Prevention for these

conditions is all about preventing escalation, relapse and reoccurrence, deterioration and preventing negative impacts of the conditions.

A big factor for us is around education with GPs and A&E doctors to support faster diagnosis and treatment. By responding quickly and appropriately, the impact of conditions such as GBS can be reduced both in the short term and the longer term.

In order to support recovery, reduce longer term impacts and disabilities, and reduce the likelihood of drawing on both the NHS and Social Care, good quality and appropriate neurological rehabilitation is needed. This needs to be specialist, timely, and not time limited. We are currently receiving reports of people being refused rehab, or it being time limited (with no link to progression, goals, or recovery). This is not only bad for an individual's quality of life, but in terms of universal commissioning, it may save an individual budget in the short term, but it is likely to lead to overall increased NHS and Social Care spend in the long term.

The same can be said for access to community support (OT, Physiotherapy, etc) which can be very limited in certain geographical areas, and is linked to primary care spend and commissioning practice. We would want to see a universal offer across the country, which provides improved outcomes to people when they need it and for as long as they need it. Failure to do so leads to increased draw on resources over an increased period of time.

We feel that in terms of prevention, mental and emotional health is equally as important (and indeed maybe more so) than physical health. We believe that to prevent impacts increasing and relapses occurring, people need access to specialist (and ongoing) emotional health support within the community. This should not simply be access to an already over stretched (and not always appropriate) NHS Talking Therapy programme, but to specialist neuro (or even condition specific) psychological and emotional health interventions and support. This could be provided virtually, or within the community.

Finally, we feel that the community sector has an extensive role to play within prevention, and that the NHS should not only work with us as equal partners in preventing escalation of needs, but that we should be funded appropriately to provide certain levels of support and intervention. We provide an appropriate and professional service, but without the significant overheads that impact NHS and other statutory services, providing a cost effective, impactful service that should be developed, funded, and grown.

2. What do we see as the biggest challenges and enablers to move more care from hospitals to communities?

There are of course a wide range number of challenges and enablers to moving care from hospitals to communities. We have outlined key examples below.

Challenges

Institutional blockers – There are likely to be a wide range of institutional blockers within the NHS in terms of moving away from hospitals. These are likely to be from within the NHS itself, with clinicians at all levels seeking to retain current ways of working. Most significantly though, will be blockers from the NHS Trusts that run secondary care, who will have a perverse incentive to retain services as is. Significant and bold restructure and organisational change management will be needed. This is a significant challenge.

Dependency on buildings and building based services – For generations we have built up a dependency on buildings and building-based services, with a cultural change needed to move away from this. We have placed hospitals at the top of our hierarchies, and a societal change will be needed to change this.

Community resistance – Changes to hospital usage have long been subject to protest and resistance from local communities. This is partly linked to the above dependency and the societal standing of hospitals, and secondly due to people's fear of losing what they have got. Any change will need to be accompanied by significant marketing that highlights the benefits of change, and how needs will be met. This will be the same in both geographical communities and communities of interest.

Lack of facilities – Due to the reliance on large site-based hospitals, most communities do not have access to appropriate resources in their local communities to provide community-based services. Most local clinics are not up to standard, and GP Practices may be too small for community services. Additional capacity and facilities will be needed at the local level.

Workforce – Quite simply, there are not enough clinicians at all levels to provide services across communities. Hospital workforces tend to be specialist and consultant heavy, and a move to more generalist services, and lower level specialist support would be needed. This would likely need increased workforce within community nurses and support staff levels, with oversight coming from floating consultants and registrars. There would be a timing challenge around recruitment and staffing structure change.

Cost – While savings would inevitably come from moving to a community based rather than building based system, there would be some transitional costs, and a time delay in realising some savings and efficiencies (from staffing and closure or part closure of hospital sites).

Enablers

Community sector – The community sector has significant history of operating at scale within the community and can demonstrate proven track record and prime examples of how to deliver complex services within community settings. It is also on hand to support the change to community-based services

Results – The biggest enabler to change will be demonstrating positive results and impact. It will be vital to use data and impact measurement to demonstrate the

positive impact of change and to drive further action. Pilot sites and front runner services could achieve this, potentially in partnership with the community sector.

Positive stories – On way of demonstrating impact is through the use of positive stories. Hearing from people with lived experience around how doing things differently positively impacted them means that we can bring more people along on a journey. It will be vital to capture and share these stories effectively.

Access – If a major blocker to service is that people haven't got the ability or resources (time or finance) to get to a hospital site, then an enabler will be the access to services that the community provides. Having things that are easy to get to, at or near your home, will be a positive enabler.

3. What do we see as the biggest challenges and enablers to making better use of technology in health and care?

Adopting technology across the NHS and society will come with challenges and opportunities. Below, we have laid out the key challenges and enablers.

Challenges

Cost – While it is very positive to see funding within budgets for technology and technological change, the level of investment needed is likely to be significant. NHS procurement has historically struggled in this area, and a bottom up design is needed (based on co-production and engagement, particularly with those who will use the technology) to ensure the most efficient design and procurement.

Exclusion and Access – We know that there are huge inequalities around access, and many people do not have access to technology or digital services for a wide range of reasons. This includes financial (data poverty), education, availability, or ability. There is a huge amount of work to do to ensure that everyone has access and the ability to access technology, particularly via digital platforms. While the traditional argument that 'not everyone can use it and we still need paper copies' does still stand, we would rather see the cause of these disparities addressed rather than an expectation that 'we don't change because not everyone can access'. We need to just make sure everyone actually can. This may be a wider societal issue, but the NHS can be a driver for change.

Historical blockers and arguments – For those of us who have worked within or around the NHS for many years, we will have heard many times that 'we just can't do that' or 'that can't happen within our systems.' These historical blockers and arguments are prevalent and strong, but need to be challenged. This links to a previous point about organisational change, which will be difficult within a long-term system such as the current NHS that doesn't like to do things differently.

Lack of innovation – As a system, the NHS has struggled with significant innovation, and relies on hierarchical structures, and outdated platforms. We are not sure that there is the right amount of innovation within the NHS to challenge this, and third-party input is likely to be needed to drive change.

Concerns and worries – We should not underestimate the amount and variety of concerns and worries that patients, families, and members of the public will have around new technology, especially around trusting their health and care outcomes to technology. These concerns will need to be addressed and managed, especially among certain demographics.

Enablers

Innovation – Conversely to the point in the last section, while most of the NHS lacks innovation, there are pockets of good practise to learn from. And as a nation, we have a strong digital and technological private sector to draw from.

Want – There is a real want and demand from certain sections of the country to have more technology involved in the NHS. From video calls for doctors, to AI led modelling, many people want to see improvement and change. However, we tend to be led by those who do not want the change, especially if they have a loud voice. We need to make sure that everyone sees the benefits and are brought along on the journey.

Good examples (although not all digital) – There are good examples in place around technology that could be used to stimulate discussion, and support change management. The use of video calls during COVID proved that you didn't always physically need to see a doctor, and in the main 111 is a positive example of system change. We don't always have to use digital examples, or showcase AI and robots, there are plenty of examples of where even smart phone apps monitoring conditions have real impact.

Speed of development – One real positive is that the speed of technological development demonstrates that we can progress quickly, even if the NHS hasn't overly adopted new technologies. We have seen AI develop exponentially, and this is likely to move forward at pace in the future, driving future technological development. This will help us adopt and accept more quickly, especially if we can all see the developments.

Funding – Normally we would be highlighting funding as a blocker (in fact we did), but in this case there are some funds available, and this makes it an incredible enabler. While current allocated resources probably aren't enough, they are there to start the work, and to prioritise investment.

Government commitment – Perhaps the biggest enabler of technology, is the fact that there is clearly government commitment to change and the use of technology as an alternative or addition to support and improve services. It should not be underestimated how important this will be to pushing through change.

4. What do we see as the biggest challenges and enablers to spotting illnesses earlier and tackling the cause of ill health?

We have noted below the key challenges and enablers to supporting a move to a more preventative way of working, both within the NHS, but also across society and the community as a whole.

Challenges

Established systems – Potentially the biggest challenge to moving towards a more preventative model are the established systems that are engrained across the NHS, mainly that of the system being set up to treat ill health. We have a completely crisis and reactive driven system that is based on treating the condition at the point of crisis. The NHS is not built at all (with the exception of underfunded and much diminished Public Health departments) to deal with prevention, and systems are not established to work in this way. The staffing structure, infrastructure and resources are not in place to support prevention, and we would need to invest heavily in terms of resources and change to move to preventative models.

Institutional change and resistance – It is our view that the system itself is unlikely to want to see a change to a preventative model. Our clinician heavy system and our building-based NHS Trusts will clearly not want to see wholesale change as it would mean significantly less financial input, and in some cases would be existential. It would be irresponsible to think that this would not be a blocker or challenge to change.

Pace of change – The run in time for the impact of preventative services on demand for reactive services is likely to be significant, easily 10-25 years. This will need to be factored in part of any modelling (financial or resourcing) in order to ensure planned change can be delivered effectively

Finance – There would be the real need to double run both new preventative services, and existing crisis services for some time while change took place. While you would never fully eliminate crisis services, and demand is likely to remain significant over time, as outlined above, the pace of change is likely to be significant, and as a result, costly.

Enablers

Good examples – There are lots of really good examples of the impact of preventative services across health and social care. Significant amounts of research, pilot studies and reports have demonstrated change, improved outcomes, and efficiencies, and while many of these are pilots or small scale change, some could easily be scaled and introduced to demonstrate impact quickly.

Commitment from government – Again, the commitment from government around moving to a more preventative model is much welcomed, and shouldn't be underestimated at being essential for driving change.

Community, people, and the community sector – A massive enabler for prevention is the fact that people and communities really want to see this happen, and that is a real driver for change. While challenges highlighted in this response based around people are equally valid, we need to look towards patient and the public as being a positive enabler. The community sector which embodies this way of working should also be used as a tool for enabling positive change.

5. Specific policy ideas for change – prioritise and timeframes

It is our view that there are some things that can be done swiftly to increase impact and drive further change, and other things that will take much longer to have an impact.

Short term priorities

- Move support (especially outpatient support) into the community
- Place lead clinicians into geographical areas
- Enable place-based community specialist nurses
- Enable place-based budgets for OT and CHC
- Enforce data collection in primary and secondary care
- Improve equipment offer
- Embed self-management tools and resources
- Improve links to specialist community sector organisations
- Ensure patients get access to preventative specialist rehab services (without time limits)

Medium term priorities

- Introduce local community rehab
- Fund emotional support
- Build and share data to support investment and support
- Introduce digital notes and passports
- Build and implement condition specific education programmes for GPS and A&E clinicians

Longer term priorities

- Develop preventative led services for recovery
- Embed community diagnosis
- Ensure that an individual GP acts as primary contact and co-ordinator for all conditions
- Establish AI Diagnosis and symptom mapping