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# Innovative Models of Care

## Evaluation of NeuroResponse

Produced by ICF for the MS Society

November 2019

# Contents

# Summary

- NeuroResponse is a social enterprise organisation that aims to improves the lives of people with neurological conditions, including MS. It is delivered in partnership with LCW (an unscheduled care collaborative that incorporates aspects of the 111 service). NeuroResponse provides urgent care for people with MS that can be accessed 24/7 through the 111 telephone number.
- The service represents a new way to support people with MS with common MS-related issues including UTIs and relapses. Innovative aspects include the use of technology to link in with existing services, the creation of digital care plans and bespoke QR labels, the use of couriers, the provision of out of hours specialist care and the co-design of the service with people with MS, staff and commissioners to ensure the service addresses local population needs.
- People with MS and their carers reported very positive experiences with the service on the whole. They highlighted the accessibility, quality and speed of the service. They also emphasised how personalised the service is, and how they were treated as experts. This had positive impacts in terms of improving health and wellbeing, improving confidence, and empowering people to self-manage.
- IUC (integrated urgent care) GPs who are responsible for delivering the service felt that it was a good concept, but noted some practical issues that need to be addressed
- We found some qualitative and quantitative evidence to suggest that NeuroResponse may be reducing people’s use of GP and emergency hospital services. Further, an existing cost utility analysis found that NeuroResponse is cost-effective for UTIs and addressing the potential complication of sepsis, and cost-saving for relapses. However, there is a small amount of evidence that there is some duplication of service use currently.
- There were several suggestions for how the service could be improved from the perspective of IUC GPs, including providing additional training and reviewing how processes work, and broader suggestions for how the service could be improved, including a need for further awareness raising and provision of clearer information about the service. However, it should be noted that NeuroResponse is relatively new and evolving service which aims to develop over time in response to the needs of service users and delivery staff. It was also suggested that the service could be expanded further in the future, which is a goal also of the NeuroResponse Clinical Lead.
- We identified a number of factors that should be considered for translating the service to other areas, including having a strong understanding of the local problems and patient population, strong leadership, and a need to work closely and raise awareness of the service among local health professionals.

# 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 by dialling 111, a simple, free and easy to remember number. NeuroResponse patients are provided with support by specially trained IUC 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 NeuroResponse.**

## 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 NHS Long Term Plan for 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** 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

**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 the 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**

# NeuroResponse

# The purpose of NeuroResponse

## Background to the service

NeuroResponse was established in response to a significant population of people with MS in the local area and an independent audit which revealed that UTIs were a leading cause of unplanned hospital admissions among people with MS, with negative impacts on people's health and wellbeing as well as significant cost implications for the NHS.

## Roll out in Camden and Barnet

- Following a trial with a small number of patients in Camden, NeuroResponse has been introduced to Barnet as "Phase One" of its expansion. Camden was selected as the location for a trial because a relevant cohort was identified by medical professionals in the area. Further, this was the borough in which the Clinical Lead was based, so she already had connections with providers.
- After demonstrating that the model could work in Camden, the model was translated to Barnet following the interest of a a commissioner in the local area, who became aware of the service from local neurology service improvement forums.
- Within Barnet, NeuroResponse is aiming to sign up 500 people with MS in the local area. Their agreed goal for a cohort of 500 people is to reduce unplanned hospital admissions for UTIs by 24 and unplanned hospital admissions for relapses by 8 in one year.

## Use of co-design in service development

- The Clinic Lead worked in collaboration with a patient co-design expert, using the King's Fund evidence-based co-design (EBCD) methodology, to develop a service which would help to address the issue of UTIs for people with MS.
- Co-design means collaboration between patients and staff to ensure that a service meets the needs of those using it, as opposed to the organisation. It aims to recognise patients and families as experts, valuing their lived experience and incorporating their priorities into service development.
- Interviews were conducted with patients, families and staff then key themes were discussed with stakeholders, who included people with MS, their families, charities, NHS commissioners, PHE representatives, and health and social care professionals.
- The resulting findings showed that people with MS and their families wanted 24/7 access to expert advice, shorter waiting times for assessment of new symptoms, faster treatment for UTIs, and a system that enabled professionals to share information securely.
- NeuroResponse aimed to incorporate this feedback through a model that supports patient self-management, co-ordinated action and technological innovation.

# An introduction to the NeuroResponse model

NeuroResponse offers urgent care to people with MS which is available at any time of day, accessed by dialling 111. When a NeuroResponse patient calls 111, their number is recognised and they are redirected to a specific team of IUC GPs who are trained to deliver the NeuroResponse service (NeuroResponse clinicians). The patient's anticipatory care plan is flagged and the IUC GPs are able to provide support with symptoms relating to an individual's condition.

Due to the high number of hospital admissions among people with MS for urinary tract infections (UTIs), the primary focus of the service is to address this issue. NeuroResponse can also provide support around relapse presentations by assessing the clinical severity of the relapse and either prescribing drugs or referring to an MS Neurology Specialist Registrar accordingly, though this is less common (see slide 24).

When NeuroResponse patients call the service and report symptoms that are indicative of a UTI, they can take a urine sample at home using home testing kits supplied by the service. The samples, which are QR-labelled to further speed up the process, are picked up by couriers for laboratory analysis. Where the sample tests positive for a UTI, prescription antibiotics are delivered to the patients' home.

**NeuroResponse aims to:**

1. Improve detection and treatment time for UTIs
2. Ensure appropriate antibiotic use
3. Reduce unplanned hospital admissions

**The NeuroResponse team consists of:**

- The Clinical Service Lead
- Three part-time Patient Engagement Officers
- A cohort of around 10 IUC GPs (NeuroResponse clinicians) who are responsible for delivering the service.

# The patient population

The NeuroResponse patient population in Barnet (people who have signed up to use the service by the end of September 2019) vary in terms of ages and the length of time that they have had their MS diagnosis. The majority of patients are female, which can be expected given the higher prevalence of the condition among this group.

Patient population in Barnet (n): **104**

| Gender | Age | Condition |
|---|---|---|
| 75% female<br>25% male | Average age: 52<br>Age range: 23 to 90 | Average years with MS: 18<br>Years with MS (range): 1 to 57 |

# Sign up process and patient pathway

### Invited to sign up

- The NeuroResponse team take a multi-faceted approach to engaging people with MS, including discussion at normal case working meetings and forums.
- Eligible patients (those residing in Barnet with MS) are invited to join by letter.
- Additional support is offered to patients who may need it to help with the sign up process.

### Patient sign up

- Patients who choose to sign up create a summary care record. This outlines their medical history and is used by clinicians when the patient uses the service
- Patients are also given a urine sample pot with a unique QR code on, for home testing.

### Patient calls 111

- In the event of need, the patient calls 111.
- They are redirected to a specialist team of IUC GPs who are familiar with the NeuroResponse service and can deliver appropriate care. Out of hours, their initial call will be dealt with by a nurse or paramedic.
- In the event of a suspected UTI, the patient will be instructed to make use of a home testing kit
- A courier will be sent to collect the patient's urine sample
- Following this, the sample will be sent to the laboratory for testing

- In the event of a relapse, the clinician will assess whether it is clinically disabling or clinically significant in accordance with NICE guidelines

Calls about relapses are less common than calls about UTI, and follow a different pathway. Once the clinician has assessed the patient, they follow NICE treatment recommendations. If a clinician deems a relapse clinically disabling they will refer the patient to an MS consultant via A&E, whereas if they deem a relapse clinically significant they will prescribe steroids or notify the patients own GP so that they can prescribe them. The patient receives a follow-up call 6 weeks later

### First call back

- Once the patient has made the initial call and a courier is arranged, an IUC GP will call them back within 1 hour
- The purpose of this call is to assess the patient, and see if they require urgent care. As generalists, the GPs are also able to offer broader condition management support as needed.
- If they require urgent medical attention, the GP can choose to prescribe medication before the laboratory test comes back, or may advise the patient to attend A&E.

### Second call back

- If in the first call back it is decided that the patient is well enough to wait for the test results to come back, the GP will call back a second time 48 hours after the initial call
- This is intended to coincide with the laboratory results being delivered
- If the laboratory results indicate a UTI, the GP will prescribe antibiotics. The choice of antibiotics will depend on the results of the laboratory test.
- The prescription will be sent to the patient electronically. In some instances, pharmacies will also deliver the prescription to the patient's home

### Third call back

- Around four days after the patient has been prescribed antibiotics, the IUC GP will follow up with the patient for a final time to ensure that their symptoms have subsided

# Innovative aspects

The NeuroResponse service represents a new approach to supporting people with MS, using technology and linking in with existing services to provide support and care that can be accessed 24/7.

**Use of technology to link in with existing services**

- The NeuroResponse service uses the framework of the Integrated Urgent Care Service, which can be accessed by dialling 111, to connect people with MS to urgent support from a trained cohort of IUC GPs.
- NeuroResponse patients and carers are identified by their telephone number, so they are correctly redirected when they dial 111.

**Digital care plan**

- Each patient creates a summary care record when they join NeuroResponse. This digital care plan informs the support they receive when they speak with a NeuroResponse clinician.

**Bespoke QR labelling**

- Each patient also receives a home testing kit. This includes the necessary equipment to perform an at home urine sample, which can then be collected and tested for a UTI. The samples are labelled with bespoke QR codes, which ensure that the sample is linked to the correct NeuroResponse patient.

**Use of couriers**

- Couriers can be arranged to collect urine samples from people’s homes and can also be used to deliver prescriptions.

**Out of hours access to specialist care**

- Most specialist care for people with MS is only accessible during office hours, while NeuroResponse offers access to specialist care and support at any time of day.

**Co-design of the service**

- NeuroResponse was developed in collaboration with people with MS and other stakeholders, to ensure that it reflected the needs and preferences of people with MS

# NeuroResponse logic model and theory of change

## INPUTS

**Funding:**
- From Barnet CCG
- From NHS Innovation accelerator programme
- From various grants

Mentorship and development from Academic Health Science Network

Support from the Clinical Entrepreneur Mentorship Programme

Input from colleagues at LCW*

Support from RERO**

## ACTIVITIES

Patient engagement

Recruitment of MS patients to service

Setting up patients on the portal / platform

Establish redirection of 111 calls to specific call centre and train staff

Collecting data from NHS Digital

Establish 24/7 pharmacy capacity to support timely prescriptions

## OUTPUTS

200 people accessing the service

Individual care plans in place for each patient

Appropriate triage and support provided 24/7 by dedicated 111 call centre

Appropriate medication provided 24/7 by dedicated pharmacy.

Identification of unmet needs

Identification of safeguarding issues

## OUTCOMES

Reduced unplanned hospitalisations

Faster testing and diagnosis

Faster and more convenient access to appropriate medication (through 24/7 pharmacy and home delivery)

Joined up, personalised health care

Fewer unmet needs

Safeguarding issues addressed

Better knowledge and self-management of symptoms

## IMPACTS

Reduced healthcare costs through avoided unnecessary admissions and better self-management

24/7 access to appropriate medical treatment for patients with MS

Better healthcare experiences for patients with MS and their families and carers.

Better health outcomes

Improved quality of life through improved self-management and resolution of safeguarding issues/unmet needs

More appropriate use of healthcare services

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

*LCW manages the NHS 111 service

**The RERO, or Regional External Relations Officer, is a member of staff within the MS Society

# Approach to the evaluation

# Methodology

The evaluation for NeuroResponse took place between May and November 2019. We conducted qualitative interviews with **16 people** in total, and received input from a further 32 people with MS who had signed up to or used NeuroResponse through an online survey. Reflecting data availability at the time of writing, we utilised quantitative data for the period of May to September 2019.

## Stage 1 Telephone interviews

Telephone interviews were conducted between May and November 2019. We spoke with medical professionals who had experience of the service in Camden or Barnet, IUC GPs who had experience delivering the service, the NeuroResponse Clinical Lead, people with MS who had signed up for NeuroResponse and their carers, and commissioners with experience in commissioning services for people with MS and other long-term neurological conditions from other CCGs around the UK, including those with experience or knowledge of NeuroResponse. In total we spoke with **16 people**, comprised of:

- **4 patients**
- **1 family carer**
- **4 commissioners**
- **4 IUC GPs, 1 GP and 1 district nurse**
- **1 NeuroResponse team member**

## Stage 2 Patient survey

We invited patients to provide responses to a quantitative survey in September 2019. The survey was open for five weeks. It included questions about respondents' MS, their use of health services, their experiences of signing up and using NeuroResponse, and how NeuroResponse has impacted them.

In total, we analysed **32 responses**. 31 of these were completed responses and an additional incomplete response was deemed suitable for inclusion in analysis as a large section of the survey was completed.

There was a further complete response which was excluded from analysis due to inconsistencies in the respondent's answers. However, we have chosen to include some of their responses to open-ended questions in the survey to ensure their views could be included as far as possible.

As part of the evaluation, we also **assessed various materials** provided to us by NeuroResponse, including background information, demographic data, and academic studies. The NeuroResponse team also provided us with HES data, which captured the number of unplanned admissions and the number of bed days per admission for people with MS in Barnet between May and September for 2018 and 2019. This data is presented on slide 50. Using NeuroResponse service data, the team could show if and when these individuals had signed up to NeuroResponse and their subsequent use of NeuroResponse and emergency admissions. These were used to produce the case studies shown on slide 49.

# 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, IUC GPs and people with MS and carers within the study. We were unable to speak with the key commissioner in Barnet with knowledge of NeuroResponse, due to staff absences. To address this gap, we spoke with other commissioners and strategic staff with knowledge of NeuroResponse and were able to obtain interviews with commissioners in other CCGs through the MS Society's regional leads. As frontline staff who are responsible for delivering the service, there were also limitations to the number of IUC GPs we were able to speak with. We also experienced challenges in identifying people with MS or carers who would be willing to take part in qualitative interviews, and not all people we spoke with had needed to use the service so were unable to provide information about this. To complement qualitative findings, we conducted a survey where people who had signed up or used NeuroResponse were able to provide their feedback on their experiences to date.

### Evaluating a developing service

As NeuroResponse is a relatively new service which is still developing, this report provides a snapshot of experiences with the service and its impacts to date, with a focus on the service in Barnet. Many of our respondents appreciated that some of the challenges that had been experienced were simply "teething problems", which they expected would be rectified over time, and the NeuroResponse Clinical Lead discussed some of the planned initiatives to address these issues.

### 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.

We aimed to utilise HES data to demonstrate the impact of the service on hospital admissions. While the HES data shows that there were fewer hospital attendances and bed days among people with MS due to UTIs in 2019 compared to 2018 (as detailed on slide 50), it is not possible to demonstrate a clear causal link due to the small size of the patient population. Instead, we have presented this data descriptively and outlined several patient journeys, demonstrating the impact the service has had on hospitalisations at an individual level. It should be noted that accessing high quality quantitative data in this context can be very challenging and time consuming.

# Patient experiences of the service

# Introduction

This section describes the experiences of people with MS who have signed up to NeuroResponse and their families and carers, including how they heard about the service, why they signed up, how easy or difficult the sign up process was, and their experiences of using the service. This is based on responses to the survey sent out to NeuroResponse patients and qualitative interviews conducted with NeuroResponse patients or their family and carers.

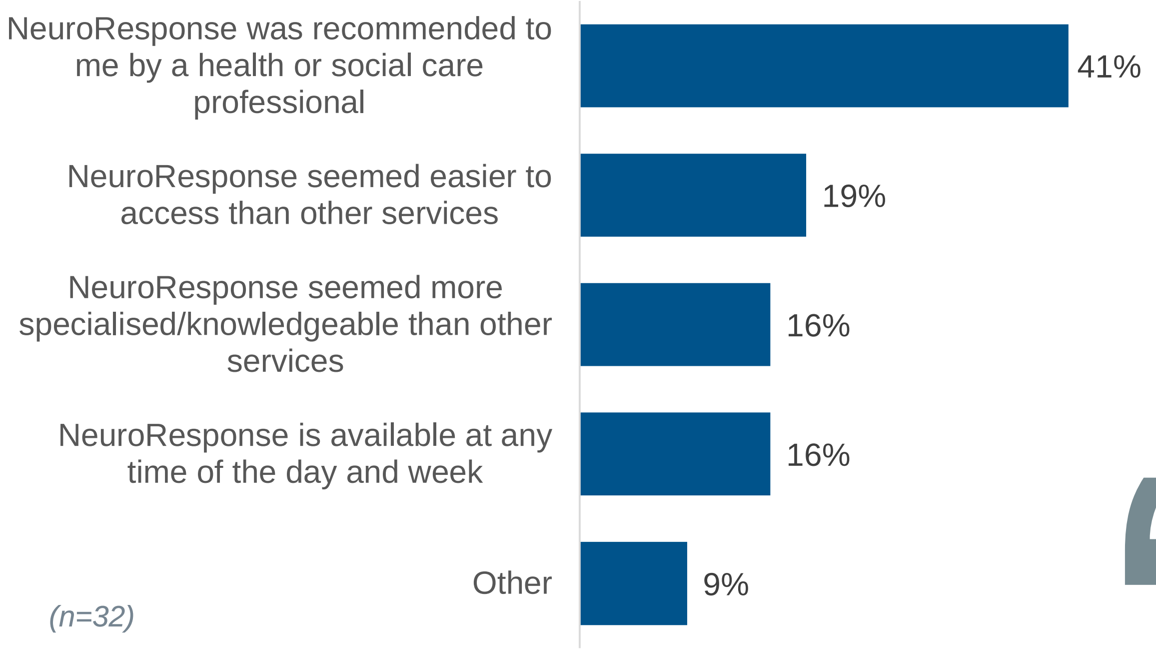
The findings presented in this section are based on the views of:

- Qualitative interviews with 4 patients
- A qualitative interview with 1 family carer
- Survey responses from 32 patients

# Health and social care professionals are key in driving sign ups to NeuroResponse

People with MS generally hear about the service after being contacted directly by the NeuroResponse team, and the main reason for signing up is often due to a recommendation from health or social care professionals, suggesting patient engagement work from NeuroResponse is key to generating sign ups.

What was your **main reason** for signing up?



*(n=32)*

- Just over half (53%) of patients heard about NeuroResponse for the first time after being contacted directly by the NR team, while almost a third (31%) heard about it through another health service (e.g. a neurologist, GP or MS nurse). Other routes to NR included hearing about them through a non-medical service, such as a local MS group, or in an online chat group for people with MS.
- Recommendations from health and social care professionals is the most frequently mentioned reason for deciding to sign up to NeuroResponse (41% said it was their main reason), illustrating the importance of engaging with potential service users and promoting the service to professionals in Barnet who are working with people with MS.
- Qualitative interviews suggested that, while people found the service easy to understand once they had understood the concept, it did require some explanation.

> *I first heard about the service around six months ago when [the Clinical lead] came to talk to our group in Barnet. I remember getting very confused, wondering what NeuroResponse was about, I really didn't understand, it sounded tremendously technical, complicated... yet the simplicity of the scheme is actually brilliant.*
>
> -Patient

- Other reasons for signing up included perceptions that NeuroResponse was easier to access (19%) or that it was more specialised/knowledgeable than other services (16%). It was also important for some patients that NeuroResponse is available at any time (16%).

> *[When I first heard about NeuroResponse, I thought] "it's about time"*
>
> -Patient

# Signing up to NeuroResponse is a straightforward process for patients

Nearly all survey respondents (78%) agreed that their experience of signing up to NeuroResponse was simple and straightforward, although a few felt that the registration process could be made easier.

- The majority of survey respondents (66%) had signed up to NeuroResponse within the last year.
- To sign up, respondents go through an online portal. The NeuroResponse team can provide support with this process if it is required.
- Support can be required due to technical issues when using the portal or challenges relating to a person's MS
- While the people we spoke with indicated that generally support was not needed, 44% of patients reported interacting with the NeuroResponse team when they signed up to the service. Furthermore, the people we spoke with told us they sometimes needed support from NeuroResponse when using the service.
- Interactions with the NeuroResponse team during the sign up process were nearly always by email (93% of all interactions). Of the three patients who had been in contact with the team by phone, all had used multiple channels of contact (either email and phone, or in person and by phone).

To what extent do you agree or disagree that the signing up process was simple and straightforward?

*(n=32)*

> *I signed up immediately, but I had initial registration problems which needed tweaking at the [NeuroResponse] office end. Just teething problems with setting things up, everything needed was quickly put right.*
>
> \- Patient

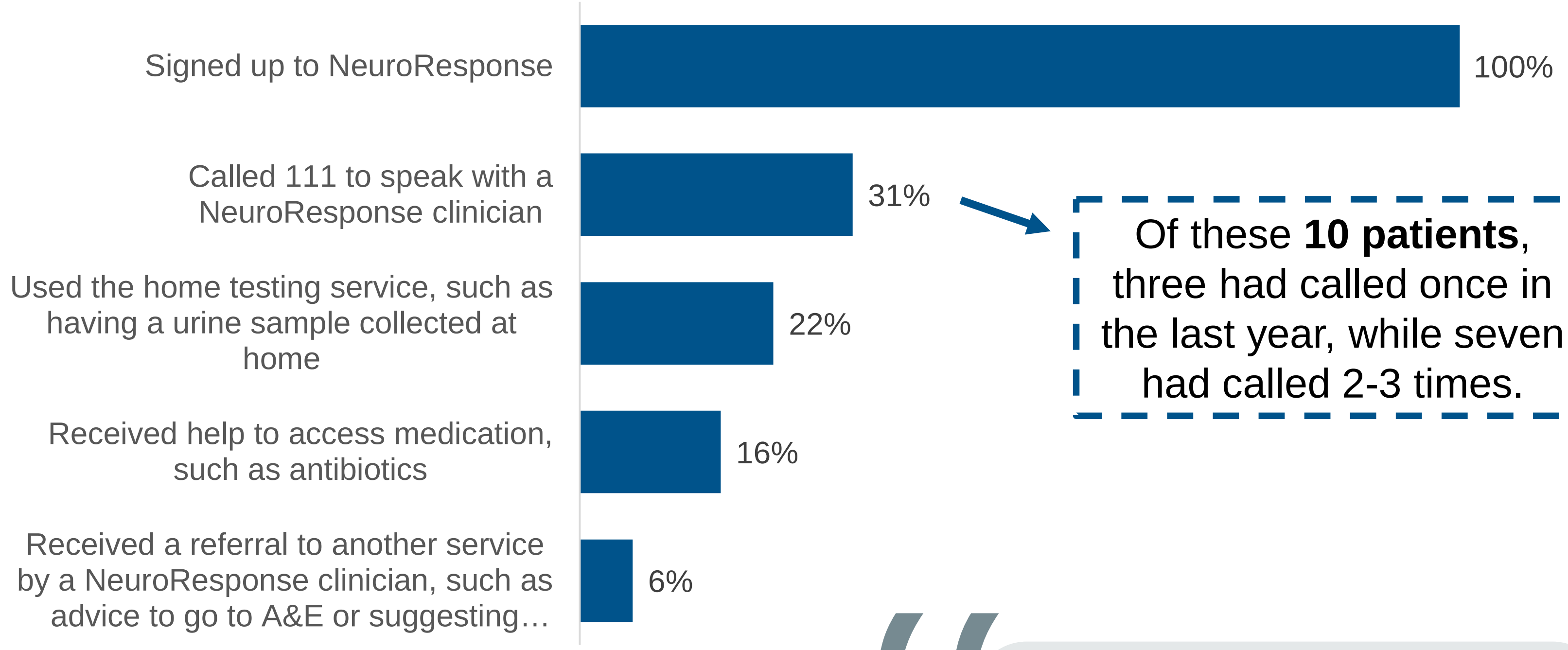
> *I emailed the info email address and said "should I sign up, this is my situation" and they said yes. I then signed up and it was fine.*
>
> -Patient

> *While I didn't need any help with sign up, I know [the Clinical Lead] supported those people in my MS group who didn't have computers.*
>
> -Patient

# Using the NeuroResponse service

Nearly a third of those signed up to NeuroResponse had used the service (31%). Sometimes patients received additional support to help them use the service. For example, a family carer we spoke with told us that they had received support in-person to use the service during a home visit.

## In what ways have you interacted with NeuroResponse so far?



*(n=32)*

Of these **10 patients**, three had called once in the last year, while seven had called 2-3 times.

> *I was confused about how it worked at the point of sign up, I didn't realise it was so luxurious. But as you get more involved, it's a very clever scheme*
> -Patient.

> *[The Clinical Lead] was there, the first time we [used NeuroResponse], I remember she was in the background saying "okay so this is what you say now" she took me right through it, [which was] very helpful*
> -Family carer

Respondents who had called 111 were asked why they chose to use NeuroResponse over another service.

3 respondents said it was because NR was **available out of hours**

3 respondents said it was because NR was **the most appropriate service for UTI/relapse**

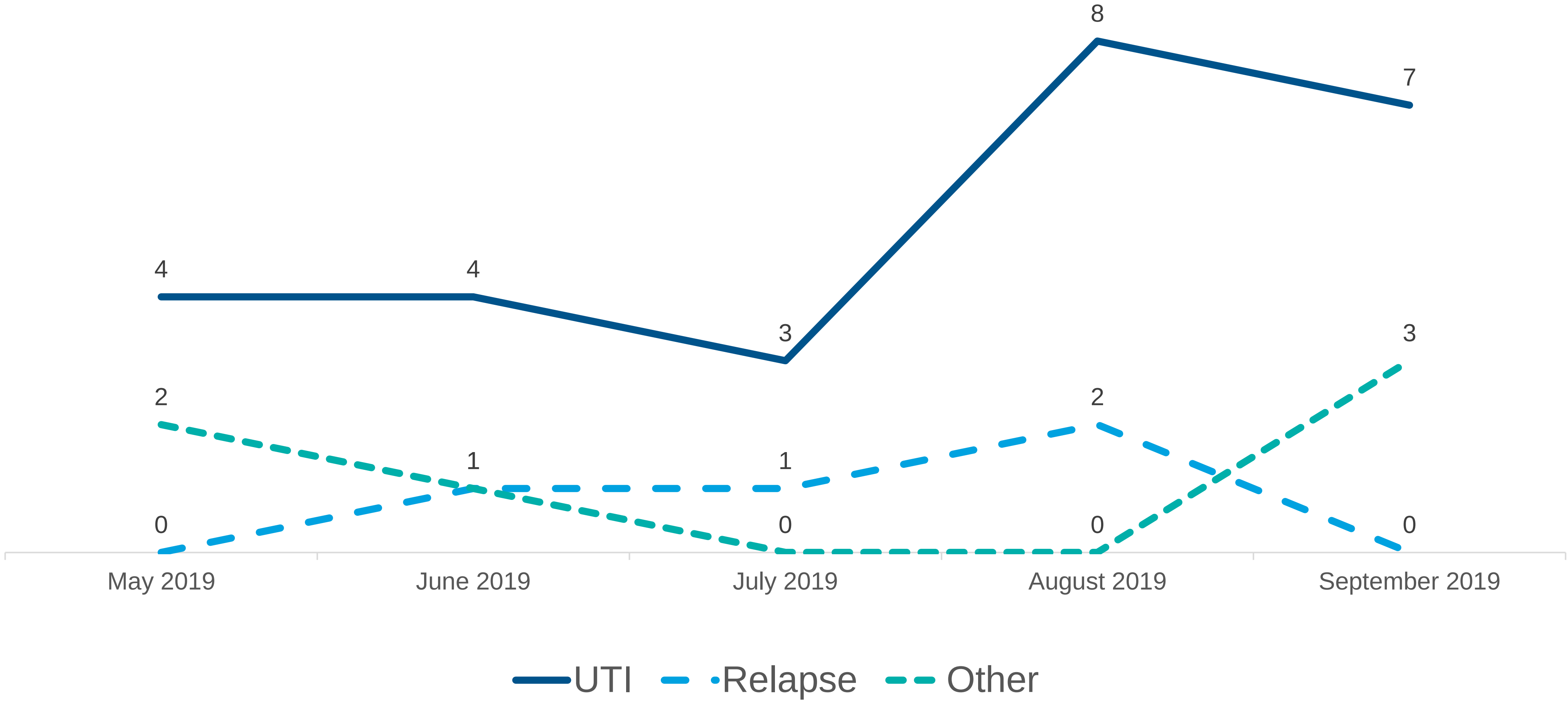
2 respondents said it was because NR was **easier to use/more accessible than other services**

2 respondents said it was because NR was **faster than other services**

*(n=10)*

# Most NeuroResponse calls currently relate to UTIs

As presented below, service use data shows that most service interactions between May and September 2019 relate to UTI symptoms (between three and eight calls per month). A small number of patients (up to two) also use the service each month to support with a suspected relapse, or to get support with another concern.

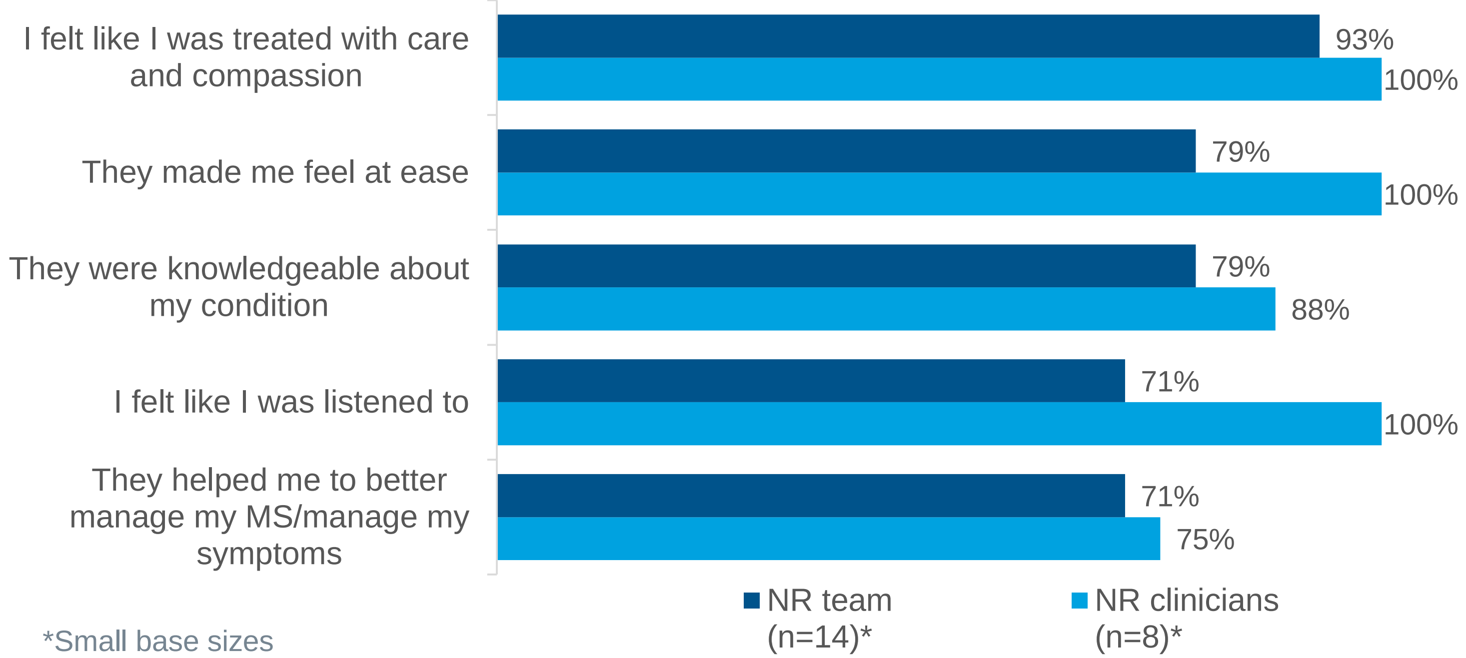


- 21 of the 104 patients who were signed up with NeuroResponse called the service at least once between May and September 2019.
- In total, these 21 patients contacted the service 50 times in this time period.

# Respondents feel that NeuroResponse staff and clinicians treated them with care

Patients come into contact with the NR team when they need support with signing up to the service. Once signed up, they are put through to a NeuroResponse clinician when they call 111. Experiences with all staff were very good – people with MS felt they were treated with care and compassion, and made to feel at ease. Staff were generally knowledgeable about MS and listened to what patients had to say, and they were often able to help them manage their symptoms.

Agreement with statements about the NeuroResponse team and NeuroResponse clinicians*



*Small base sizes

71% also felt that they were able to **tell their story to the NR team**

Interviews with people with MS and their carers similarly found that people have a positive experience with NeuroResponse staff and clinicians. They reported that they felt they were listened to and treated as experts by NeuroResponse. They also felt that they were being given a personalised service.

> *I felt I was treated as an individual and I wasn't put into a category. I was treated as a person and an individual, and that made so much difference*
>
> -Patient

> *Everybody was kind, they listened, took note of what I said, and trusted that I had all the information that they needed to deal with me.*
>
> -Family carer

# NeuroResponse clinicians solved patient issues in the majority of cases

Of the seven respondents asked about the advice they received from NeuroResponse clinicians, all but one had a urine sample collected from their home. One was also visited at home by a GP and one had an ambulance dispatched for them. In total, five of the respondents reported that the NeuroResponse clinician solved the issue(s) they were having.

- All of the respondents who reported the NeuroResponse clinician to have solved their issue were those that had supplied urine samples
- This is unsurprising as the service primarily deals with UTIs and could arrange antibiotics to be delivered to patients according to their results
- The symptoms of the patient who had to go the A&E in an ambulance were not indicative of a UTI – they required hospital treatment, therefore the NeuroResponse clinician would have been unable to solve their problem directly. However, the patient praised NeuroResponse for reacting quickly
- Just one of the respondents who had supplied a urine sample did not have a positive outcome – this was due to a reaction they had to antibiotics they were prescribed

- Findings from qualitative interviews corroborated the survey results – for patients with UTIs, NeuroResponse was the most appropriate option due to the speed with which they could react
- Using NeuroResponse also means that UTIs can be addressed before they progressed to the point that hospital treatment was required. This is important as hospital admittance is considered a *“big risk”* by some, as it can negatively impact a patient’s health in other ways
- NeuroResponse also provides reassurance to carers who are familiar with the condition of their friend or relative. They can send a urine sample at any time of the day or night if they suspect a UTI, rather than struggling to contact a medical professional and potentially ending up in A&E during out of hours

> *It was very helpful as it was my first UTI and I felt this was understood and it took away my anxieties.*
>
> \- Patient

> *Most appropriate service for UTI or relapse.*
>
> \- Patient

# Experiences of using NeuroResponse are very positive overall (1)

**Overall experience of the NeuroResponse service**
Average score given by users of the service, where 0 is very poor, 10 is very good.

**8.6**

(Small base size, n=8)

**+63%**

**Net Promoter Score (NPS)***
Measurement of overall satisfaction with the service based on willingness of service users to recommend NeuroResponse to a friend or colleague, where 0 is not at all likely and 10 is very likely.

(Small base size, n=8)

## Key benefits of NeuroResponse for people with MS:

### Accessibility

Leaving the house can be challenging for people with MS due to fatigue and mobility limitations. NeuroResponse means patients can receive care from home rather than going to their GP.

### Consulting patients and carers

People using the service feel that they are at the centre of the care provided – clinicians trust them, listen to what they have to say and provide appropriate treatment accordingly.

### Service quality

NeuroResponse clinicians are knowledgeable about MS and its symptoms, and they are available at any time. People with MS felt like they were treated as individuals, which doesn't always happen in other health care settings.

### Reacting with speed

NeuroResponse means that patients can provide urine samples and get their results faster than when they go through their GP, which requires the completion of paperwork and another follow up appointment with the GP for the results.

One of the District Nurses interviewed similarly emphasised the importance of NeuroResponse's speed, due to delays in the current pathways available in the area, which meant a longer wait for results**. Before NeuroResponse, the only way to get a sample tested quickly was by physically going into the local hospital**.

---

*NPS is calculated by subtracting the proportion of detractors from the proportion of promoters. Detractors are respondents giving a score of 0-6, passives give a score of 7-8 and promoters give a score of 9-10. NPS can be positive or negative, and is a useful measure for tracking performance over time.

# Positive feedback from patients and carers (2)

## Accessibility

NeuroResponse is planning to release a patient app in the near future which will allow patients to navigate the service through their smart phone, providing another way to remotely access support.

> *It gives [people with MS] a great deal of peace of mind that they don't have to make an appointment at their doctor, which can take forever, and it's not the easiest thing to go and see the doctor [for some people with MS].*
> - Patient

> *I didn't have to go to my doctor which is very challenging, as I have to call dial a ride.*
> - Patient

## Service quality

> *If anything, slightly better [than I expected]. It's just incredibly responsive, relative to the rest of the NHS.*
> - Patient

A commissioner reinforced this view, noting that the service was innovative because it was highly user-centric compared to other services available to people with MS.

> *They're there on a Sunday night, they're there all the time. It's good. You could think that you're rich.*
> - Family carer

## Consulting patients and carers

> *Its hard when someone is bedbound and hides their illness. I have to advocate for him…previously my expertise wasn't taken into account.*
> - Family carer

> *Everybody was kind, they listened, took note of what I said, and trusted that I had all the information that they needed to deal with me.*
> - Patient

## Reacting with speed

> *Responding speedily to needs to those suffering MS. It is an excellent addition to the other services provided.*
> - Patient

> *One of the frustrating things about having a UTI is you give your sample in on a Monday to your GP and quite often you don't get the results back until the following Monday. And so it's very delayed…So I thought 'NeuroResponse will be faster and more responsive', and they are.*
> - Patient

Several NeuroResponse users also pointed out that they **felt NeuroResponse was "personalised" to their needs**, whereas other services often only provide generic treatment that is not tailored for people with MS. This view was supported by a commissioner involved with the service.

# However, several areas are highlighted which could further improve the NeuroResponse service (1)

**Overall communication between patients and NeuroResponse**

Several people reported challenges relating to communication between themselves and NeuroResponse. For example, one individual knew that NeuroResponse had sent information to their GP but did not know what it contained. Another had experienced results not being sent to their GP due to perceived miscommunication, while one patient wasn't sure who at the IUC service had access to their information as a result of signing up. Some also mentioned being unsure about how specific aspects of the service worked. Patients felt they would ultimately benefit from receiving more information during the sign up process about some areas of the service, such as who could see their medical information when they call 111 and whether or not they needed to re-order urine testing kits, as well as more clarity on the service as whole.

> *The onboarding could be improved. Like, for instance, I'm not really sure whether I should be reordering my urine testing kits or if they come to me automatically after I've used a couple of them, I've just had no information about that. So the onboarding, the processes could be explained better.*
>
> \- Patient

**Clarity on what the service offers**

Some patients were unsure about what they could call NeuroResponse for other than UTIs, and there appeared to be disconnect between what patients were being asked and what they themselves knew. For example, one individual was asked if he had tested his urine using a dipstick as the expectation of the IUC GP was that they had been provided as part of the NeuroResponse registration, but he had not been provided with any of the testing kits. There was a general lack of understanding around whether they could call NeuroResponse with general concerns relating to their MS and it was felt that they would benefit from clearer information on this.

> *The one thing that was probably suboptimal about it is there is very little information about what the service does or is. And actually user instructions are minimal. So there are lots of instructions on how to use the urine testing kit. But if you look at the website, it suggests you can get help with other aspects of MS. But I'm not quite sure what NeuroResponse service offers other than phenomenally quick bladder infection testing.*
>
> \- Patient

# Suggested improvements for NeuroResponse (2)

**Awareness among 111 call handlers and medical professionals**

An issue observed by some people who used the service was that the NeuroResponse clinicians were unavailable out of hours when calling 111, and the call handlers and out of hours GPs were not always familiar with the service. Patients also indicated that medical professionals they were in contact with did not always know about the service and felt it would benefit from more promotion among this group, so that they could recommend it to other people with MS.

In response to feedback and as part of ongoing service improvements, a 3-part e-learning module was developed and made available to GPs in September 2019. This is now a mandatory component of GP inductions and LCW is working with existing GPs to make sure they have completed the training to manage NeuroResponse cases. This should help to improve awareness among those supporting NeuroResponse cases.

> *Make 111 doctors aware of Neuro Response after hours. My experience with 111 spanned several hours - too long! After 6pm I was dealing with different people. They had no idea what NeuroResponse was.*
>
> - Patient

**Access for people outside of Barnet**

Another individual reported issues with NeuroResponse's Barnet catchment area, which meant that those living just outside who attended the Barnet MS meeting knew about the service but were unable to access it due to their address. It was felt that the geographical scope was not clearly defined and so people with MS who could benefit were missing out. They suggested broadening the area within which people could sign up, and making this clearer to patients.

> *People come to Barnet meetings but they're not based in Barnet. So you learn about the service, and access services in Barnet, but you're not able to use it. It would be great if there was some way you could access it, even if only through a compromise approach.*
>
> - Patient

**Difficulties updating patient records**

One individual felt it would be helpful if the 111 medical records could be updated, after they experienced a relapse and needed treatment to be added to their personal record. They suggested that the service could be improved by allowing people who are registered with NeuroResponse to update their own record, or enabling IUC professionals to update it.

> *I would like the ability to update my own record or have 111 update it.*
>
> - Patient

# Systematic challenges for NeuroResponse

### Teething problems

NeuroResponse in Barnet has been running for around a year. Some patients noted that there had been issues during this period which were still being ironed out. This included difficulties with the registration portal which had required “tweaking” by the NeuroResponse team, and a lack of familiarity with the service among 111 call handlers and GPs covering 111 out of hours. Despite this, users of the service were generally understanding about such issues due to the service being relatively new. Fundamentally, **NeuroResponse was felt to be a valuable addition** to the services already available to people with MS and therefore experiencing teething issues did not deter patients from using it.

> *On both occasions I felt after dialling 111 it took time to be put through to a clinician most appropriate for my condition despite the fact that it was explained to me that my mobile number was on a specific list to indicate I was a NeuroResponse patient when I called. I know it is early days and once sorted it is an amazing service.*
>
> - Patient

### Variable experiences

An issue mentioned by patients who have used NeuroResponse on multiple occasions, and which is corroborated by IUC GPs, is that the level of service can vary considerably. For example, for one patient their first use of NeuroResponse was very positive, but the second time round they found it challenging to get hold of their results after being told they would receive a call and never getting one. Conversations with IUC GPs substantiated this view, due to the challenges relating to the system they use which created duplicate cases and the lack of training (see slides 35 and 37).

> *I feel as someone who is quite informed…I can work my way through the system. I think if I was less activated as a patient I would be a bit frustrated by the process and not quite sure how to deal with it where the system isn’t quite working, whereas I can push it through. So I think the consistency and standard of treatment and process could probably be tightened a little bit.*
>
> - Patient

# Staff experiences of the service

# Introduction

This section describes the experiences of professionals involved in NeuroResponse, including the NeuroResponse team, IUC GPs, and other clinicians who have experience of the service, based on qualitative interviews. It focuses primarily on the experiences of delivering the service in Barnet, but also considers challenges and lessons learnt in the pilot study in Camden.

The findings presented in this section are based on interviews with:

- 1 member of the NeuroResponse team
- 4 IUC GPs
- 1 District Nurse
- 1 GP

# Delivery staff experiences

We spoke with four IUC GPs who have delivered the NeuroResponse service. Their level of understanding of the service varied. However all respondents had dealt with a fairly low number of NeuroResponse patients (between one and eight people each). All of the cases that the IUC GPs had dealt with related to a suspected UTI. We also spoke with two medical professionals who had been involved in the Camden pilot.

- Overall, the IUC GPs interviewed felt that the NeuroResponse process was "**a good process in theory**", although they identified several challenges in delivering the service in practice.
- Interviews with the Clinical Lead of NeuroResponse and health professionals in Camden suggest that **many of the challenges that the GPs are experiencing currently are related to the service being new**. For example, a district nurse in Camden mentioned "teething problems" with the NeuroResponse pilot in Camden, which were resolved over time. Additionally, the small scale of the service can also explain some challenges. The NeuroResponse Clinical Lead noted that people are not completely familiar with the process because the service is at an early stage, and the small scale means staff don't have that many opportunities to become more familiar with it.
- One of the IUC GPs interviewed stated that "the process normally works well" and felt that **patients were normally dealt with appropriately.**
- While patients are occasionally sent to another service after speaking with an IUC GP, including A&E, it was felt that these referrals are normally appropriate. However, occasionally it was felt that referrals to other services were unnecessary and constituted a duplication of efforts.
- Several GPs highlighted other current challenges with delivering the service, which are explored in more detail in slides 34-38. For example, they reported that patients were contacted unnecessarily, due to the requirements imposed by the system. The NeuroResponse Clinical Lead noted that this is because the system is designed to be risk averse during the pilot stage, and this will be reviewed as the service develops.
- There were **mixed reports on how well the different parts of the service are working together**, including the links between the GPs, the laboratory and the couriers.

> *Dealing with [the process] is fine…arranging the couriers etc. is fine*
> - IUC GP

> *The service has good intentions and will be good when everyone is on board and patients are on board*
> - IUC GP

> *In theory it would work well but there are some major barriers which prevent it from being effective*
> - IUC GP

> *The thinking behind it is in the right place*
> - IUC GP

> *While it can be confusing, I do think the process makes sense in theory*
> - IUC GP

> *I do think it's working well, we just need to sort out IT teething issues, and increase training provision*
> - IUC GP

# Key challenges faced by IUC GPs in delivering NeuroResponse

- Level of training
- Level of specialist MS knowledge
- Technical issues
- Understanding the process

# Level of training

**The NeuroResponse Team provided a dedicated training session to IUC GPs**, which all the GPs who would be delivering NeuroResponse were invited to. Two leading experts helped to develop this training session, which covered both neurology and microbiology. The training provided detail on how to manage cases and notified GPs of the on-call support that GPs can access if they have any specific concerns or have specialist questions that they cannot answer. Those who attended were provided with a certificate of attendance which goes towards professional development.

Four GPs attended this session. For those who were unable to attend, a video of the educational session was uploaded to the GP portal and policy documents were circulated. In addition, all GPs working in the IUC service received a summary document outlining the NeuroResponse process and support available in managing MS during their sessions. However the **GPs interviewed for this project did not appear to be aware of these resources,** or did not believe they had access to them. The Clinical Lead noted that there had been a recent increase in recruitment, and as such many of the GPs were new to the service and could have been in their induction period. This may help explain their lower level of familiarity with NeuroResponse.

Two of the IUC GPs we spoke with had attended the training session in person. One felt this had been **"very useful induction**", as it explained why the pilot had been rolled out, explained the GPs' role in delivering the service in ensuring that patients get antibiotics (if needed) in a timely fashion, and explained who to call if there were any issues. However, they noted that only a "handful" of GPs attended this, which reduced its effectiveness.

The second IUC GP who had attended **felt that she still needed further practical information explaining how to deal with cases**. Her perception was that no formal training has been offered for this aspect of delivering NeuroResponse, and she also did not feel she had received sufficient support from her manager when she had raised queries. The two GPs who had not attended the training had similar views; they felt that a clearer induction was needed, with training "from the ground up", explaining what the service is and how to practically deal with each case.

One participant highlighted that a particular barrier to completing training was their perception that they were **expected to do training in their own time** (both for NeuroResponse, and more broadly within the wider IUC service). Due to the long shifts that the IUC GPs work, it was felt that they did not have sufficient free time outside of working hours to complete this.

The **level of training was seen as a significant issue by all participants**, with some highlighting this as the main challenge in delivering NeuroResponse.

As described on slide 30, NeuroResponse have **already taken steps to improve their training provision** and ensure that all current GPs have completed this training. There are future plans to develop this further to create a formalised accredited course with the Royal College of General Practitioners and the Royal College of Medicine.

# Level of specialist MS knowledge

Several IUC GPs highlighted that they were **not confident in dealing with a suspected relapse**, due to a lack of specialist knowledge about MS. Some felt there **should be additional training provided** to improve their ability to support with this, although as described on slide 35, it is not clear if the GPs we spoke with were aware of all of the NeuroResponse training that is already available.

> *I know how to support patients clinically, in terms of ensuring their safety, but I lack [MS-]specific knowledge*
> - IUC GP

However, one GP had understood from the training session that most relapses would require hospitalisation, so the **IUC GP role was mainly focused on suspected UTIs**. She noted that she would be "a bit hesitant" to get involved in relapses. She felt that if they were required to provide further specialist support, such as prescribing specialist medication, this would be beyond their level of competence and would cause further challenges in delivering the service.

> *Patients may have lots of questions, but we are not experts*
> - IUC GP

For support with a suspected UTI, a person with MS highlighted that the level of specialist knowledge of the NeuroResponse clinicians was not important to her; rather she simply wanted someone who would listen to her.

# Technical issues

IUC GPs highlighted that **multiple case numbers may be generated for one patient interaction**. One IUC GP explained that, if a patient calls back once an initial case has been generated, this will generate a second, separate case. From our discussions with the IUC GPs, it appears that it is not currently possible to link cases that apply to the same patient.

Similarly, while cases should be in a dedicated queue, occasionally in practice they sometimes "pop up" elsewhere, such as the out of hours GP list.

There also appears to be **poor visibility of previous interactions with a patient**. More broadly, there is a perceived **lack of access to patient data**. GPs were uncertain whether this was due to an issue with the system, or whether this was related to patient consent.

> *It could be more efficient if you could see the past information*
> - IUC GP

GPs reported that the inability to link cases and lack of visibility of previous interactions means that, in some cases, it is unclear whether a patient has been dealt with. This can lead to **duplication of efforts**, as each case number is followed up separately.

Some GPs also felt **concerned that they might not be aware of the patient's full medical history**, including information that is relevant to prescribing decisions such as allergies, although the NeuroResponse team clarified that allergy information is recorded within care plans.

GPs reported experiences of other technical issues, such as **difficulty finding and accessing passwords** to access the system.

A medical professional involved in the pilot study in Camden highlighted that they had also experienced some initial technological difficulties around the 111 service, such as people not being put through to NeuroResponse when they called 111, however they viewed these as **teething problems, which were resolved over time**.

> *There's no way of finding out what the previous doctor has done, because each interaction has a different case number*
> - IUC GP

# Understanding the process

The IUC GPs reported that they, and many of their colleagues, **found the system confusing**, and at times were not fully aware of what the service consisted of or how it worked. For example, one participant explained that she was not clear on how patients were redirected to NeuroResponse after calling 111. She tried to investigate this, but struggled to find an answer. Only one appeared to fully understand the system – and reported that this had “taken a while”.

Relatedly, participants reported a **lack of awareness** of the process among IUC GPs, and more broadly, a lack of awareness of the service both within the IUC service and among staff in other local services, including GPs and hospital consultants.

Some participants felt that **the multiple stages of the process made it confusing**, and were not always clear on the purpose of the different stages. One GP noted that it is unusual for IUC GPs to have so many interactions with each patient, which may help to explain this view.

Some participants also felt that **too many people were involved in the process**. One noted that the IUC GPs do not directly receive laboratory results, which can creates a barrier to following up with the patient.

**Insufficient communication** within the service and between the service and other services may contribute to the confusion and lack of awareness. For example, one IUC GP reported being told that they would be taking on Camden patients as well as Barnet patients, but they were not informed about why this change was taking place or whether it would have any impacts on the patient pathway, while another IUC GP reported a lack of communication between services, for example between NeuroResponse and local GPs.

**Technical issues,** such as the generation of multiple case numbers for one patient and a lack of visibility of patient history, appeared to make the system more difficult to understand.

Similarly, a **lack of training** appeared to exacerbate existing confusions. A medical professional involved in the NeuroResponse pilot in Camden emphasised the importance of raising awareness of the service among GPs, suggesting training as a key means of doing this.

The NeuroResponse Clinical Lead noted that the NeuroResponse team have already reviewed the system and are in the process of creating plans for a simplified process, which should help to address this issue.

# 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

# Impacts of easier access to support

- NeuroResponse is more accessible than many other health services in that it does not require people to attend a service in person, and it is available at any time of day.
- People with MS also told us **how difficult it can be for them to access some health services**, such as getting to the GP or going to a walk-in clinic, due to mobility issues.
- This was a particularly difficult and frustrating experience for people when they knew that all they needed was to get a prescription for antibiotics, and when they were in pain.
- Furthermore, some people also highlighted that **attending health services in person can negatively impact people with MS in other ways**. One person told us that she felt very vulnerable when going to the GP or hospital because of the severity of her condition, while a family carer told us how her Dad's health has been negatively impacted when he has gone into hospital in the past.
- Similarly, a medical professional involved in the Camden pilot noted that hospital admissions can be traumatic for both patients and carers
- Further, a person with MS highlighted that the long waiting times at other services can impact other areas of their lives, such as interfering with work.

> "*The hospital is a big risk [for my Dad], it's not their fault, they're doing absolutely everything they can, they just don't have enough time [to take care of him properly]*
>
> - Family carer

> "*[When you've got an infection, the last thing you want to do is to have an argument with a surgery receptionist to try and get an urgent appointment, you just want it dealt with, you want to find out what the problem is.*
>
> - Patient

> "*The timeliness and responsiveness – it's much faster. Trying to see a GP, you either have an emergency appointment on the day or you wait a month…It means I don't have to take time off work, so I can continue working, I don't have to hang around trying to get to the GP."*
>
> - Patient

> "*[Before NeuroResponse] I had to sit for hours in a walk in clinic…in agony, when I know that all I need is antibiotics.*
>
> - Patient

# Impact on health

Some people mentioned how NeuroResponse had positively impacted their health, or the health of a family member. Health impacts were related to the more targeted and faster response that NeuroResponse is able to offer compared to other health services.

A commissioner familiar with the service suggested that the positive impact on the health of people with MS was because NeuroResponse catered for them at both a clinical and an emotional level. They feel reassured that the GPs understood their condition, thereby reducing their level of anxiety about their care. The commissioner felt that this level of care had developed and improved as the service evolved.

> *They are emotionally catered for and their practical needs, clinical and emotional needs are met.*
> - Commissioner

> *[If NeuroResponse hadn't been available] I would have waited until the GP was open, at which stage I would have been seriously ill.*
> - Patient

> *I've got treatment faster, and more targeted treatment faster, so they actually know the bug that they're actually trying to deal with, which is good.*
> - Patient

> *If NeuroResponse had been available earlier… I think it would have helped reduce the deterioration in my Dad's health.*
> - Family carer

# Impact on wellbeing

People with MS and their families told us about the reduced stress, increased peace of mind and increased confidence that they, or their friends or relatives, have experienced through being able to sign up with NeuroResponse.

Similarly, the two medical professionals involved in the Camden pilot who we spoke with noted the impacts of NeuroResponse on carer wellbeing, with one suggesting this is the most significant impact of the service.

> *"I'm incredibly grateful that I've got this, I think it has made a big difference to my confidence and wellbeing .So there's a physical side but there's also a security side to it which has significant benefit. I feel much more confident, because I seem to be getting a lot of UTIs at the moment, and I feel I'm getting the responsive treatment I need. And that's a function of NeuroResponse."*
>
> \- Patient

> *You listen to people who have had problems and they've been able to use it. The fact they can get things done so quickly makes an enormous difference, and gives enormous peace of mind*
>
> \- Patient

> *It's a lifesaver…"I can send the sample at half ten at night…otherwise I'd be kind of panicking and trying to get in touch with the nurses."*
>
> \- Family carer

> *It's made me more confident, at weekends, that I can get help.*
>
> \- Patient

> *This is so, so clever, it just takes so much aggravation and concern away from people, and that's half the difficulty. When you're upset about something it escalates and you get into a situation of thinking everything's falling apart…it's a circle that explodes. Whereas this response line actually is so clever, it takes away so much of the frustration.*
>
> \- Patient

# Empowering patients and carers

> *Everybody was kind, they listened, took note of what I said, and trusted that I had all the information that they needed to deal with me*
>
> \- Patient

Patients and a family carer described how NeuroResponse staff listened to them, and treated them as experts on their own, or their family member's, health.

**Case study:**

- A person with MS explained that she had used the NeuroResponse service due to a suspected urinary tract infection.
- She did a urine test and the results were negative for an infection. However, based on her symptoms, she believed that she did have an infection and needed treatment.
- The doctor she spoke with accepted her judgement and agreed that she should take antibiotics.
- It was later confirmed that she had an infection which was missed in the original test.

> *I think one of the key things is to empower patients, activate patients, to be able to self manage as far as is possible. And NeuroReposnse absolutely helps me do that, it helps me continue to catheterise and continue to be active*
>
> \- Patient

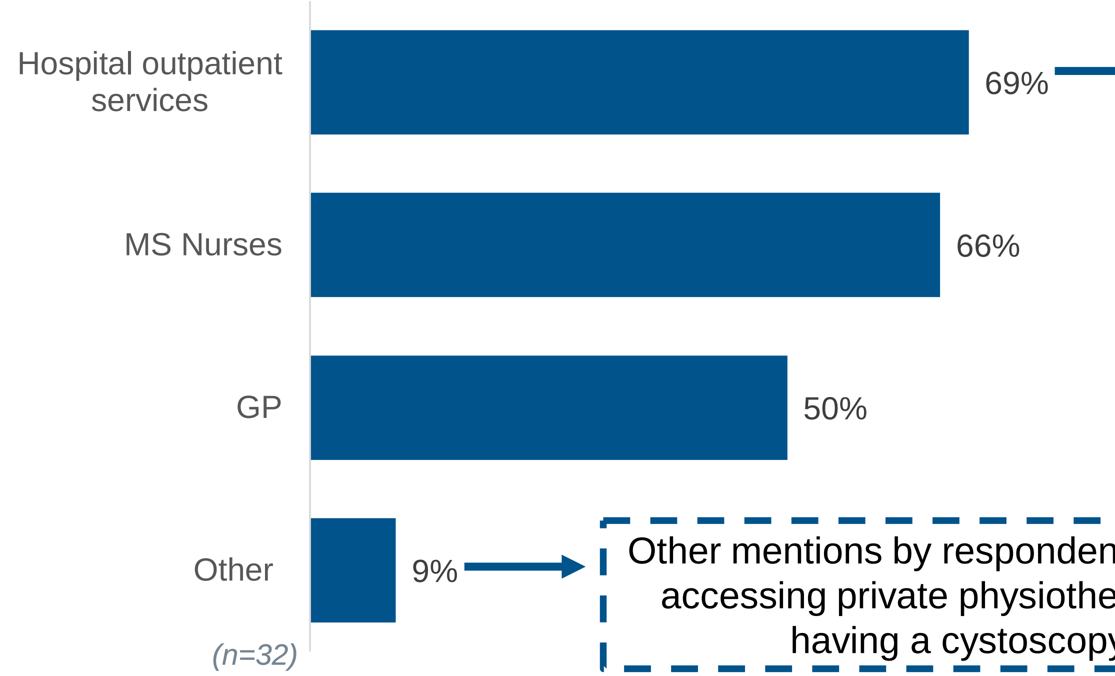
> *I was treated as a person and an individual, and that made so much difference*
>
> \- Patient

A medical professional we spoke to who had experience of the pilot study in Camden similarly felt that NeuroResponse can empower patients by enabling them to take more control over their own care.

# Highlighting unmet needs

- A medical professional we spoke to who had experience of the pilot study in Camden felt the one of the impacts of NeuroResponse was identifying unmet needs in the community, including carer needs. Similarly, the Clinical Lead of NeuroResponse noted that they have been able to identify carer needs and wider psycho-social issues, including poverty. They have worked with regional welfare officers to apply for grants to get support where these issues are identified.
- We asked survey respondents what health services they were using and whether they felt they had any unmet needs. Most people did not report any unmet needs. Among the unmet needs raised, NeuroResponse may be well placed to address some, such as clinical questions about MS symptoms, but not others, such as lack of access to medication.

## Are you using any other health services in relation to your MS?



Where specified, these generally referred to annual **hospital appointments with consultants / neurologists.**

Other mentions by respondents included accessing private physiotherapy and having a cystoscopy.

> *The problem with MS is your complete lack of certainty about your future…you have an individual trajectory that no one can predict or help. It means everybody's got a lot of questions, because you can't look it up on the web and see what's going to happen next. So when something happens, you're worried: Is this MS, is this something different? I think it's really important that people with MS are able to have access to medical advice about specific symptoms and episodes on a timely basis, and I don't think the NHS is very good at providing that. Now maybe NeuroResponse is well placed to provide this because you can phone up and ask about it.*
>
> - Patient

**The majority (75%)** felt that the health services they were using **met their needs**.

Those who felt the health services they were using **did not** meet their needs provided a range of reasons: awaiting referral for disease modifying therapy (DMT); the lack of treatments available; not receiving sufficient physiotherapy; recurring issues with infections; and the lack of visits by the MS nurse.

# 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

# Reducing strain on other health services

Survey respondents that had used the service were asked where they would have gone if NeuroResponse had not been available.

The majority (7 out of 10) said their local GP, and one said A&E.

This suggests that **NeuroResponse could have a positive impact on efficiency**, by reducing the need for people with MS to see NHS health professionals face-to-face to obtain medication for issues such as UTIs.

The people we spoke with similarly felt that NeuroResponse had reduced their use of their GP or emergency services.

Medical professionals who were involved in the pilot in Camden similarly felt that NeuroResponse could have a positive impact on other services. For example, one noted that it had a positive impact on community nurses by reducing the number of visits they need to do.

However, this person also highlighted that NeuroResponse could create additional work at times, where people with MS or their carers were over-cautious. Through learning more about how to manage their condition, however, she felt this could be addressed.

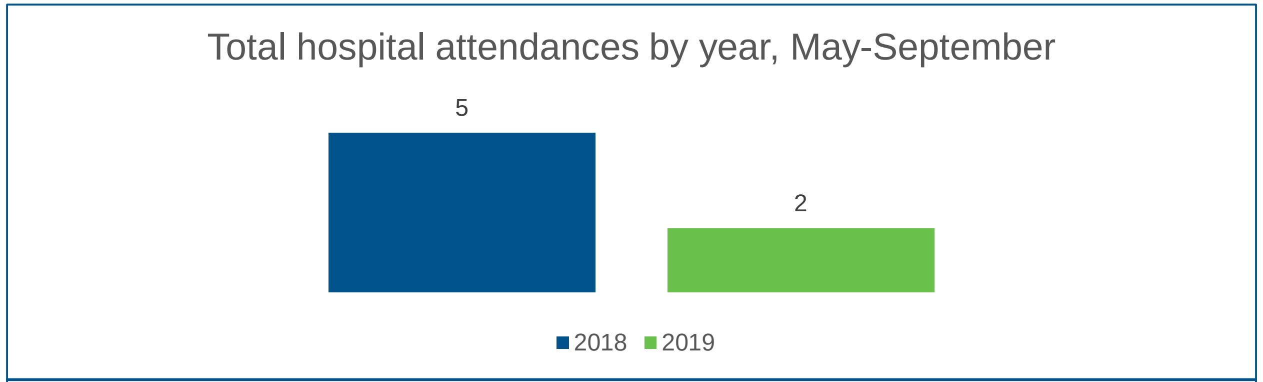
> *[Before NeuroResponse, my Dad] was sick every 6-8 weeks [and would need to be hospitalised]. Now it's only twice a year.*
>
> - Family carer

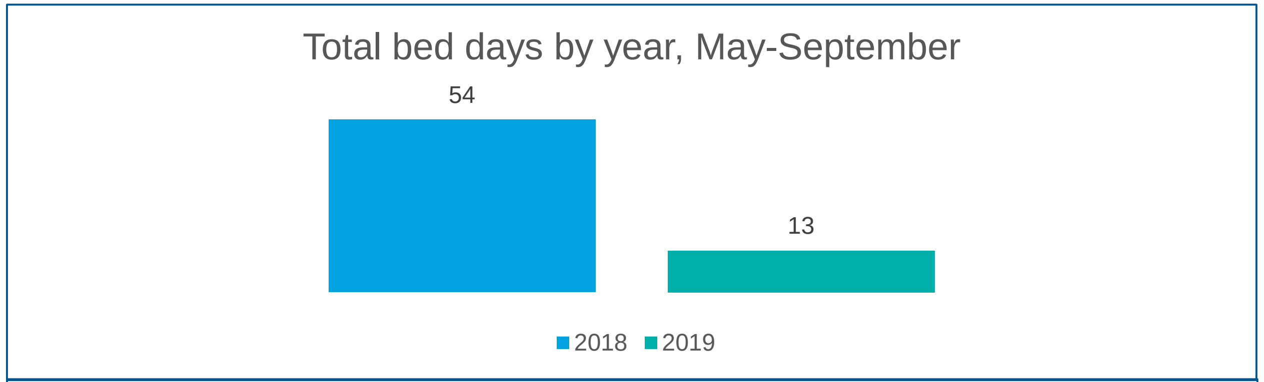
> *"I've had four or five urine tests done through NeuroResponse. They would all have involved a trip to the GP surgery, dropping off the sample, having a call with the GP. I would have gone to the GP each of those times, so it's averted those each of those times.*
>
> - Patient

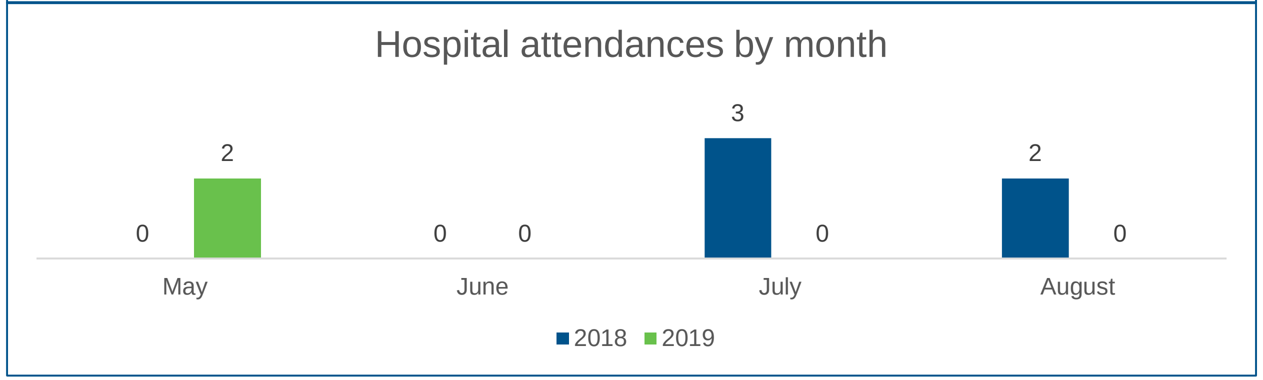
> *I will use the team when I next have any problems. Sometimes I get a chronic movement and pain problems at the base of my spine. I have been to my GP as when I phoned the MS nurse and physio they were clueless even though I was in chronic pain and couldn't move well. I went to my GP rather than A&E, but next time I will call NeuroResponse for help.*
>
> - Patient

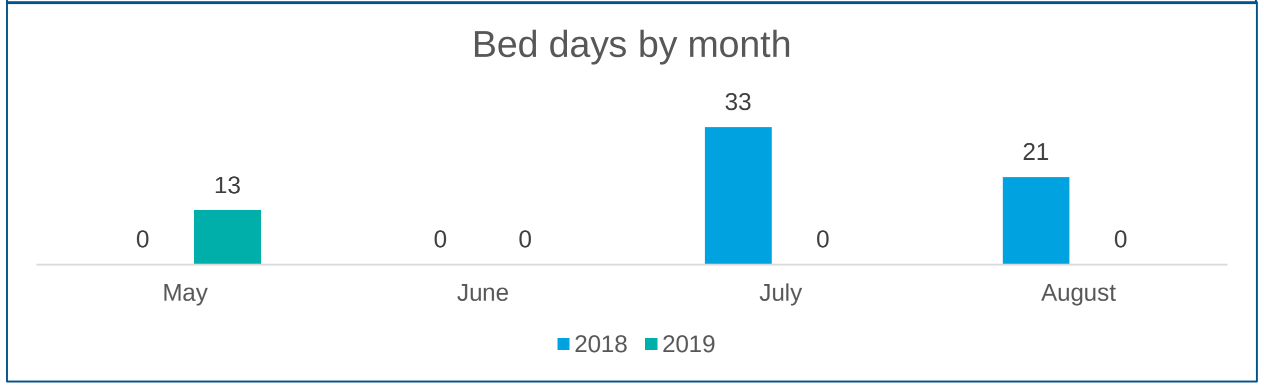
# Impact on unplanned hospitalisations

NeuroResponse provided us with HES data for May to September 2018 and 2019. This data includes people who are registered with a GP within the Barnet CCG and attended the Royal Free London NHS Foundation Trust. The hospital attendance data shows those who have presented into secondary care with a primary diagnosis of ‘MS’ and symptom code as ‘UTI’. The graphs below show the total number of hospital attendances, which refers to the number of times that a patient presented at A&E, and the total number of bed days, which refers to the number of days that the patients stayed in hospital following an A&E presentation.


Total hospital attendances by year, May-September


Total bed days by year, May-September


Hospital attendances by month


Bed days by month

As the data shows, there were a **lower number of both hospital attendances and bed days in Barnet among people with MS for UTIs in 2019 compared to 2018**. While it is not possible to determine a causal link between the introduction of NeuroResponse and these changes due to the small size of the population, this appears to be a positive development which is in line with NeuroResponse’s aims.

# Impact on unplanned hospitalisations: case studies

Based on HES data and service use data, we can see that NeuroResponse has reduced the number of unplanned hospital admissions among its patients. Several case studies illustrating the impact of NeuroResponse on unplanned admissions are presented below.

| Before NeuroResponse | Sign up | After NeuroResponse |
|---|---|---|
| Between July 2018 and October 2018, Alex* had **two encounters with hospital services**, amounting to a total of **three bed days** over a four-month period. | Alex signed up with NeuroResponse in February 2019. | Alex used NeuroResponse in relation to a UTI in March 2019. **No further emergency hospital attendances have been reported** |
| Between March 2019 and April 2019, Bella* had **five emergency visits to hospital**, amounting to **one bed day**. | Bella signed up with NeuroResponse in July 2019. | Bella used NeuroResponse in relation to a UTI in July 2019. **No subsequent emergency hospital attendances have been reported**. |
| Between July 2018 and September 2018, Clare* had **two encounters with hospital services**, totalling **19 emergency bed days** and 38 elective bed days. | Clare signed up with NeuroResponse in November 2018. | Clare has used NeuroResponse for UTIs in January, August and September 2019. She has also had **one emergency hospital visit in June 2019, with no overnight stay.** She did not contact NeuroResponse during this episode. |

*Names have been replaced with pseudonyms to protect people's identities.

# Cost-effectiveness

While an assessment of cost-effectiveness was not conducted as part of this evaluation due to data and resource limitations, a previous cost-utility analysis of NeuroResponse was conducted by the Department of Applied Health Research at University College London[1].

This study considered the cost per QALY (quality-adjusted life year) gained, and the overall financial impact to the hospital provider or CCG per year of the NeuroResponse service for three different scenarios: supporting people who presented with UTI symptoms, supporting people who presented with potential complications of sepsis, and supporting people presenting with a relapse.

- **NeuroResponse was cost-effective for managing people with MS who presented with UTI symptoms**. By diagnosing and treating these patients at home compared to visiting their GP, there would be a cost of £5,160 per QALY gained, with a net financial impact of £27,157 per year for the hospital provider or CCG.
- **NeuroResponse was cost-effective for managing potential complications of sepsis.** The use of NeuroResponse compared to existing pathways would cost £1,483 per QALY gained with a net financial impact for the hospital provider/CCG of £12,779 per year.
- **NeuroResponse was cost-saving when used to manage patients presenting with an MS relapse**, and improved QALYs. The net saving for the hospital provider/CCG would be £16,813 per year.

[1] This source has not yet been published.

# Upskilling generalists

One of the aims of NeuroResponse is to upskill and provide support to non-specialist medical professionals, including GPs.

This was noted among medical professionals involved in the Camden pilot, with a GP stating that NeuroResponse offered specialist knowledge that was easy for her to access.

However, there is less evidence of this being the case within Barnet. While some of the IUC GPs had increased their knowledge of how to support people with MS, this was not the case for all, and all four IUC GPs we spoke with felt that they could use more training and support.

> *As a [generalist], when you're dealing with people with "rare" conditions, especially where severe, it's hard to gain sufficient experience. It's useful to have a resource [like NeuroResponse] you could tap into – is it MS, should I be thinking about something else?*
>
> - Medical professional

# More appropriate and reduced use of antibiotics

One of the aims of NeuroResponse is to reduce inappropriate use of antibiotics, which is extremely important in the context of rising antibiotic resistance.

**This is achieved through:**

- **Fast testing of urine samples**. Tests are completed within two or three days, compared to the standard time frame of around a week where tests are done through the GP. This means that patients may be able to wait until the test results come back before starting an antibiotic, rather than beginning treatment without confirmation of an infection.
- **Targeted use of antibiotics**. Patients are told what type of infection they have, and prescribed the antibiotics that are most suitable for addressing this, based on their test results.

A medical professional involved in the pilot in Camden told us that there is pressure on GPs to keep people out of hospital, and GPs have concerns about not treating when there might be an issue.

As such, before NeuroResponse, antibiotics would sometimes be prescribed when they were not really needed.

> *One of the frustrating things about having a UTI is you give your sample in on a Monday to your GP and quite often you don't get the results back until the following Monday. And so it's very delayed, that can mean you're on the wrong antibiotic if you take an antibiotic immediately, and it's all kind of slightly suboptimal. I thought NeuroResponse [would] be faster and more responsive, which they are.*
>
> - Patient

> *In the past , I've taken the [same] antibiotics regardless of what infection it was.*
>
> - Patient

> *Since my Dad came out of hospital, he's had symptomatic UTIs twice. We used the NeuroResponse team. Otherwise, we would have had to just try antibiotics until something worked.*
>
> -Family carer

> *No one was talking to me [before NeuroResponse] about what kind of infection it might be. It's such a difference. Even sending a sample to the GP, they're like "oh there's a little bit of growth there". But what [infection is it]?*
>
> - Family carer

# Translation

# Commissioner views on factors for translation

Commissioners suggested several factors that need to be considered in replicating services for people with long-term neurological conditions 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).
- The Clinical Lead noted that she hoped that NeuroResponse could be expanded in the future to cover both a greater range of MS pathways (such as early diagnosis) and a broader population, encompassing multiple long-term neurological conditions. Similarly some people with MS noted other needs that they felt NeuroResponse could help with. For example, one person felt there might be a need for a NeuroResponse pathway to support with chest infections.

**Geography**

- The spread of the population in other areas could also impact translation.
- While the service is delivered remotely, the ability to provide support to people with sign up or use of NeuroResponse (necessary in populations where digital capabilities are low) and the ability to provide a timely courier service could be more challenging in a geographically spread out area.
- To date, the service has only been implemented in densely population London boroughs.

**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.
- As such, areas that are similar to Barnet or Camden but are underperforming could be receptive targets for translation.

# Considerations for translating the service elsewhere

We identified additional factors that need to be considered for translating NeuroResponse elsewhere, based on discussions with the Clinical Lead at NeuroResponse and two medical professionals involved in the pilot in Camden.

| | |
|---|---|
| **Understanding your local problems** | • The Clinical Lead of NeuroResponse emphasised the importance of really understanding what the problems are in your area, through independent audits and co-designed solutions. |
| **Patient population** | • It was expected that the patient population in Barnet would reflect the pattern of approximately 80% with relapsing remitting MS, and 20% with progressive MS. However, the opposite pattern was found in Barnet, with a majority of people with progressive MS and a minority with relapsing remitting MS. Due to differences in age and level of disability among people with different types of MS, this means that assumptions around digital capabilities were skewed, and as such the NeuroResponse team needed to provide a much more hands on approach to support sign up and use of the service than originally planned. |
| **Leadership** | • The importance of leadership, and the significance of the Clinical Lead's role to date, was emphasised.<br>• Making sure that the right leadership, and the right training to support future leaders, are in place were identified as key factors for expanding or translating the service. |
| **Identifying and working with champions** | • It is important to identify medical professionals in the local area who already understand the network of community and hospital healthcare professionals within the local area and already have established contacts to act as champions for the service and help to raise awareness among professionals and people with MS. |
| **Developing links in the community** | • Ensuring that community services are aware of the service helps to ensure that all eligible people with MS are being identified and introduced to NeuroResponse.<br>• The Clinical Lead of NeuroResponse noted that the community MS nurses in Barnet acted as a central point and helped to identify patients who otherwise might not be known to the NHS. |
| **Working with GPs** | • It is important to "get the word out" to GPs, and ensure that they are aware of what the service offers.<br>• This can be done through GP trainee teaching and use of existing sources of information such as CCG websites, which was already being done in Camden.<br>• As GPs frequently move around, regular training updates and integration of NeuroResponse training into induction training may be needed.<br>• As a service which provides specialist support, NeuroResponse may be able to further add value where referral processes are developed further. For example, by developing stronger links between generalists and the service, so that eligible patients are redirected to NeuroResponse when they present elsewhere. |

# Conclusions

# Conclusions: Care and quality, health and wellbeing

## Care and quality

- People who had interacted with NeuroResponse staff or clinicians during the sign up process or when they had used the service told us that they feel NeuroResponse staff and clinicians treated them with care, and felt they were being listened to and treated as experts.
- In most cases, survey respondents reported that NeuroResponse had been able to solve the issue they were having.
- While there are still some teething problems in service delivery, the people with MS that we consulted with had overall very positive experiences of NeuroResponse.
- People with MS and their carers reported that the service is accessible, fast, high quality and personalised. Some people likened the service to private healthcare, with one person describing it as “luxurious”.
- NeuroResponse are currently developing a patient app which can be used by people with MS who want to navigate the service using a smart phone, which may increase the accessibility of the service even further.

## Health and wellbeing

- The accessibility of NeuroResponse positively impacted people as they were able to get help sooner and more easily, avoiding visits to health services that were challenging due to mobility limitations, which could be traumatic or even have a negative health impact on them.
- Some felt their health had been positively impacted by NeuroResponse, as a result of receiving more targeted treatment, more quickly.
- People also told us about their reduced stress, increased peace of mind, and increased confidence as a result of NeuroResponse.
- Patients and carers felt empowered by NeuroResponse, as they were really listened to and treated as experts, and supported to self-manage their MS.
- In some cases, NeuroResponse was able to identify unmet needs. However, this did not come out strongly from our consultations with people with MS and their carers.

# Conclusions: Efficiency

- Efficiency is perhaps the most important consideration for commissioners when commissioning services
- HES data shows that there were a lower number of unplanned hospitalisations and bed days caused by UTIs for people with MS living in Barnet in May-September 2019 compared to 2018, which correlates with the introduction of NeuroResponse. However, due to the small scale of this data, it is not possible to demonstrate that this reflects a wider trend in reduced hospitalisations and bed days among this group, or suggest a causal link between this data and the introduction of NeuroResponse.
- There is some qualitative evidence to suggest that NeuroResponse replaces the use of GPs or A&E. In one instance, we were told that the use of NeuroResponse had avoided up to eight hospitalisations a year for one person, while other people pointed out that one use of NeuroResponse was equivalent to as many as four or five GP visits.
- There is also qualitative evidence to suggest that NeuroResponse has led to more appropriate and reduced use of antibiotics.
- There is some quantitative evidence to suggest that NeuroResponse has reduced hospitalisations for some patients, as demonstrated through the patient journey case studies.
- A previous cost utility analysis found evidence that NeuroResponse is cost-effective for managing UTIs and the potential complication of sepsis among people with MS, and is cost-saving in the case of managing MS relapses.
- In contrast, IUC GPs felt that there could also be duplication of efforts in some cases.

# Conclusions: Translation to other areas

Based on interviews with commissioners, medical professionals with experience of the NeuroResponse pilot, and the NeuroResponse Clinical Lead, we identified several factors to consider for translation:

| | |
|---|---|
| **Understanding your local problems** | Understanding the specific issues in your local area and involving service users in coming up with solutions |
| **Patient population** | Considering the scale of the patient population and their composition (particularly to the extent that it may influence digital capabilities), and the extent to which the service can support all people with MS or other long-term neurological conditions |
| **Working with local health professionals** | Linking in with local health professionals, including community services and GPs, and establishing links between services. |
| **Leadership** | Ensuring the right leaders are in place, and training is available to support future leaders |
| **Raising awareness of the service** | Getting the word out about the service through the use of local champions, training, and using existing media (for example, CCG websites) to share information about the service |

# Conclusions: Challenges

- **Awareness of the service**. Interviews with IUC GPs and people with MS highlighted that local awareness of NeuroResponse still needs to be improved. For example, a patient told us that they found out about the service through an encounter with the Clinical Lead, but their GP and consultant had not mentioned the service to them. One person felt more should be done to ensure that people with MS are aware of all the services available to them at the point of their diagnosis. The NeuroResponse Clinical Lead notes that one of their ambitions for the future is to ensure that everyone in the patient's journey is aware of NeuroResponse.
- **Clarity about the service and its processes**. Both people delivering the service and people using the service highlighted some confusion about how processes worked. For example, some people had questions about whether NeuroResponse is only a service to support people with MS with suspected UTIs, or whether it is able to provide support for other issues. Further, the Clinical Lead noted that IUC GPs are linked in to a specialist registrar, but the IUC GPs we spoke with did not appear to be aware of this aspect of the service. There were also practical questions around how different stages of the pathway worked, such as whether there were any differences in the support provided to people residing in Camden compared to those in Barnet, and whether patients have to re-order urine sample kits or whether replacements are sent out automatically. The Clinical Lead noted that it is challenging to embed learning and teaching among clinicians for a small-scale service, and hopes that as it scales up, there will be greater understanding of and familiarity with the service.
- **Training**. While training had been put in place for IUC GPs, few attended the training session in person, and others were not aware of how they could access training or felt they did not have time to complete it. The Clinical Lead of NeuroResponse noted ongoing and planned work to improve training and ensure all staff complete this. For example, they have created a training programme that is embedded within the training tracker for new staff and are working with LCW to ensure that new staff are trained.
- **Technical difficulties**. IUC GPs highlighted that they had experienced issues with accessing a person’s medical record or summary care record. The system creates a new case every time a person interacts with the service, which can make it additionally complicated to understand their medical history and previous interactions. Some people with MS also had queries around who had access to their data, whether information was being passed on to their GP, and how the data could be accessed or updated.
- **Lack of resources**. The Clinical Lead highlighted that their biggest challenge is their lack of resources. She noted that commissioners are looking for evidence of the effectiveness of the service before they are willing to fund it, and the NHS lacks an innovation budget to fund innovative models, which makes it challenging for these to be tested.

# Conclusions: Potential improvements

- **Raising awareness locally.** Continued efforts are needed to raise awareness of the service in the local area, to ensure that eligible patients are aware of it and that local services are being used in the most effective way.
- **Clear information about the service.** A few patients felt that the available information about the service, such as information available online, did not make all of the aspects of the service and how it can be used completely clear. Similarly, some felt that the service seemed complicated initially, but once they understood the service they realised it was actually a simple idea. An easy to read summary of the service, with information on how to sign up and what NeuroResponse can help with might be a beneficial addition for some people with MS and their families and carers. Similarly, some patients felt that additional information around what the service offers and how the processes work could be built into the onboarding process.
- **Increase (awareness of) training provision.** Interviews with IUC GPs found that they all felt they would benefit from additional training, specifically more "hands on" training that covered how to use the system and what to do in different scenarios.
- **Improve the IT system.** IUC GPs felt that the IT system they were using could be improved. The NeuroResponse team have already begun taking steps to address this, including reviewing the system and creating plans for a simplified process.
- **Expanding the service to cover other issues or patient groups**. The Clinical Lead hopes that the service will be expanded in the future to cover a greater range of people and medical issues, which coheres with the idea of "generalist specialist" services put forward by a commissioner. Similarly, a person with MS suggested that the service be expanded to cover people who are living just outside of the local area but access health services in the area.