

### 1. Background

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. Improving access to appropriate healthcare, information and holistic support has a significant role to play in achieving better outcomes for people with MS. Identifying innovative and impactful services, evaluating the translatability of such services and communicating the findings widely will aid in reducing variation in service provision for people with MS. The Long Term Plan for the NHS in England, published in 2019, sets out the strategic direction for the NHS 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**; **More integrated and personalised care**; **Improved access to specialists**; **Reducing health inequalities** within care services, and for carers; **Reducing unwanted variation in services**; **Meeting mental health needs**; **Greater investment in research and reduced time to bring new treatments to market**; **Improving data**; **Shifting the workforce** away from a large number of highly specialised roles towards more generalist roles, and **ensuring better alignment of doctors' speciality choices with geographical needs**.

Better evidence can inform the development of integrated neurology care for people with MS, in line with the Long Term Plan. Significant, unwarranted variation in MS treatment, care and support is driven by:

- A lack of standard guidelines on MS standard practice, both in practice and on paper
- Increasingly limited neurological specialists
- A lack of oversight and responsibility for the entire care pathway, driven by fragmented commissioning arrangements
- A lack of evidence demonstrating the impact of MS services
- Expected heavier workloads as new treatments are approved for MS, and further unmet need is identified
- Sociodemographic inequalities
- Financial pressures within the NHS and social care

### Aims

The MS Society commissioned ICF to evaluate 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**.

*"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

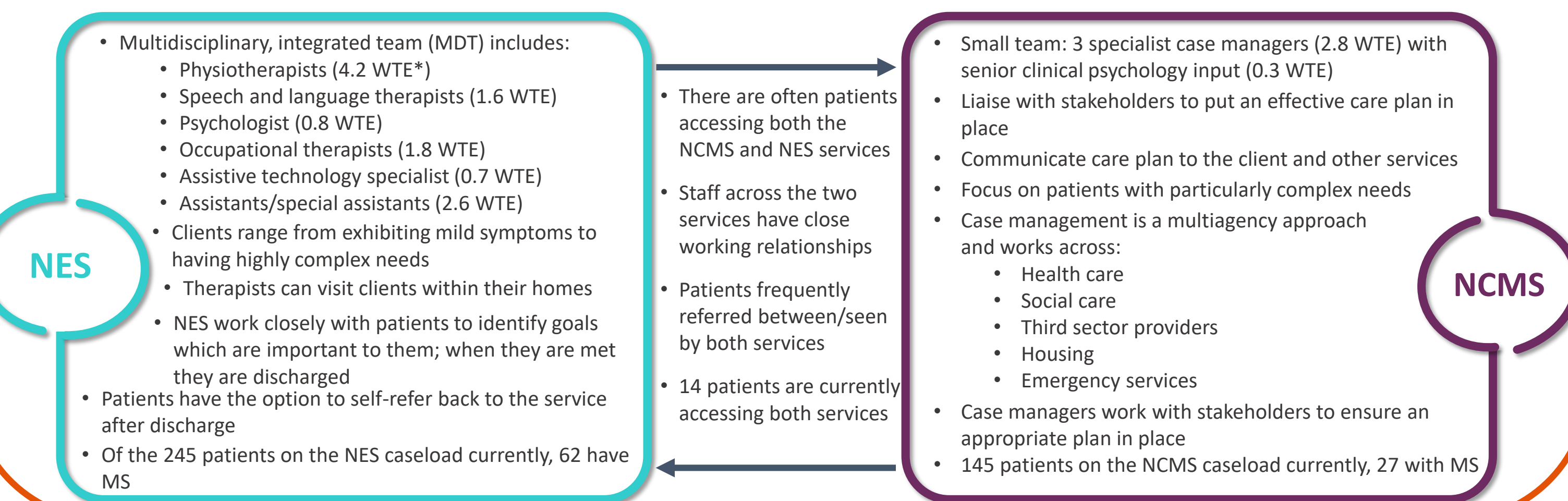
### 2. The Services

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

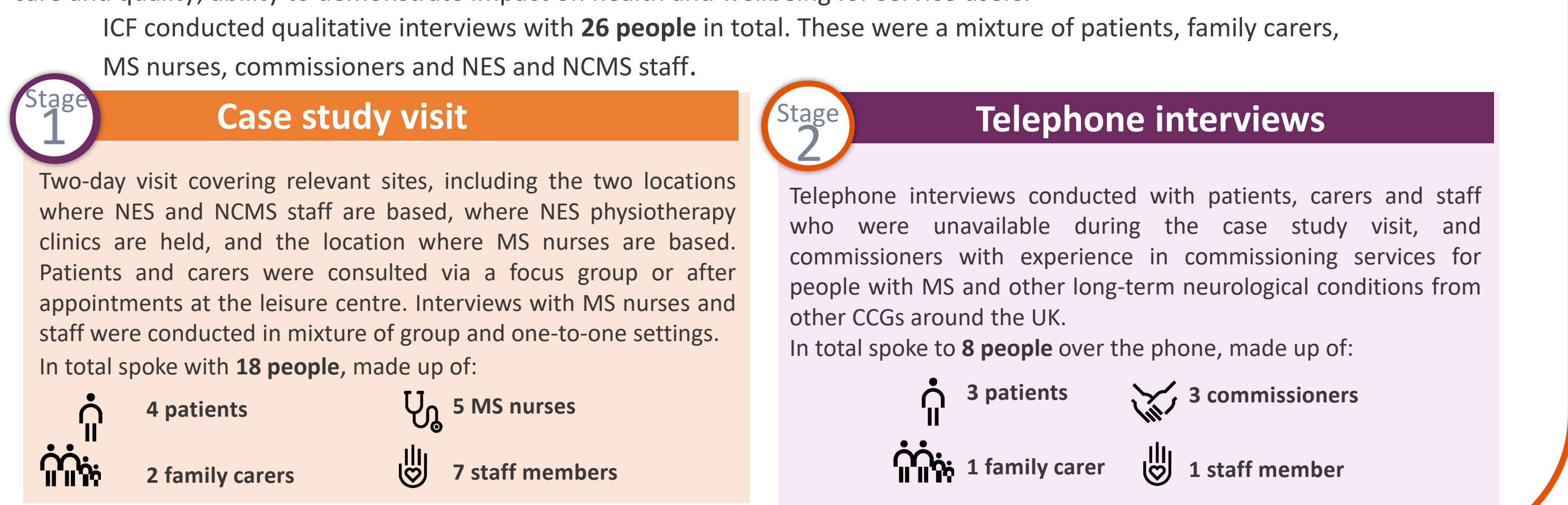
Both the NES and NCMS are based at the same location, but the service provided by each is distinct:



*"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

### 3. Evaluation methods

Services for people with MS across the UK were asked to apply for their service to be evaluated. Nine submitted applications. These were assessed against a set of key criteria by two panels. Assessment criteria included: presence of an intervention which could be evaluated (with a focus on cost-benefit analysis); evidence of need for the intervention; need for improvement of the specific service; indicative translatability; ability to demonstrate impact on efficiency, care and quality; ability to demonstrate impact on health and wellbeing for service users.



### 4. Findings

*"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

#### Innovative activities

**A multidisciplinary team specialising in long-term neurological conditions**  
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.

**Case managing individuals' complex 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.  
• 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**

**Assessments, goal setting and care planning**  
Goals are **person-centred** and focus on what is **important and achievable** for the individual. Examples provided by staff and patients included:  
**Home appointments** mean that patients can work with therapists in a familiar environment. It can also make the work of the therapists more effective.  
**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**  
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 many health services in the Trust 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.

#### Impacts on patients and families

**Good quality services** for people with MS and other long-term neurological conditions should **support patients and their families to live in the way that they want**, which means being tailored to the individual and supporting with self-management.

- 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 increase in wellbeing and quality of life

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

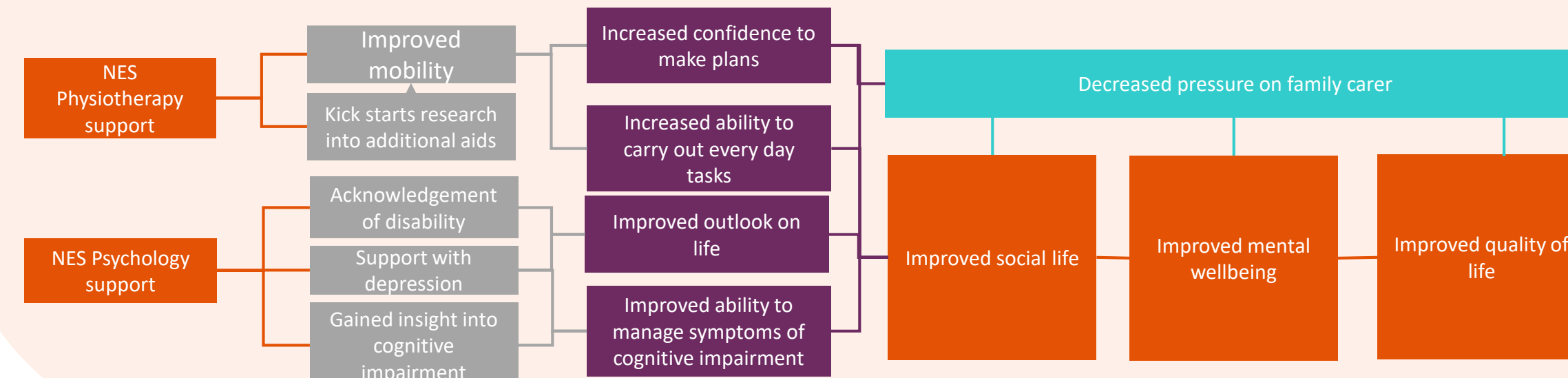
Key accessibility characteristics that are important for patients:

- 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.

#### 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. 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**.

#### The ripple effect: One patients experience



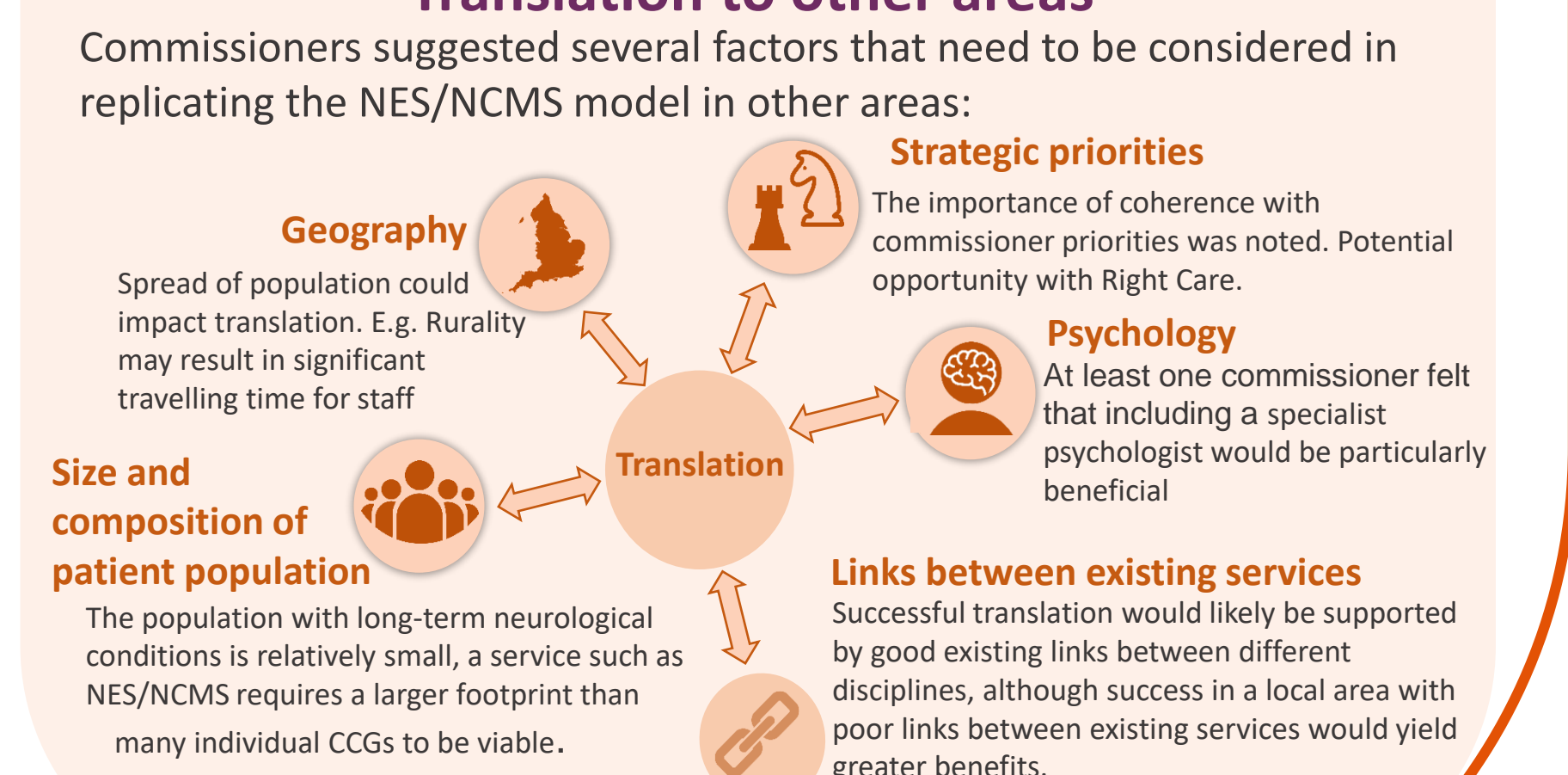
#### Impacts on the wider health service

- 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.
- Reduced administrative costs**: By bringing services together means reduced administration work and costs.
  - Linking services**: Within NES and NCMS, disciplines can easily refer a patient to another part of the service. Both work to link in other services beyond NHS boundaries.
  - Efficient use of services**: Where there are barriers the team can work together to identify these, to ensure the interventions are as effective as possible.
  - Easier communication**: As the services are co-located, they are able to share knowledge. This helps staff come up with solutions for complex cases, and helps patients to receive well-thought out interventions.

#### Challenges and improvements

- Resourcing is a recognised issue among patients and staff**. Particularly for case management and access to the team psychologist.
- Disconnected systems**. 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
- Follow up**. Patients and MS nurses would like to see more follow-up with patients after they have been discharged, though this presents a resource challenge
- Support to self manage**. By providing useful resources in one place (such as support services, information on mobility aids or technical equipment, and resources for patients and carers), and more clarity on care plans.
- Out of hours appointments**. Working family carers would like more appointments available outside of standard working hours, but this again presents a capacity challenge for NES.

#### Translation to other areas



### 5. Conclusions

This process was successful in identifying a number of innovative services for people with MS. NES/NCMS specifically is one such service that fulfils the requirements identified by commissioners and experts in the field as a successful service for people with MS and other long term neurological conditions. As a pilot programme we received a good number of applications considering the limited application window and have been able to complete a robust qualitative evaluation of a high quality service.

The evaluation process did encounter some challenges. **1. Evaluating outcomes and efficiency**: specifically around 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 also 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 was explored. However this option was not feasible. **2. 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 staff. 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. **3. 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.

Despite these challenges we believe that a programme such as this is beneficial to MS services in order to better understand and support the spread of best practice, as well as to highlight interventions that could be adopted and implemented elsewhere in order to address unmet need and unwarranted variation in service provision for people with MS. The MS Society will be reviewing the programme and addressing any particular limitations prior to re-implementation in 2020.