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Innovative Models of Care

Evaluation of the Neurological Enablement Service (NES) and Neurological Case Management Service (NCMS)

Produced by ICF for the MS Society

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Contents

Summary

- The Neurological Enablement Services (NES) and Neurological Case Management Service (CMS) community services provide coordinated, responsive care, centred around the needs of people with MS and other acquired/ congenital neuro conditions, and those closest to them.
- The innovative service takes a multi-disciplinary approach to care, and ensures patient input into design of services as well as their own care. As a result, people feel in control of their care and listened to.
- The type of support provided is highly personalised and the positive impacts are highly specific to an individual, their life and their priorities. People described the positive impact of the service on long-term health and wellbeing outcomes.
- Patients often reported that the NES and NCMS have reduced their reliance on other health services, such as their GPs and hospital services, as they can contact the NES/NCMS directly when they have issues relating to their condition.
- People with MS and providers felt that improved signposting, care planning, follow-up and carer involvement could improve the service even further.
- We found some evidence to suggest that the coordination of care increases the efficiency of all the services an individual is involved with. However, the lack of quantitative data available means that further research is required to make conclusive judgments.

- Patient caseload is 245 (NES) and 145 (NCMS) as of September 2019
- Of these, there are currently 62 NES patients and 27 NCMS patients with MS
- There are 14 patients accessing both NES and NCMS
- NES capacity is 11.7 WTE*
- NCMS capacity is 3.1 WTE*

*WTE refers to Whole Time Equivalent hours

An introduction to the study

Improving access to appropriate healthcare, information and holistic support have a significant role to play in achieving better outcomes for people with MS. At the same time, however, the NHS faces challenges which have placed considerable emphasis on demonstrating the value of interventions both to patients and wider society.

The MS Society commissioned ICF to evaluate two innovative models of care and draw out what can be learned from their experiences of improving services. The objective of these evaluations is to understand more about the value of the services by exploring their impact on **people's health and wellbeing, care and quality, as well as the models' suitability for translation in other areas**.

Services for people with MS across the UK were given the opportunity to apply for their service to be evaluated, which was promoted through MS Society networks. Eight services submitted applications which were shortlisted to five by a MS Society staff panel. Five went through to the next round and assessed against a set of key criteria (see right) by a panel including people with MS, MS Society and ICF.

The two services chosen for the evaluation were the **Neurological Enablement Service (NES) and Neurological Case Management Service (NCMS)** in Sheffield, and **NeuroResponse** in London.

NES & NCMS
Community services that specialise in working with people with long-term neurological conditions. The NES comprises a multidisciplinary team of therapists who work directly with patients, while the NCMS are a small case management team who support clients with complex needs.

NeuroResponse
Provides urgent care for people with MS that can be accessed 24/7 through NHS 111. NeuroResponse patients are provided with support by specially trained 111 GPs. Home testing kits and medication are couriered to patients' homes where needed, to enable quick and accessible treatment.

This report is an evaluation of the NES and NCMS.

Assessment criteria

- Presence of **an intervention which could be evaluated**, particularly in terms of cost-benefit
- **Evidence of need** for the identified intervention
- Need among the UK's MS population for **improvements** to be made to the service
- Evidence to indicate potential for the intervention to be **translated elsewhere**
- Ability to demonstrate the impact of the intervention on **efficiency**
- Ability to demonstrate the impact of the intervention on **care and quality**
- Ability to demonstrate the impact of the intervention on the **health and wellbeing** of people with MS and other neurological conditions

Background

Policy priorities for health care

The Long Term Plan for NHS England, published in 2019, sets out the strategic direction for the next 10 years.

Key priorities within this plan with relevance for people with MS and other long-term neurological conditions include:

Preventing emergency admissions by investing in community and primary care, and moving towards better integration of these types of services

Reducing delayed discharge from hospital through involving therapy and social work teams from the start of the acute care pathway

More integrated and personalised care, as reflected in the Comprehensive Model of Personalised Care. The Long Term Plan aims to achieve this by involving social prescribing link workers within primary care networks, increasing the use of personal health budgets, and creating apps that will support people with certain conditions. Patients, carers and volunteers will also be given support to improve “supported self-management”, particularly for long-term conditions.

Improved access to specialists through the use of virtual services in addition to face-to-face services, and changes to the design of outpatient services to make these more accessible

Reducing health inequalities within care services, and for carers, through the redistribution of funding to support areas with high health inequalities

Reducing unwanted variation in services, as highlighted also in the planning guidance for 2019/2020 specifically in relation to neurological services

Meeting mental health needs by expanding access to IAPT, expanding access to community-based mental health services to better support children and young people and integrating primary and community mental health services for adults with severe needs

Greater investment in research and reduced time to bring new treatments to market by increasing the number of people participating in health research, technological improvements, and a faster pipeline for developing innovations within the NHS

Improving data by continuing to develop the Emergency Care Dataset, developing a new dataset on ambulance use, and improving population health data availability for Integrated Care Systems

Shifting the workforce away from a large number of highly specialised roles towards more generalist roles, and ensuring better alignment of doctors’ specialty choices with geographical needs

NICE Quality Standards on good quality care for people with MS in England and Wales

Quality statement 1: Support at diagnosis

- Newly diagnosed people with MS should be given information about MS, its progression and how it can be managed

Quality statement 2: Follow-up after diagnosis

- People with MS should be seen in a follow-up appointment six weeks after their diagnosis

Quality statement 3: Coordinated care

- People with MS should have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS

Quality statement 4: Physical activity

- People with MS are offered support to remain physically active, where they experience issues with fatigue or mobility

Quality statement 5: Managing relapses

- After a relapse that would benefit from treatment, people with MS are offered treatment within 14 days of onset

Quality statement 6: Comprehensive review

- People with MS are offered a comprehensive review by a medical professional with expertise in MS at least once a year

Better evidence can inform the development of integrated neurology care for people with MS, in line with NHS England’s Long Term Plan

Significant, unnecessary variation in MS treatment, care and support is driven by:

A lack of standard guidelines for MS care standards, both on paper and in practice

Financial pressures within the NHS and social care

A lack of oversight and responsibility for the entire care pathway, driven by fragmented commissioning arrangements

Increasingly limited neurological specialists, due to workforce pressures and a high proportion of neurological staff that are predicted to retire in the next 10 years

Expected heavier workloads as new treatments are approved for progressive MS, and as further unmet needs are identified

Sociodemographic inequalities

A lack of evidence demonstrating the impact of MS services

The NES and NCMS

An introduction to the NES and NCMS model

- The Neurological Enablement Services (NES) and Neurological Case Management Service (CMS) are community services in Sheffield.
- They support people aged 16 and over who are living with long-term neurological conditions, including MS
- Clients can be referred by any professional, or they can self-refer if they have used the service in the past. The largest proportion of referrals are made by specialist nurses
- Both the NES and NCMS are based at the same location, but the service provided by each is distinct:

NES

- Multidisciplinary, integrated team (MDT) includes:
  - Physiotherapists (4.2 WTE*)
  - Speech and language therapists (1.6 WTE)
  - Psychologist (0.8 WTE)
  - Occupational therapists (1.8 WTE)
  - Assistive technology specialist (0.7 WTE)
  - Administrative assistants (2.6 WTE)
- Clients range from exhibiting mild symptoms to having highly complex needs
- Therapists can visit clients within their homes
- NES work closely with patients to identify goals which are important to them; when they are met they are discharged
- Patients have the option to self-refer back to the service after discharge
- Current caseload of 245 patients, of which 62 have MS

- There are often patients accessing both the NCMS and NES services
- Staff across the two services have close working relationships
- Patients may be referred between the two services
- 14 patients are currently accessing both services

NCMS

- Small team of 3 specialist case managers (2.8 WTE) with some senior clinical psychology input (0.3 WTE)
- Liaise with stakeholders to put an effective care plan in place
- Communicate the care plan to the client and other services involved
- Focus is on patients with particularly complex needs
- Case management is a multiagency approach and works across:
  - Health care
  - Social care
  - Third sector providers
  - Housing
  - Emergency services
- Case managers do not always have direct contact with patients, instead working with the above stakeholders and families, to ensure there is an appropriate plan in place
- Current caseload of 145 patients, of which 27 have MS

*WTE refers to Whole Time Equivalent hours

The purpose of NES and NCMS

Background to the service

- Before the NES and NCMS were set up, there was a specialist city-wide speech and language therapy team and two small multidisciplinary teams. There was no city-wide, full multidisciplinary coverage
- In 2010, the commissioner at the time wanted to establish a city-wide service encompassing both case management and therapy services with no age cut-off
- Initially, the function of the NCMS was to be involved with care from diagnosis. However, due to the volume of referrals, they now tend to get involved when patients' needs become more complex or if there is a lack of coordination in the care they are receiving

Focus areas

- **Care coordination:** Both services aim to provide holistic care for a patient through effective coordination; with patients seeing the right services at the right time and in the right order, and the team around the patient working together rather than in disciplinary silos. The NCMS places particular emphasis on addressing wider issues which may be impact on a patient's health and wellbeing, such as housing conditions or social care to achieve positive outcomes for patients
- **Patient goals:** NES work with patients to identify and set goals around their social participation and quality of life which are important to the individual and their families/carers. Initial assessments look to understand patient priorities so that they can work with the appropriate therapy services

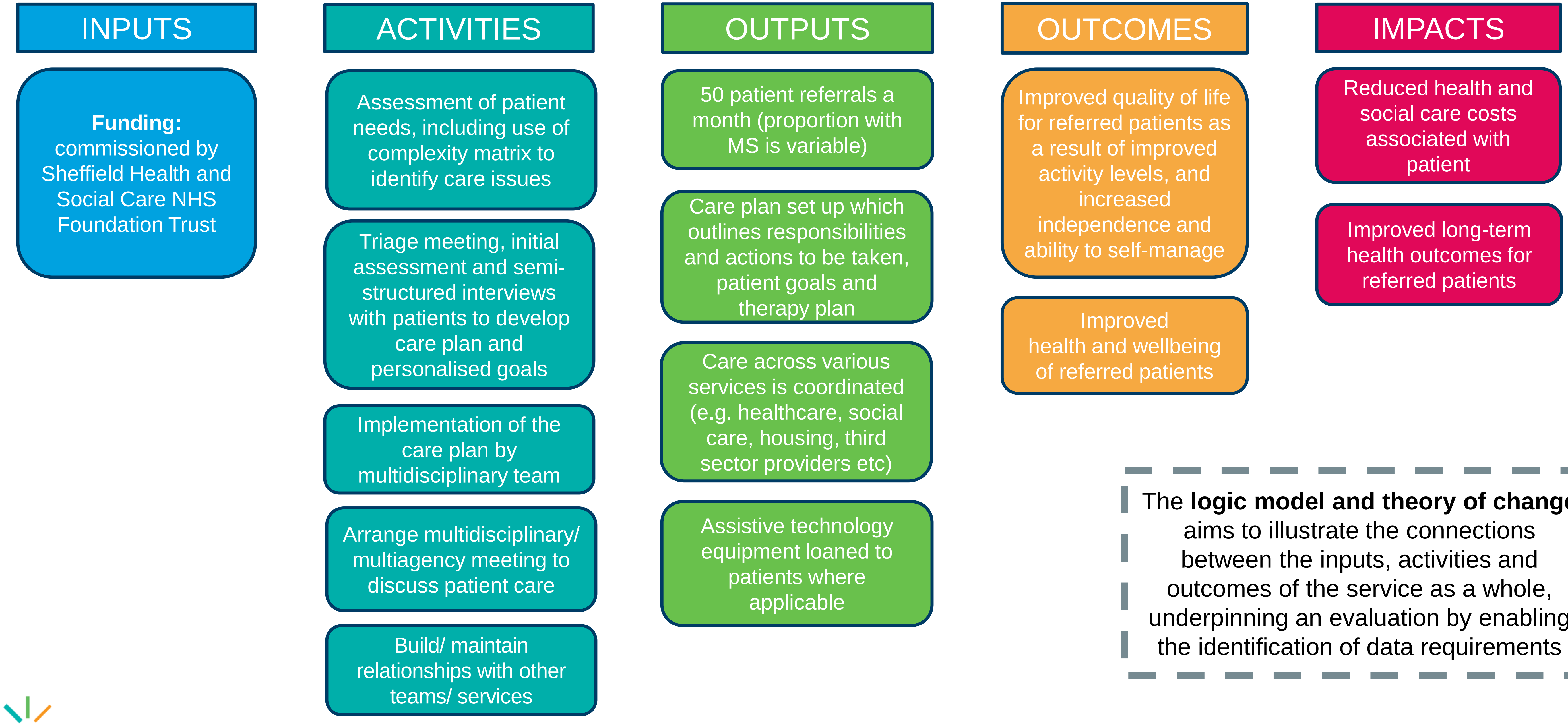
Community-based

- It is important to the NES and NCMS model that their staff are in the community, are mobile and are able to visit patients in their homes. They also hold appointments in different community locations (NES) and visit other service providers (NCMS)
- This is significant as specialist nurses (such as MS nurses) no longer carry out home visits

Target patient population

- People aged 16 and over with long-term neurological conditions in Sheffield, with the NCMS also providing support to people with brain injuries
- At the point that the research was undertaken, 25% of the NES patient population and 19% of the NCMS patient population had MS, though this is variable and staff estimates were higher which could potentially be due to their specific workload. The NCMS tend to be involved with patients in later stages of MS when their condition has become more complex, or when there are other issues they are facing alongside to their condition, such as problems with their mental health
- Families are often involved with a patient's care, particularly if they have more complex needs; the NES and NCMS encourage their engagement with care planning and goal setting

NES and NCMS logic model and theory of change



INPUTS

Funding: commissioned by Sheffield Health and Social Care NHS Foundation Trust

ACTIVITIES

- Assessment of patient needs, including use of complexity matrix to identify care issues
- Triage meeting, initial assessment and semi-structured interviews with patients to develop care plan and personalised goals
- Implementation of the care plan by multidisciplinary team
- Arrange multidisciplinary/ multiagency meeting to discuss patient care
- Build/ maintain relationships with other teams/ services

OUTPUTS

- 50 patient referrals a month (proportion with MS is variable)
- Care plan set up which outlines responsibilities and actions to be taken, patient goals and therapy plan
- Care across various services is coordinated (e.g. healthcare, social care, housing, third sector providers etc)
- Assistive technology equipment loaned to patients where applicable

OUTCOMES

- Improved quality of life for referred patients as a result of improved activity levels, and increased independence and ability to self-manage
- Improved health and wellbeing of referred patients

IMPACTS

- Reduced health and social care costs associated with patient
- Improved long-term health outcomes for referred patients

The **logic model and theory of change** aims to illustrate the connections between the inputs, activities and outcomes of the service as a whole, underpinning an evaluation by enabling the identification of data requirements

Approach to the evaluation

Methodology

We conducted qualitative interviews with **26 people** in total. These were a mixture of patients, family carers, MS nurses, commissioners and NES and NCMS staff.

Stage
1

Case study visit

Two-day visit covering relevant sites, including the two locations where NES and NCMS staff are based, Graves Leisure Centre, where NES physiotherapy clinics are held, and the location where MS nurses are based. Patients and carers were consulted via a focus group or after appointments at the leisure centre. Interviews with MS nurses and staff were conducted in mixture of group and one-to-one settings.

In total we spoke with **18 people**, made up of:

- **4 patients**
- **5 MS nurses**
- **2 family carers**
- **7 staff members**

Stage
2

Telephone interviews

Telephone interviews were conducted with patients, carers and staff who were unavailable to during the case study visit, and commissioners with experience in commissioning services for people with MS and other long-term neurological conditions from other CCGs around the UK.

In total we spoke to **8 people** over the phone, made up of:

- **3 patients**
- **3 commissioners**
- **1 family carer**
- **1 staff member**

As part of the evaluation, we also **assessed various materials** provided to us by the NES and NCMS, including background information and the types of feedback collected, and we **reviewed other services available for people with MS across Yorkshire and the Humber** based on service mapping carried out by the MS Society's regional lead for the area.

Study limitations

There were several limitations which impacted the data which could be collected for the study.

Engaging with respondents

Challenges were experienced in engaging commissioners, patients and carers with the study. We were unable to speak with a commissioner in Sheffield with knowledge of the NES and NCMS. To address this gap, we were able to obtain interviews with commissioners in other CCGs through the MS Society's regional leads. In order to overcome patients' and carers potential reservations about taking part and make interviewing as easy as possible for them, those agreeing to take part were given the option of joining the focus group or being interviewed over the phone. As a thank you for taking part, patients and carers received a £10 Love2Shop voucher. Nevertheless, not all patients and carers that were invited by us to take part in the evaluation agreed to do so.

Interviewing patients

Patients were not always able to be clear about the services they had accessed, and could not always distinguish between the NES and NCMS and other healthcare services. Some patients also had cognitive impairments which created additional barriers to distinguishing between the support from the NES and NCMS, and the support provided by other services. This must be taken into account when interpreting the results.

Evaluating outcomes and efficiency

There are also difficulties in measuring outcomes for patients with long-term neurological conditions in particular, as their conditions are progressive rather than curable so a positive outcome may actually be the fact that a symptom does not get any worse as opposed to 'getting better'. Similarly, an intervention may have consequent impacts on different areas of an individual's life which are challenging to measure or comprehend in full.

It was not possible to conduct an economic analysis to assess the service's efficiency due to a lack of data. To address this, the possibility of using patient health records to quantitatively assess the impact of the NES and NCMS was explored. However this option was not feasible.

What makes the NES and NCMS innovative?

A multidisciplinary team specialising in long-term neurological conditions

Care for people with long-term neurological conditions lacks consistency and is often disjointed. The NES is unusual in being a specialist team made up of therapists from across several disciplines, enabling support to be provided to patients efficiently.

The team take a **holistic approach to patient care:** rather than a narrow focus on a specific issue a patient might have, the NES address multiple problems in a coordinated way. Often, for example, patients need to overcome one issue before another can be addressed effectively and the MDT approach accommodates this.

The team **specialise in long-term neurological conditions** so their knowledge of their patient population is extensive. Patients do not have to keep explaining their condition or the impact it has on them, because the team they are working with are already aware.

There are a **broad range of disciplines** providing multiple inputs. For example, speech and language therapists work with the psychologist to help patients with their speech - structuring sentences or word-finding; or the occupational therapist and assistive technology specialist can work together to identify solutions for issues that individuals face in their home.

Working in the same location means that the NES team have **close working relationships**. They can discuss the care a patient is receiving and ask each other for advice informally, helping to avoid unnecessary referrals and saving time – in most settings it is very difficult to get this kind of informal input from a psychologist, for example.

> *You need the **right people at the right time, coming together and creating a team around someone until their needs are met**, not just ask other people to intervene without knowledge of what else is going well for the patient.*
> - NES/NCMS staff member

> ***The team work so well, I don't know what I would do without them.** I just need to speak to one person and within minutes it's forwarded to whoever I need.*
> - Patient

> *If **specialists can work together and share knowledge with generic services that's really important**. When you have people with complex needs you need specialists, and generalists need to be having discussions with them.*
> - Commissioner

Case managing individuals’ complex needs

The needs of people with long-term neurological conditions like MS can become increasingly complex as their condition progresses. They may be unaware of the services they can access and need help in other areas of their lives to make health interventions effective. The Neurological Case Management Service (NCMS) takes a multiagency approach in identifying and coordinating the services that an individual needs.

Case managers work across **all areas of an individual’s life**, working with multiple agencies across different sectors. This can include social services, housing associations, third sector providers and family members involved with an individual’s care. Case managers are mobile, visiting providers, schools, and care homes, as well as attending hospital appointments and child protection meetings, to help individuals obtain the right care and support.

- NCMS are in **daily contact with social services**, often referring patients into them where issues are identified
- They attend social care meetings alongside patients to **provide advocacy** and **support with social services assessments** to ensure the effectiveness of the service is maximised for the individual
- NCMS will also **advocate for packages of social care to be amended or increased** on behalf of patients

Coordinating the services an individual needs optimises the effectiveness of interventions as the patient is seen at the right time. The support provided is highly tailored and, as a result, patient pathways for those referred to the NCMS vary significantly from person to person, with case managers being flexible to a patient’s individual needs.

Case managers offer patients and their carers a **single point of contact** as they oversee the entirety of their care. This is particularly important for patients with complex needs who are involved with many services, and provides reassurance for both patients and carers that there is someone they can approach with knowledge of their condition regardless of the issue they are experiencing.

> *In my area LTNCs are catered for in generic services. A case management approach is what’s needed as coordination is key. Patients will be receiving care over a number of years, it’s difficult for everyone to keep track of what’s going on.*
>
> - Commissioner

> *Having a central point of contract is a safety net – if [a patient is] stuck and they’re panicking they can contact us. Sometimes people receive a diagnosis but feel abandoned. It can be aggressive MS which makes them feel like they need to be at the doctor every week. But instead there’s reassurance that there’s someone there if you need them.*
>
> - NES/NCMS staff member

> *Sometimes [use of different services] can result in confusion for clients. Case managers are important in this respect too as they know which services are involved.*
>
> - NES/NCMS staff member

Assessments, goal setting and care planning

Patients referred to the NES undergo an initial assessment process which is usually carried out in their own home. The assessment aims to take a holistic view of the individual and results in a care plan encompassing their personal priorities, their medical history, their home environment and the therapeutic disciplines which they need to access.

After the assessment phase, clients receive a **NES care plan** – a letter summarising the interview, broad goal areas and referrals which have been actioned. Patients are added to a waiting list for each of the therapeutic disciplines they need.

At their first appointment, the therapist will work with them to identify a specific goal that they want to achieve. These goals vary between disciplines and are tailored according to an individual's priorities. Patients have the option to have appointments in their home or a location suitable for them and the care they need.

NCMS care plans relate to the other services and individuals involved in the delivery of care, and their responsibilities. It is produced when the NCMS have mapped available services and is distributed to everyone involved with a patient's care as well as the patient themselves.

Goals are **person-centred** and focus on what is **important and achievable** for the individual. Examples provided by staff and patients included:

- Walking from home to the local shops and back
- Making a hot drink and taking it through to another room
- Reducing choking or coughing when eating or drinking
- Improving ability to express themselves when speaking
- Being able to get in and out of the bathroom

Home appointments mean that patients can work with therapists in a familiar environment. It can also make the work of the therapists more effective. Occupational therapists and assistive technology specialists, for example, can more easily identify improvements which could be made to the environment to improve things for the patient. Physiotherapists can also set exercises based on an individual's everyday environment and work on goals specific to within the home, like using the kitchen or bathroom.

There are weekly physiotherapy clinics held at a local leisure centre. This is particularly appropriate for patients with goals around physical activity, enabling sessions with patients to take place in the gym or in the swimming pool.

Co-production is integrated in service development

Patient input into the service

NES and NCMS use patient feedback **to drive improvements to care and quality**. Patients are input is gathered through several feedback avenues:

Microsystems: This project runs across all health services in Sheffield and encourages a 'bottom-up' approach to service quality, engaging healthcare staff and patients to identify areas for improvement and taking steps to address them.

Reader's panel: Before changing documentation, a reader's panel, comprised of service users, provides feedback.

Feedback forms: After patients are discharged from NES, they are sent a short questionnaire to complete, which asks about their experience of the service.

Care Opinion: Patients are asked to provide feedback on the Care Opinion website in communications from the service, such as in letters containing their care plans from the NCMS.

However, gathering feedback can be a challenge. Some patients may have more complex needs, such as cognitive issues, which impact the feedback they can give, and patient attendance at Microsystems sessions can vary.

To address this, the NCMS collect feedback informally. They are also planning to use **e-surveys** to collect feedback in the future for speed and ease of access.

Patient input into their own care

Involving patients and their families/carers in the development of their care plans is highlighted as key to a successful intervention.

- Many patients reported feeling that NES and NCMS staff *"listened"* to what they had to say and the care they received was shaped around this. This was reflected by staff, who noted that patient concerns were prioritised in goal development
- The importance of involving families and carers was also recognised – they could add another dimension to care planning discussions and, for particularly complex patients, families play a substantial part in the initial assessment

> *The families will help to unravel differences between goals and expectations, particularly with the older end of the spectrum.*
>
> \- NES/NCMS staff member

> *They're dedicated, very professional but still very caring, there's somebody there who listens, and hears.*
>
> \- NES/NCMS patient

Impacts on patients and families

Commissioners expect good services to have a range of impacts on patients and families

There are two key features of **good quality services** for people with MS and other long-term neurological conditions which were mentioned in discussions with commissioners: being **highly accessible**, such as reducing the burden on patients to travel; and **supporting patients and their families to live in the way that they want**, which means being tailored to the individual and supporting with self-management.

Commissioners expect to see a wide range of impacts for patients and families from such services :

In the shorter term:

- Patients and families should feel that the care they need is easily accessible
- There should be a high level of satisfaction with the service they are using

In the longer term:

- Patients and families should be equipped with the confidence to self-manage their condition and symptoms
- They should feel in control of their lives and able to live the way they want
- There should be an in increase in wellbeing and quality of life

> *Patient satisfaction is ultimately what [commissioners] are looking for; access for patients, not having to travel to different places.*
> - Commissioner

> *It's what support we could potentially give to patients in the community so it's closer to their home*
> -Commissioner

> *People with MS want to be more in control of their lives and conditions*
> - Commissioner

> *[Commissioners] would want to see more increase in wellbeing and quality of life living at home.*
> - Commissioner

> *The impact [of a good service] would be the person with MS and their family being helped to be as cohesive as possible, [and] live together as long as possible*
> - Commissioner

The impact of co-production and patient input

Patient inputs **enable the voices of people with MS and other long-term neurological conditions to be heard**. This is important as some symptoms of MS, such as fatigue and issues with concentration, can cause difficulties in accessing and fully utilising services.

As a result, the service is well placed to meet the needs of the people using it and patients recognise this. They felt valued in being asked to take part in identifying service improvements, believing that it demonstrated a high level of care for people using the service, and they felt it illustrated a commitment to continually improve. Some patients felt passionately about getting involved in the service, as a way of “giving back” for the support they had received.

The ‘person-centred’ approach was similarly recognised by patients in the development of their individual goals. **Tailored and personalised services provide patients with clarity on why they were receiving a certain type of care** or being asked to do a certain kind of exercise, for example.

> *I’m helping the [NES] team with meetings to discuss improvements to the service, I appreciate the patient engagement.*
>
> - NES/NCMS patient

> *Clients don’t feel rushed or like they’re not being listened to.*
>
> - NES/NCMS staff member

> *We try to do as much as possible to get patients involved with service design and improvement.*
>
> - NES/NCMS staff

> *[At the first appointment with NES] I was given a lot of time to talk through the issues I was having. With the [NHS] nurses it can be 10-30 minutes max… NES contextualise any issues you have and ask the right type of questions.*
>
> - NES/NCMS patient

Patients can better manage their conditions

Personalised care supports the self-management of a long-term neurological condition after discharge

Both patients and staff acknowledge that it can be challenging for patients to sustain the self-care required to best minimise the negative impacts of the symptoms of their condition – patients cannot be conventionally ‘cured’ and as a result they can lack motivation to adopt advice provided to them by health professionals, such as exercises or dietary guidance.

By setting goals that are meaningful to an individual and taking the time to explain how and why following the advice provided will be beneficial to them, NES provide both an incentive and an eventual outcome which patients themselves can understand and observe. This means they are more invested in maintaining the level of self-care required as its purpose is more visible.

Examples: How this works in practice

Physiotherapy

Patients using physiotherapy services within NES are typically given exercises they can continue to do at home, which means they do not need to attend a gym or buy specialist equipment. NES physiotherapists may also help to train carers in supporting with exercises.

Speech and Language therapy

Some of those using the Speech and Language Therapist services for problems with choking and swallowing noted that this intervention enabled them to manage issues with eating in the future, without any need for additional support.

> “*My treatment plan was produced years ago, but it’s still helpful now. I slow down when I eat, and I’ve taken on all the other advice. It’s good enough that I’ve not needed to go back.*
>
> - NES/NCMS patient

> “*I know what I can do to help myself.*
>
> - NES Patient

> “*The NES physiotherapist provides exercises that can be done at home, and even in bed, and are customised to suit me and the available space in my home. This allows me to take more control over it.*
>
> - NES/NCMS patient

The multidisciplinary model means that multiple needs can be met holistically (1)

Physiotherapy

- All the patients we spoke with had worked with a NES physiotherapist
- Exercises provided by NES physios were felt to be highly customised as they could be done in environments that patients were comfortable in, depending on their goals – if they wanted to improve their mobility around the home, they might have their appointments there; if they wanted to go swimming, they could access water-based physio at the leisure centre
- Water-based physio was considered especially effective for some issues, but it brings with it other challenges. One patient noted that the combination of travelling to the pool, using the changing rooms and doing the exercises was exhausting

Psychology

- Not all patients had needed to access the NES psychologist, but those who had emphasised the benefits, including improved cognitive functioning and support with mental health
- One patient, for example, had experienced periods of depression. The psychologist diagnosed them with a mild cognitive impairment and helped them to understand how this was impacting their mood
- A commissioner noted that psychology had been identified as a gap in the services available for people with long-term neurological conditions in his CCG

Speech and language therapy (SLT)

- Patients receiving SLT usually did so as a result of coughing or choking episodes. Ability to manage these episodes has benefits in terms of people's ability to socialise – they are more confident to eat out, for example
- SLTs also worked closely with the team psychologist in cases where patients were experiencing challenges 'word finding', or expressing themselves, due to difficulties with cognition

> *We've used [NHS] physio services before…this time we were not abandoned.*
> - NES/NCMS patient

> *The physio helped get me a walker, and they came and worked with me to walk from my house to the shops.*
> - NES/NCMS patient

> *Neuro clinical psychology has been identified as a gap. We're writing a business case to get that addressed.*
> - Commissioner

> *I had a lot of problems with the way I eat…now I know how to avoid these.*
> - NES/NCMS patient

The multidisciplinary model means that multiple needs can be met holistically (2)

> *I know if I'm worried about something I can give them a call. I wouldn't be able to live without them, where would you go? GPs have too many patients.*
> - NES/NCMS patient

> *[The occupational therapist] helped us in making housing adaptions…we're planning to go back for support on where to put grip rails in the bathroom.*
> - NES/NCMS patient

> *I've always had computers and I've always been good with them. NES got me in contact with someone and they sorted all my computer things out so I could use them as my symptoms got worse.*
> - NES/NCMS patient

Case management

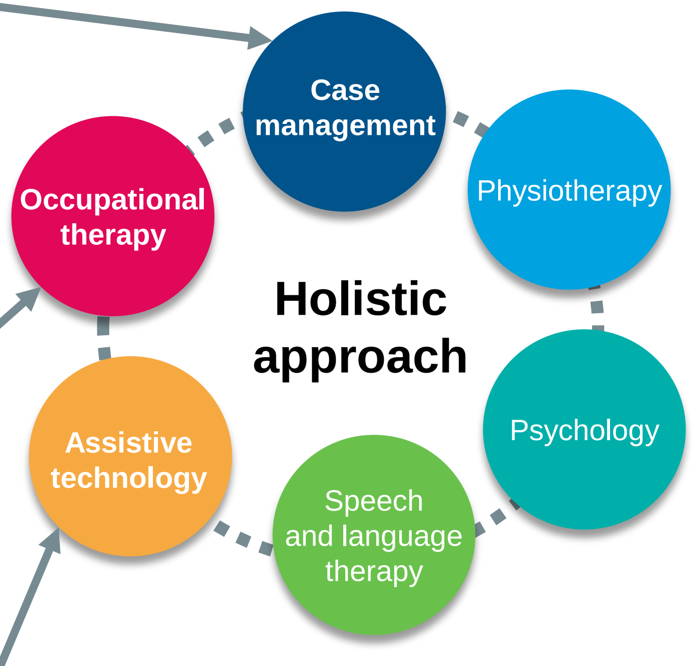
- Some patients were accessing both NES and NCMS. Case managers were praised for their ability to help with any situation – they would help them access any service they needed, they knew their situation and the care they were receiving. One patient noted that their family knew to contact their case manager if ever there were any issues, and described how the case manager had dealt with problems experienced with the social care they received.

Occupational therapy

- OTs were able to suggest practical solutions to any issues patients were experiencing within their homes, suggesting adaptions and assisting with their installation such as getting a shower chair or hand rails. Some patients were also supported to obtain mobility aids
- OTs also provide some technological support, such as adjustments for computer use. More complex issues involve input from an assistive technologist, with the two disciplines working closely together

Assistive technology

- Assistive technologists specialise in high tech solutions for complex issues, such as environmental controls (e.g. within the home) and augmentative/alternative communication (e.g. computer-assisted speech)
- Fewer patients had received support in this area. Those who had not received the support were often unaware that it was available.
- However, where it had been accessed it was considered invaluable. One patient, who struggled to touch or write anything, highlighted the 'Omni' system which *"controlled everything – TV, phone, sockets, the lighting, the CD player…"* making them feel *"in control of [their] life"*



Patients also reported feeling that **NES and NCMS have good relationships with some other services**. Several patients mentioned seeing dieticians, who the SLTs work with frequently – often attending joint training sessions and conferences together

Patients and carers are able to access the service in a way that is suitable for them

Patients are aware of the resource pressures on NHS services, but the service is viewed as highly accessible in spite of these challenges.

Key accessibility characteristics that are important for patients:

Access at home

For people with long-term neurological conditions, visiting a clinic for an appointment can be draining. Home visits mean patients are less fatigued so appointments are more productive and they can still do something else with their day.

Access to long-term support

The service is viewed as a 'safety net' by patients and their families as they could call up about any issues they were experiencing and self-refer if they had been discharged, even if they hadn't used the service in a long time.

Access to the right person at the right time

Care coordination means that patients feel that they are put with the right person in the team based on the issue they might be having. Case managers are recognised as important points of contact for both patients and their families.

Access to support is quicker

After referral, it is felt that the waiting times for therapists are fairly quick in comparison to referral to other NHS services, and it was recognised by patients as a priority for NES. While a carer noted that their waiting times to see the psychologist took longer than for other areas, this has been addressed through employment of psychology trainees and an increase in psychology staffing within NCMS.

> *I'd only go to a GP if things were dire, but it's nice to know that before things get to that point I can speak to a case manager.*
>
> - Patient

> *Getting to an appointment can be draining. I'm more able to engage [with therapists] at home because I've got higher energy levels.*
>
> - Patient

> *I get fatigued, I find that I'm only able to do one thing a day now. When the service comes to you it means your appointment doesn't need to be 'your thing for the day'. You can do something else too.*
>
> - Patient

> *When you have MS or a neurological condition you don't think anyone is going to help you. With [NES/NCMS], because you're told who they are and feel that they want to help, it makes them open, I'm confident enough to pick up the phone and ask about something.*
>
> - Patient

> *Without NES, I expect I'd be battling with the GP; on waiting lists for months, if not years. The waiting time is relatively short.*
>
> - Patient

The ‘ripple effect’: wider impacts on wellbeing

The direct support provided by NES and NCMS has an indirect effect on other areas of patients’ lives, and the lives of their family carers

What is the ripple effect?

While the key aim of the service is to support individuals to meet their short-term goals, in practice it has a much wider, ongoing impact for both patients and their families. This is described by staff as a ‘ripple effect’ which is hard to quantify or measure – the type of support provided is highly personalised and the positive impacts are highly specific to an individual, their life and their priorities. However, qualitative discussions with patients help to build a picture of these **long-term health and wellbeing outcomes**.

Improved quality of life

Being diagnosed with a progressive long-term neurological condition like MS can mean individuals feel like things are only going to get worse. They reported feeling *“lost”* and increasingly restricted in what they could do. In some cases, this led to reduced confidence, a diminished social life and mental health issues. Support from the NES and NCMS helped to turn this around, with patients reporting improvements relating to multiple aspects of their condition which in turn impacted their overall quality of life. This had a knock-on impact on family carers, who felt reassured that their relative was getting the right care and found the burden on them reduced where their relative had become more independent.

Short-term outcomes → **Long-term impacts**

Reduced discomfort
Better quality sleep
Improved social life
Ease of eating/ drinking
Ability to self-manage
Better quality of life
Improved mobility
Increased confidence
Reduced burden on carers
More independence
A more positive outlook
Improved mental health

> *It’s holistic, it’s about addressing the whole person. The ramifications for meeting their goals affects a lot – their confidence, their appetite, their social life, their wellbeing and their family’s wellbeing.* ***There’s a ripple effect which is hard to measure****.*
> - NES staff member

> *Now I am more confident in doing things, as I know I can get help if an issue does arise.*
> - NES patient

> *[NES] will always signpost me to different things available and encourage me to go. [As a result] I have met lots of wonderful people.*
> - NES patient

> *The physiotherapists gave my sister a “bean bag” that she uses to support her legs at night. This has stopped her leg spasms so her husband is no longer woken at night.*
> - Carer

> *The service acts as a safety net, which helps you carry on*
> - NES patient

The ‘ripple effect’ in action: a patient’s experience

Tom* was diagnosed with MS about 16 years ago. He lives with his partner and part-time carer and has accessed support at intervals from the NES for the last five years. He found out about the service through a friend who had a relative involved with it, and he asked his MS nurse for more information. He was subsequently referred but he felt he should have been told about the service earlier.

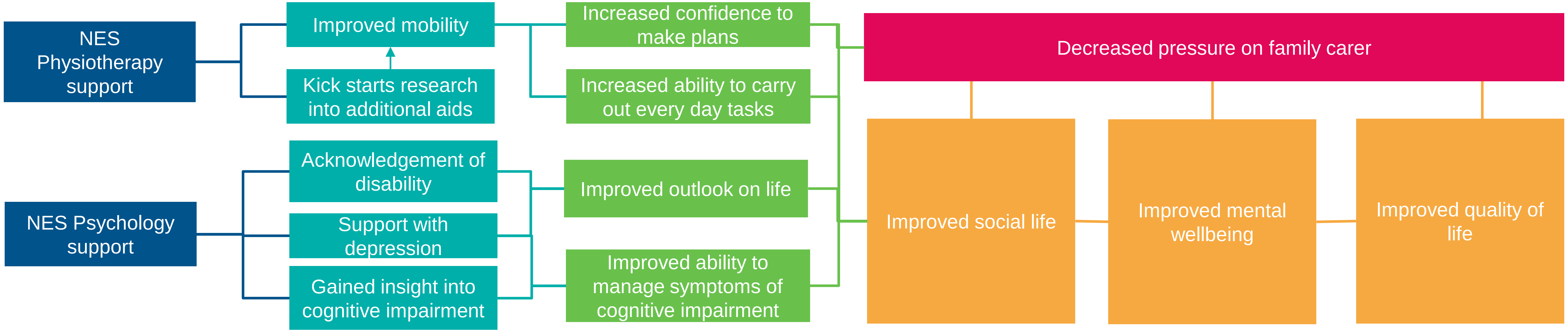
Tom has since received physiotherapy, occupational therapy, speech and language therapy and psychology through NES. Support with his mobility included pool-based physiotherapy sessions and working with his physiotherapist to use a walker to get around his local area. He viewed the walker supplied by the NES positively as he felt mobility aids *“help you feel that your disability is not all in your head”* and, combined with the support from the therapist, he felt it increased his independence and freedom. For example, he reported being able to go from his house to the shops and the pub to meet friends, positively impacting his social life. Tom and his partner were subsequently inspired to begin their own research into a better quality mobility aid which they had since purchased and considered a *“life changing”* piece of equipment.

Tom also experienced issues expressing himself which, undiagnosed, he felt contributed to his developing depression. The psychologist diagnosed him with a cognitive impairment and provided mental health support, and he felt that this enabled him to recover from his mental illness. He felt better able to manage the issues around expressing himself and as a result he felt more confident to go out and socialise.

The improvements to his social life had a knock-on impact on his mental wellbeing and improved his quality of life – Tom felt that the NES support *“changed [his] view that things were getting increasingly worse”* and that *“it stopped the world getting smaller”* for him. Tom’s partner had similarly observed the positive impact that NES support had on his attitude and behaviour, which reduced the burden on her to an extent. Without the service, Tom felt that he would likely be *“battling with [his] GP, on waiting lists for months if not years”.*

**Tom’s real name has been changed to maintain his anonymity*

The impacts of NES support for Tom:



NES Physiotherapy support

Improved mobility

Kick starts research into additional aids

Increased confidence to make plans

Increased ability to carry out every day tasks

NES Psychology support

Acknowledgement of disability

Support with depression

Gained insight into cognitive impairment

Improved outlook on life

Improved ability to manage symptoms of cognitive impairment

Decreased pressure on family carer

Improved social life

Improved mental wellbeing

Improved quality of life

Impacts on the wider health service

Commissioner views on how good MS services can benefit the wider health system

In addition to benefiting patients, commissioners look for services that benefit the health service, in terms of working efficiently with existing services, improving existing services, reducing the burden on existing services, and being cost effective. These cohere well with the policy priorities outlined in the Long Term Plan for the NHS, such as the move towards more integrated primary and community care and the aim to reduce emergency admissions.

Supporting other services

- Working to fill gaps between services
- Upskilling other services

> *If specialists can work and share knowledge with generic services that's really important*
> - Commissioner

> *There is a real, big gap in education, and actual skills with dealing with people*
> - Commissioner

> *[A key thing commissioners are looking for is] where you can link to other services so you're not duplicating or separating anything*
> - Commissioner

Reduced demand on other services

- Reduced demand on A&E
- Fewer and shorter hospital admissions
- Reduced demand on GPs

> *Colleagues in the acute sector would want to see reduced admissions and reduced length of stay*
> - Commissioner

> *Key performance indicators could include a reduction in GP consultations…reduction in A&E visits, reduction in neurological consultant appointments…reduction in length of stay and reduction in hospital attendances*
> - Commissioner

Providing higher quality at lower cost

- Affordable
- Providing good value
- Suitable for the entire relevant population

> *It needs to be potentially available to all of the target population in the area. Otherwise what do you do about the rest of the population?*
> - Commissioner

> *Unfortunately what we have to do, because of our financial position, is identify what the savings are [when putting forward the case for a new service]*
> - Commissioner

Reduced burden on other services

Patients often reported that the NES and NCMS have **reduced their reliance on other health services**, such as their GPs and hospital services, as they can contact the NES/NCMS directly when they have issues relating to their condition.

There is also some limited evidence from staff interviews that **the coordination of care increases the efficiency of all the services an individual is involved with** because the right people are brought in at the optimal stage of the patient pathway. However, the lack of quantitative data available means that further research is required to make conclusive judgments.

> *[Without NES] there would be a great deal more pressure on hospital services, as people would go there instead when they had a problem, or would simply have worse health and wellbeing which would create greater pressure overall when their problems become more severe*
> - NES/NCMS patient

> *We try not to put pressure on local doctors, instead we go straight to NES or the relevant hospital department.*
> - Carer

> *I don't know where I'd go if NES/NCMS weren't available, I'd really struggle*
> - NES/NCMS patient

> *For Psychology services, if NES was no longer available the only alternative would be to go private. For Physiotherapy, we would have to rely on doctors to a much greater extent, so they would have a much bigger case load*
> - Carer

The impact of NES and NCMS on efficiency

In addition to reduced burden on other health services, the way that NES/NCMS work together helps to deliver good quality care more efficiently, although a lack of quantitative data means that it is not possible to assess the scale of efficiency savings that the services make.

Reduced administrative costs: By bringing these services together, there is reduced administration work and costs.

Better linking between services: Within NES, disciplines can easily refer a patient to another part of the service. For example, someone with physiotherapy needs can be referred to an NES occupational therapist. Patients can also be easily referred between NES and NCMS, and both NES and NCMS work to link in other services beyond NHS boundaries.

More efficient use of services: Where there are barriers that negatively impact the effectiveness of an intervention, it is possible for the team to work together to identify these, to ensure the interventions are as effective as possible. For example, interventions in other disciplines may not be successful where a patient has an unmet psychological need. Once this is need is addressed by the NES psychologist, the patient can then work towards their original goals with a greater chance of success.

Easier communication between services: As the services are co-located, they are also able to share knowledge. This helps staff to come up with better solutions for complex cases, and helps patients to receive well-thought out interventions.

Challenges and suggested improvements

What are the challenges for NES and NCMS?

It is widely recognised that there are challenges around resourcing and NHS patient data systems

Staffing is the chief budgetary constraint

The nature of the team means there are no ‘excess’ staff, resulting in capacity issues if a staff member is off due to illness. However, when staff members leave or are off for an extended period of time, service requirements are reviewed with an aim to recruit replacements.

Patients feel that the NHS is generally underfunded, and expressed understanding that this was likely an issue which affected the NES and NCMS. They stressed that, despite these conditions, the team were *“really caring”* and doing *“everything they can to support people”.*

Staffing constraints were particularly evident to patients accessing psychology. It was noted that this issue was not necessarily specific to the NES, as there was a general lack of psychological support across the NHS. However, this issue had been recognised by NES and NCMS and they have responded by increasing their capacity in this area – there are now psychology trainees on the team and senior psychology input for the NCMS.

In other areas of the UK, commissioners had identified gaps in psychological services for people with long-term neurological conditions.

Patients want someone who has an overview of their care

Patients who did not have case managers wanted someone with an overview of all the different teams and services that they were involved with, indicating the importance of the case management service to those who were receiving it.

The NCMS is currently aimed at those with more complex needs. When the service was set up, it was intended that NCMS would get involved from the point of diagnosis, however resource constraints have meant that this is not possible. Staff recognise that the service would similarly benefit less complex patients if there was resource available to accommodate them. Resource constraints also mean that staff are very clear about their scope as a service – they *access* services on behalf of patients, but they cannot *provide* them or *“fill the gap”* for services which aren’t providing effectively.

Different data systems create difficulties for health professionals

NES and NCMS operate within community services and have a wide range of access to different electronic record systems, but they cannot access hospital records or those used by specialist nurses. MS nurses highlight this as a significant challenge, as they cannot see what care an individual might have had in the past, so they make calls to ask about it. Similarly, they cannot keep track of the care a patient is receiving after they have referred them. It is particularly challenging to work with people with long-term neurological conditions as they may have cognition or memory problems which mean they cannot fill any ‘gaps’. Similarly, NCMS have no access to social care records which means time is spent making calls to find out what’s happening.

While this is seen as an NHS-wide problem, it was seen as being “particularly slow” in Sheffield, with data sharing taking place more effectively in other areas of the UK for the benefit of patients.

Suggested improvements for NES and NCMS (1)

We asked patients, their families and carers, staff and MS nurses about aspects of the service that could be improved:

Patient follow-up

As the aim of NES is enablement (providing information and education to patients, and support them to help themselves), follow-up is not part of the service. Instead, it aims to make re-access straightforward when needed. However, some patients, family carers and MS nurses felt the service would benefit from being more proactive in following up with patients between periods of care, being *"reactive rather than preventative"*. Sometimes people would feel forgotten, with nurses and carers reporting that patients did not always realise they could self-refer themselves back. This was considered particularly important given the nature of long-term conditions, where things can get progressively worse. It was suggested that patients and/or carers would benefit from a courtesy call 3 months after discharge.

Signposting and information provision

Patients and carers felt that potentially useful information was not always made available. In particular, they felt they would benefit from information around wider issues relating to an individual's condition, such as financial support or advice on equipment which might help, as there was no single resource available detailing this. They were willing to pay for better equipment privately, for example, but struggled to identify where to go for what they needed. It was suggested that a *"catalogue"* or webpage to point people with long-term neurological conditions and their carers in the right direction for different things they might need would be extremely useful, and potentially save staff time.

> *They should give people the full picture, make them aware that they can re-refer at any time. It would be nice to get a courtesy call…feel like you've not been forgotten.*
> - Carer

> *Re-referral could be easier, NES patients could be kept on the case load for longer. There's a lack of clarity around cut-off points for self-referral.*
> - MS nurse

> *There's leaflets in the waiting room, but it's all dependent on you being proactive. Sometimes it's helpful to have someone who can give you a nudge or a hand. Leaflets also don't necessarily provide all the information, or the information isn't specific enough.*
> - Patient

> *Some kind of catalogue would be really useful. I had to do serious research to find an appropriate walker for [patient]. We've been stopped by friends and even strangers, they're so impressed with it and want to buy one. But we found it by ourselves.*
> - Carer

Suggested improvements for NES and NCMS (2)

We asked patients, their families and carers, staff and MS nurses about aspects of the service that could be improved:

Goals and care plans

Some patients and carers were not aware of having an overarching care plan. It was felt that this would be beneficial by providing a longer term outlook for their care and joining up their different goals. Long-term neurological conditions are often progressive but the focus on short-term goals meant patients and carers sometimes felt that they were not always made aware of things that might help them in the future. MS nurses felt that sometimes the goal setting system lacked flexibility – it could be difficult for them to refer patients who they knew could benefit unless they were able to provide clarity on their reasons for referral and patient goals, and as a result the referral process could be time consuming.

NES and NCMS have already identified this as an area for improvement and are making changes as a result. They are working towards more consistency across disciplines on the information available for patients, including providing a written action plan for each specific discipline on request (to account for patients who may prefer verbal discussion and to avoid overwhelming those who are accessing several clinicians with information). The initial invite letter to patients will highlight how they can request this plan from their clinicians.

> *I don't know if I have a care plan. It's not been made explicit.*
>
> - Patient

> *[NES] can be frustrating to access – it's goal driven, so they won't see patients unless there is a specific goal. It can be a long wait as there's a long triage process.*
>
> - MS nurse

Carer involvement

While it is acknowledged that families and carers are welcomed by NES staff and able to ask questions and attend appointments, the 9-5 working week means that carers may be at work during these appointments. This can make it difficult for carers to stay on top of the care that is being delivered, particularly when a patient has a cognitive impairment, and means they do not have the same opportunity to ask questions. One carer felt that it would be beneficial if staff could check in with carers to see if further input was required, rather than relying on carers to contact them for help.

> *[The service] rely on us to ask for help. There's no checks on whether further input would be useful. I know what's available…but others might not.*
>
> - Carer

> *Discussions with NES haven't involved me…it's partly because I'm not available at appointment times. I'm at work. Out of hours appointments to include carers would help. The impact of a cognitive impairment means that [therapists] might not get the full picture at appointments [when the carer is not there].*
>
> - Carer

Conclusions

Conclusions: Care and quality, health and wellbeing

Overall the NES and NCMS model illustrates an effective and innovative approach for engaging with people with MS and other long-term neurological conditions.

The impact on care and quality

- The service is patient-centred and customised with emphasis placed on co-production and self-management, making it well-placed to meet the needs of those using it
- As a multidisciplinary team, multiple needs can be met in a holistic way, and the right discipline can be brought in when the patient needs it
- Case managers co-ordinate across agencies, which means individuals with complex needs benefit from a more joined-up approach
- In combination, care is more effective, which provides better outcomes more efficiently for patients

The impact on health and wellbeing

- The impacts on patients and families of the NES and NCMS model are reflective of commissioner expectations about what a good service should do, and cohere with policy priorities and NICE guidelines
- Setting personal goals and receiving tailored support meant patients were better able to understand why they were receiving a specific type of care, and consequently enabled them to better manage their conditions
- Patients felt able to access the service in a way that suited them, as a ‘safety net’ whenever they faced challenges relating to their condition
- The experiences and short term outcomes for patients and their families vary for each individual – their mobility and quality of sleep may improve, they may see improvements (for example) in the ease of eating and drinking, minimisation of discomfort, and they may be better able to manage any cognitive issues impacting their ability to express themselves
- The ‘ripple effect’ from these changes can be seen on patients’ social life, confidence and wellbeing, ultimately improving quality of life for both patients and their carers

Conclusions: Efficiency

- Efficiency is perhaps the most important consideration for commissioners when commissioning services
- Quantitative impacts on efficiency could not be assessed due to data limitations, and further research is needed here. A possible methodology might involve analysing patient health records for hospital stays before and after accessing NES/NCMS. This was discussed, but could not be carried out due to capacity and data protection constraints.
- However, qualitative data suggests that NES/NCMS work efficiently together, adding value to the quality of care provided by both services. This is achieved by:
  - The multi-disciplinary nature of the team
  - The multi-disciplinary nature of support provided
  - Co-location of the teams
- Qualitative data also suggests that NES/NCMS reduce the burden on other parts of the health service, including GPs and hospital services. This is achieved by being **accessible**, through patients having a point of contact and being able to self-refer, and offering home visits.
- The **range of services** that NES/NCMS are able to provide, and the signposting to other services where they are unable to meet specific needs, is another reason that it is viewed as a “port of call” for patients and carers.

Conclusions: Translation to other areas

Commissioners suggested several factors that need to be considered in replicating the NES/NCMS model in other areas:

Size and composition of patient population: Commissioners highlighted the benefit of services covering as wide a patient population as possible (described by one as “generalist specialist services”), and the importance of services covering the entire intended population (e.g. all people within a given area with specific long-term neurological conditions). Because the population with long-term neurological conditions is relatively small, a service such as NES/NCMS requires a larger footprint than many individual CCGs to be viable. The NES and NCMS patient population includes 25% and 19% of people with MS respectively, and a substantial proportion of patients with Parkinson’s, and includes many patients who were reported to have multiple, but not particularly complex, needs. The integration across local systems foreseen in the Long Term Plan may therefore help to develop similarly viable services in between highly specialised care and community services.

For a population with more complex needs, an expanded NCMS might be required. As such, translation would require careful consideration of population need, and the resultant staffing requirements.

Geography: The spread of the population in other local systems could also impact translation. For example, delivering the service in an area with a lower population density, such as a rural rather than an urban area, may mean that staff would spend a higher proportion of their time travelling between patient homes. This would mean more staff would be needed to carry out the same number of home visits as are currently achieved in NES/NCMS. A possible solution would be to consider technological solutions such as remote consultations, to help ensure accessibility while reducing staff travel time. However the success of this solution might depend on the technological literacy of the patient population.

Strategic priorities: The importance of coherence with commissioner priorities was noted, and because RightCare is now identifying local areas that are relatively underperforming, those areas may give greater priority to long-term neurological conditions. These areas could be receptive targets for ideas that can translate, if they are similar to Sheffield.

Inclusion of psychology: At least one commissioner felt that including a specialist psychologist within community-based MDTs for people with long-term neurological conditions would be particularly beneficial as a resource for other members of staff and patients.

Other factors that could support effective translation include:

Data systems: Recognised as a challenge for NES/NCMS, data systems that are accessible to all professionals involved in an individual’s care would help to support the integration of this type of service with other local specialist and generalist services.

Sufficient staffing: While NES/NCMS is able to meet patient needs with the current level of staffing, it is recognised that staff are stretched, and improved funding would likely result in patients being seen sooner. This is something to consider when aiming to successfully translate the service elsewhere.

Links between existing services: The successful translation of an MDT model to another area would likely be supported by good existing links between different therapy disciplines, although success in a local area with poor links between existing services would yield greater benefits.

Conclusions: Challenges and improvements

Challenges for the NES and NCMS

- Resourcing is a recognised issue among staff and patients
- This is particularly pertinent with regard to case management and access to the team psychologist - there was a demand for a case management-style service from patients without case managers, but the NCMS are limited in capacity and focus on those who are more complex; it was also observed that waiting times for psychology input were longer than for other NES therapy services
- However, it was recognised that waiting times for NES psychology were still quicker than for the NHS more widely, indicating a general shortage of such services in the UK
- The electronic systems used in different areas of the NHS in Sheffield was seen to impede quality of care, particularly between NES and NCMS, and the MS nurses who could not access the same patient records

Potential service improvements

- Patients and MS nurses would like to see more follow-up with patients after they have been discharged, though this presents a resource challenge – follow-up currently happens only for clients on the NCMS case load with particularly complex conditions where their health is deteriorating, and they do not have a “reliable reporter” in place to help them re-refer. There is not the capacity to adopt this approach for all of those who are referred to NES and NCMS
- Useful resources (such as support services for issues relating to long-term neurological conditions, information on mobility aids or technical equipment, and resources for patients and carers) could be compiled in a single location for the benefit of patients and their carers. They are willing to actively pursue other avenues of support and purchase equipment privately, but it can be difficult to know where to go for this
- This is likely to become more important given the wider policy environment. Public healthcare resources are increasingly stretched and people with MS and other long-term neurological conditions are expected to self-manage their condition - a repository providing the information they need could potentially save staff time in gathering information for patients, and would provide self-management support
- Self-management could also be further supported by providing patients with clarity on their care plans, ensuring they can see how goals set with each therapist are joined up
- Working family carers would like more appointments to be available outside of standard working hours and for staff to be more active in involving them in their family member’s care, but this again presents a capacity challenge for NES