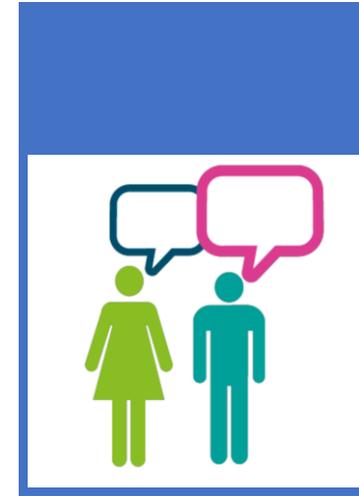


# Healthwatch Kingston Pulse Check report: Multiple Sclerosis services

Survey and Focus Group - August and September 2021

Published 9 March 2022

**healthwatch**  
Kingston upon Thames



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## 1. About Healthwatch Kingston

Healthwatch Kingston upon Thames is your local health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need. Healthwatch Kingston upon Thames is part of a network of over 150 local Healthwatch across the country.

We're here to listen to the issues that really matter to people in the Royal Borough of Kingston upon Thames and to hear about your experiences of using local health and social care services. We're entirely independent and impartial, and anything you share with us is confidential.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

It's really important that you share your experiences – whether good or bad, happy or sad. If You've had a negative experience, it's easy to think there's no point in complaining, and that 'nothing ever changes'. Or, if you've had a great experience, that you 'wish you could say thank you'. Remember, your feedback is helping to improve people's lives. So, if you need advice, or you're ready to tell your story – we're here to listen.

## 2. Introduction

Multiple Sclerosis (MS) is the most common disabling neurological disease of young adults in the UK. More than 130,000 people in the UK have MS. In the UK people are most likely to find out they have MS in their thirties, forties and fifties. But the [first signs](#) of MS often start years earlier. Many people notice their first symptoms years before they get their diagnosis. ([MS Society](#)).

MS can affect how people see, move, think or feel. [Watch this MS Society video to understand more.](#)

### The 3 main types of MS are:

- Relapsing remitting (RRMS) - Where ‘...people have attacks of new and old symptoms; this is called a relapse. Around 85% of people with multiple sclerosis are diagnosed with RRMS. Taking a disease modifying therapy (DMT) could mean fewer relapses and slow down your MS.’ [Learn more about RRMS.](#)
- Secondary progressive (SPMS) - ‘Comes after relapsing remitting MS for many people. With this type of MS your disability gets steadily worse. You're no longer likely to have relapses when your symptoms get worse but then get better.’ [Learn more about SPMS.](#)
- Primary progressive (PPMS) - ‘Affects about 10-15% of people diagnosed with MS.’ [Learn more about PPMS.](#)

In April 2021 Healthwatch Kingston launched our ‘Pulse Check’ engagement programme to work more closely with our diverse communities in Kingston and listen to their views and experiences of health and social care services.

In July 2021, we were approached by the Chair of the [‘Richmond and Kingston MS Group’](#) to help raise awareness of MS in Kingston. The group has MS Support Volunteers who are trained to confidentially offer emotional support, information, help to access specialist services and help to get financial support, to encourage people with MS to talk about their experiences of services. Healthwatch Kingston then ran Pulse Check community engagement throughout August and September 2021.

### 3. Community engagement methods and limitations

Healthwatch Kingston, initially worked with the Chair of the MS Society - Richmond and Kingston group to understand how the group works and the needs of our local MS community. We wanted to encourage Kingston residents with MS to talk about their experiences of services. We sought views to help services work better for the people who use them.

The findings from this Healthwatch Kingston Pulse Check are drawn jointly from a focus group discussion, held in association with the Richmond and Kingston MS group, as well as returns to an online survey which was featured on the Healthwatch Kingston website for the months of August and September 2021. The survey asked how easy it was to access a service, the quality of the service offered and how they felt about their aftercare. A combined total of 15 people shared experiences with us. Healthwatch Kingston notes the limitation of this report in terms of numbers engaged with, but every voice is important to us, and our engagement evening provided rich qualitative information from people with lived experience.

#### Methodologies used to collect data for this compilation report included:

- Online survey, promoted via our [website](#), social media and local health and social care stakeholder communications
- Targeted engagement with a local community group on 14 September 2021.

### 4. Local Multiple Sclerosis service offer

To find out about support available for people living with and affected by MS in the Royal Borough of Kingston upon Thames, go to the [Healthwatch Kingston All About: Multiple Sclerosis services](#).

## 5. Key messages and recommendations

- A. **Face-to-face versus online meetings** People with MS that Healthwatch engaged with said there were pros and cons to the switch from face-to-face to online meetings during the pandemic. The Richmond and Kingston MS Group had continued to run regular online meetings throughout 2020 and 2021 due to the vulnerability of some members in order that people felt safe. Healthwatch Kingston heard mixed responses about the switch from face-to-face meetings in a social environment, to meetings being held online. Some participants shared they had missed the opportunity for face-to-face interaction, but others had found they were able to attend meetings more frequently than prior to the pandemic, in an online environment.
- B. **Variable access across boroughs** Based on what we heard, pathways to hospital treatment and care for people with MS varied between boroughs. At our engagement evening with the Kingston and Richmond MS group, we engaged with residents from both boroughs, and it became apparent that residents in Kingston were receiving most of their MS treatment and care in Kingston whereas Richmond residents were more widespread and included treatment and care services in Paddington / West Middlesex / St Georges and St Helier Hospitals.
- C. **Need to travel for care** Participants explained that due to the nature of MS, and the variety of symptoms, people living with the condition may have a need to travel to hospitals that were not necessarily local to them to receive specialist treatment, however, they fully appreciated why this was necessary.
- D. **Issues with long distance travel** Some shared that travelling long distances for treatment was not always comfortable or convenient and expressed concerns that hospital transfers sometimes prove unreliable. This can be particularly problematic for those who have bowel conditions as well as physical disabilities.

- E. **Hospital parking** Blue Badge parking can prove to be a challenge for some because of limited space availability, and parking at hospitals for MS appointments was described by one person as:



*I worry about people with MS who do not have a Blue Badge, as parking is ridiculously expensive for those without one.”*

Another shared a similar concern about the high costs associated with hospital parking:



*I often find myself driving around hospital car parks for ages before I find a space, and even though I am not parked, but doing circuits, I still have to pay for the time and not the space.”*

- F. **MS and Blue Badge disability requirements** We were also informed that trying to obtain a Blue Badge can be complicated and people felt the validity of their requests for a badge were overly questioned by authorities:



*I feel as if I have to justify my MS as being a disability.”*

- G. **Problems with fluctuating MS symptoms and assessments for access to support** We heard that initial MS assessments can be time consuming and difficult especially with brain fog (a common MS symptom) or with physical disability/pain. Again, participants in the group expressed frustrations with “the system”. This is what one person said:



*It was incredibly frustrating when I had to justify the disabling impact that MS has had on my life and why is it that an MS diagnosis from a doctor wasn't enough evidence for my assessor."*

Disability assessments for access to Personal Independence Payment (PIP) can help with extra living costs but were a cause of concern as participants felt that assessors were not MS specialists, or even medically trained and did not understand the varying complex conditions associated with MS.



*I felt like I was being tested and found the process very stressful. It was even stressful and exhausting preparing for the assessment as I had to collect all my medical evidence without any support and it made the symptoms, I was experiencing at the time worse."*

We heard that this sort of experience was particularly problematic for those who have Relapsing Remitting Multiple Sclerosis (RRMS) - where the severity of attacks and recovery times between relapses vary widely from person to person. People shared that they can find it difficult to prove how severe their symptoms are, if an assessment is booked at a time when their symptoms are not at their worst. Two others noted:



*I only got my PIP after having to go through an appeals process."*



*Why do we have to be reassessed when there is currently no cure for MS?"*

#### H. Differentiating between MS (and other longterm conditions such as ME/Chronic Fatigue) and Long Covid symptoms

One respondent in our [‘Living with Long Covid’ report](#) noted the difficulty they had experienced since having Covid:



*Living with RRMS has made it tricky for me to distinguish between potential Long Covid symptoms and my intermittent RRMS symptoms - apart from loss of taste and smell and weird hair loss.”*

Advice on how to prepare for a Personal Independence Payment (PIP) assessment can be found [here](#).

- I. **Hospital treatment and care** There was concern raised by some about limited access to an MS specialist nurse in the borough as participants felt that the nurse-to-patient ratio did not support the numbers of Kingston residents living with MS. However, there was positive feedback for the MS specialist nurse who works with people at Kingston Hospital.

Kingston Hospital informed Healthwatch Kingston that their current MS specialist nurse to MS patient ratio was, 1 nurse per 437 patients, however, this is still well above the recommended caseload of 315 (MS Trust [ms-trust-specialist-nurse-mapping-2018.pdf \(mstrust.org.uk\)](#)), and the range of new Disease Modifying Treatments places significant workload on MS specialist nurses. We also learned that there is no MS specialist nurse working as part of the Multidisciplinary Team (MDT) in Kingston, unlike in other south west London boroughs (for example, there is an MS community-based nurse provision in Richmond). This difference has been highlighted by the acute based MS specialist nurses at Kingston.



Kingston Hospital   
NHS Foundation Trust

*your* healthcare

### Survey respondent on MS hospital treatment and care in the community:

One respondent to our survey who is living with Stage 3: Primary Progressive MS shared experiences of the MS specialist nurse service at Kingston Hospital and MS neurology, physiotherapy, or rehabilitation service via Your Healthcare in the community. When asked the following three questions they said:

1. How easy was it to access the service you needed? - *“Very easy.”*
2. How did you feel about the quality of service you were offered? - *“Very satisfied.”*
3. How did you feel about the aftercare you were offered? - *“Very satisfied.”*



*I've always found the MS Specialist Nurse and the community MS Neurology Specialists very helpful and efficient.”*

Another MS patient replied about both emergency services and MS treatment and care at a different hospital:



**St George's University Hospitals**  
NHS Foundation Trust

### Survey respondent on emergency and MS hospital treatment and care:

One respondent to our survey who is living with Stage 2: Secondary Progressive MS shared her experience of St Georges Hospital. When asked the following questions about their MS treatment and care they said:

1. How easy was it to access the service you needed? - *“Difficult.”*
2. How did you feel about the quality of service you were offered? - *“Dissatisfied.”*
3. How did you feel about the aftercare you were offered? - *“Very Dissatisfied.”*

Adding the following:



*Emergency at St George's is excellent but Neurological services seem bad for older age groups.”*

J. **Housing needs** Participants noted the need to modify housing for some people with MS and severe disabilities.

An example was shared by one person we spoke with that helped illustrate this issue but was an example from a north London borough. They said that a person with MS they knew was offered a commode rather than additional work being done on their home. They had to fight for support from their council to put in a downstairs toilet.

K. **Support networks** Several times Healthwatch heard how important their support networks were as people needed to rely on family and friends to help with their care. Another person shared that they themselves were expected to be a care giver:



*Even though I'm receiving help and care with living with my MS, I still find I need to provide care to my elderly relatives."*

### KEY RECOMMENDATIONS for Commissioners and Providers of Multiple Sclerosis services:

1. **Health and social care service leads should explore ways to increase awareness of Multiple Sclerosis within the workforce** in particular better understanding of the variety and intermittent nature of symptoms and the disabling impact that Multiple Sclerosis has on both the mental and physical health of people living with the condition.
2. **Review service provision in relation to the key messages shared in this Pulse Check Kingston report** to ensure that both direct services and support (accessible treatment and care, such as MS specialist nurse to MS patient ratios both in hospital and as part of the community MDT/informed assessments/housing etc.) and associated services (Blue Badges/parking etc.) have capacity to appropriately meet the needs of people with Multiple Sclerosis in Kingston.

## 6. Thank you and next steps!

Healthwatch Kingston would like to thank everyone that has shared their experiences with us. Everything we say and do is informed by what local people tell us. We will publish this report on our [website](#) and share with Healthwatch England, the Care Quality Commission, the Royal Borough of Kingston upon Thames, South West London Clinical Commissioning Group, Multiple Sclerosis service providers, the Voluntary and Community sector in Kingston and other stakeholders.





*Tell us what you think about NHS and social care.*

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