

Review and Reform of a community Multiple Sclerosis service

Introduction

The community Multiple Sclerosis (MS) service has 1 WTE MS Specialist Nurse, supporting a caseload of approximately 200+ patients. There is no other clinical support for the service and it has only recently been allocated one day a week of admin support, since the service resumed in the past two weeks. The MS service links closely with other community and hospital teams in order to meet recommended standards of practice and guidelines. (1, 2). The service accepts any patient 18 years and above, with evidence of neurologically diagnosed Multiple Sclerosis and is registered to a local GP. The present caseload consists of 50 % diagnosed with relapsing and remitting MS (RRMS) and the remainder, Secondary Progressive MS (SPMS) or Primary Progressive MS (PPMS), with approximately 40% in the advanced stages of MS.

As a consequence of the pandemic, the government and NHS directives led to organisational change, however, the local impact severely affected the MS specialists service. In Harrow, the MS service was completely stopped during the first lockdown resulting in patient distress This was especially when they were unwell and unable to access ANY specialist advice at the time they needed. (Figure 1 and 2). As a result of highlighting the risks associated from removing all MS support, managers then permitted one day a week of urgent MS work during the second lockdown.

Even with this input, on returning to the MS role for the second time, each call has resulted in a higher level of work than would have been expected in the pre-pandemic service. (Figure 4). On reviewing Hospital episode statistics (HES 2019-2020), the past year has shown an increased level of MS admissions for some local pwMS. This information requires further review in order to locate where to target service admission avoidance. (3) For Harrow, the process for MS service review is a live project and is aiming to continue to include the opinion and recommendations from experts in the field. (4,5,6)

The focus is to provide evidence to support a suitable and sustainable MS service to cope with future risks from service disruption or potential National lockdowns. For the time being, there is now a new local strategy used to gather evidence and then aim to use this information to further develop a tailored MS service. Patient engagement is at the heart of this project and decision-makers are the targeted recipients so that clinical cover and resources will be appropriate to support local people with Multiple Sclerosis.

Objective

To ensure the post lockdown MS service is fit to meet the needs of patients and demonstrates quality care to meet national standards for a specialist community service. The project has only recently started due to redeployment and service closure, therefore it is in the early stages of implementation.

- To demonstrate how a single handed community service aims to re-evaluate and further develop quality care, taking into account the changing landscape within the Multiple Sclerosis field and the NHS future plans.
- To show how returning from a long period of redeployment following severe service disruption can be used productively, to reflect on good practice and eradicate less effective strategies from previous service interactions.
- To highlight patients' experiences, when they are unable to access specialist support at the time it is required, and the adverse impact this experience has on patients' health.
- To show that lack of service support has resulted in patient's experiencing increased symptoms and higher levels of disability that have intensified the need for extra resources to help patient's return to their pre-lockdown baseline.
- To show how collaborating and engaging with stakeholders can help to mould and reform the community service, with patients opinion being integral in developing new pathways and protocols tailored to local needs.

Service development

- Although the resumption of the community MS service has been challenging, reinstating the service can be viewed as a good opportunity to reconsider the importance of specific aspects of service provision and what can help patients to maintain self-management when specialist support is not available.
- Restarting the service requires intense work to completely review the caseload, processes, pathways and protocols, but also provides an opportunity to fully engage with patients and other stakeholders. This helps in remodelling the future facilities in accordance to recommendations and guidance. (4,5,6)
- On reinstating the service, future patient safety and welfare has to be the priority and a post-pandemic community service needs to be fit for purpose. The new model has to learn from patients' experience in order to improve and will aim to prevent the extra time and resources required when patients have not been able to self-manage when their situation changes as seen during the lockdown. (Figure 4).
- By using a clear process and development plan, further data is now being collected and reviewed for this purpose. Figure 3a summarises the process used to resolve problems found on returning to the MS role. Figure3b indicates the process used in reviewing and reforming the service.
- Continuing to use PROMs and monitoring HES data, can also help to have productive and informed discussions with key decision-makers and can be utilised when the need arises and supporting service changes (6)
- Although this project is in the early stages, to further develop the community service there have already been indications for potential changes to improve service provision as stated in Figure 5.
- For the time being, this live project will continue to engage further with patients and gather information from a wide group of pwMS. By working collaboratively with the MS Society a questionnaire has been devised and will be circulated to seek service users opinion and to help mould and reform their MS service, as well as local support groups. The final goal is to highlight results to inform decision makers.

Figure 1. Patient voice- Summary of findings following home visit to assess the patient

Patient PROFILE ;
 Review of 44-year-old gentleman, living with his wife and 6 months old baby. He was working with minimal occupational support, but now unable to work effectively, even with help.

- Diagnosed with relapsing remitting Multiple Sclerosis and now escalated to advanced secondary Progressive MS during the Covid-19 pandemic. When community MS service was NOT available to review his needs close to home.
- He is now unable to carry out any activities of daily living without assistance and has comorbid conditions.
- Disease modifying therapies - Initially, Avonex, but did not continue due to side effects. Declined Tecfidera or alternative treatment 5 years ago.

Family struggling to cope
 Main findings following MSSN re-engagement after lockdown;

- Patient unable to carry out activities of daily living
- Struggling to speak, and no longer able to mobilise or use upper body functions
- Experiencing high anxiety and depression.
- He asked if he would soon need end-of-life care and did not understand his recent diagnosis or the explanation the results of recent investigations why he is no not eligible for DMTs at this time.
- He was contacting multiple services and organisations in the community and hospital settings, but without any coordination of his care or setting collective goals for and agreed CARE Plan

References:
 1. NICE Institute for health and care excellence (2019) Multiple sclerosis in adults management (CG186).
 2. NICE (2016) Quality standard (QS108) Multiple sclerosis. <https://www.nice.org.uk/guidance/qs108>
 3. Hospital episode statistics (HES) (2020) courtesy Biogen and Wilmington healthcare
 4. NHS reset and reform, a new direction for health and care in Multiple Sclerosis (2021) <https://www.nhs.uk>
 5. Optimum pathway (2019) <https://www.nhs.uk>
 6. NHS RightCare (2021) <https://www.england.nhs.uk/rightcare/problems/solutions/secondary-progressive-multiple-sclerosis/>



Figure 2. Patient voice- Sample of quotes from patient and carers

Stakeholders feedback	Coping WITHOUT the community MS specialist service and advice	Response on RESUMING community MS specialist service contact and interventions
• Patient's	Case 1; 59-year-old female with secondary Progressive MS, who was admitted with a severe infection during the pandemic lockdown and required rehabilitation in a nursing home said, "...I cried all of the time... felt isolated in my room..." and said she was left "...unable to use the nurse alarm." I was so low and frightened... I just wanted to be at home with my (RECES) equipment, so I could manage better."	Case 2: 56-year-old male with relapsing remitting MS and due to start new disease modifying therapy. New to the community MS service and said, "...your first call was a massive help to me and my wife and today's appointment has been fantastic." "...you answered all my questions (about MS and treatment), before I even asked." "You have helped to clear the clouds"
• Family / carers	Case 3: The partner of 35-year-old man with relapsing remitting MS said, "we have been so upset and struggling to know what to do when the community MS service could not be contacted and we could not call the GP or contact the hospital team between infusions" "We were told that the service was closed and thought that that would be for good, therefore became more anxious."	Case 4: The daughter of a 51-year-old lady with advanced SPMS, was very pleased to hear that the community MS service had restarted. As a young adult carer who has a mother with highly complex health needs, she was struggling to cope. On the first appointment to re-engage with family, she expressed her gratitude for the advice and guidance. This was especially important for her studies as she also required support her University studies. Daughter said, "I know we had other contacts, but could not get answers and needed to speak with someone who really understands how difficult it has been (helping her mother) when my mum has been so unwell."

Figure 3a Problem solving within the community MS service

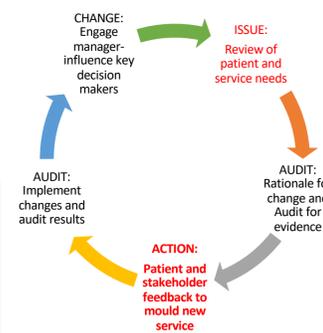


Figure 3b Process for reinstating and reforming the community MS service

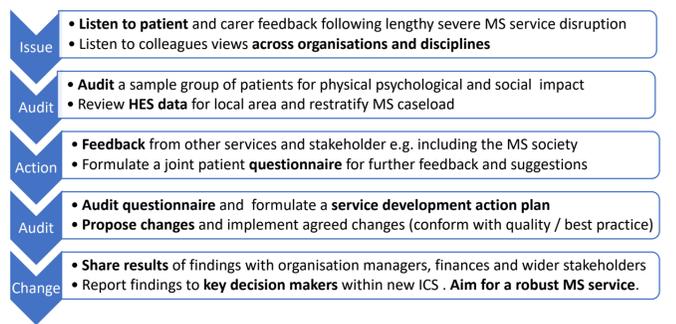


Figure 4 Patient MS service interactions during 16 days of recommencing MS role

Type of MS in sample group of 10	Number of pnt contacts	Number of service liaison	Number of referrals	Would you respond to a questionnaire
SPMS	13	5	5	Yes
RRMS	6	2	3	Yes
SPMS	5	3	1	Yes
PPMS	5	8	1	Yes
PPMS	6	3	2	Yes
PPMS	5	4	2	Yes
PPMS	3	3	1	Yes
RRMS	4	4	1	Yes
RRMS	6	5	3	Yes
SPMS	5	5	3	Yes
3	4	58	22	10
30%	30%	40%		100%

Figure 5 Patient and service focus leading to service development and improvement

Patient focus
 Patients voice to be heard by gathering feedback to highlight issues
 Patient involvement in moulding the post lockdown MS service
 Involve patients in trialling the questionnaire and suggesting further relevant information
 Work in partnership with MS society and community to send final joint questionnaire to all known patients on the caseload -
 Restart patient support group and MS carer support group

Service development focus:
 Continue to audit patient reported outcome measures to evidence effective care
 Aim to increase clinical and administrative resources
 Prepare business case to ensure succession planning
 Aim to upskill community teams and continue to support training with other Specialist teams
 Complete Leadership training
 Aim to engage with managers, key stakeholders and provide sufficient data for

Results

Figure 1 outlines the severity of deterioration a patient has undergone within a short period of time and the devastating impact it had on them as an individual and his family. It highlighted how patients can misunderstand information they have received and that the presumptions, which are not necessarily true can lead to worsening mood. Although this patient had undergone traumatic changes in his ability, interventions have now been put in place to support him and his care is now coordinated.

Figure 2 shows a few statement or opinions from patients or carers who wished to comment on their experience when they were unable to access community support. Further comments have been logged from colleagues from health and social services, other clinicians as well as charity /voluntary organisations.

Figure 3 summarises the process used in order to review service issues and the process for reforming the service. Figure 4 This is a small samples group of 10 randomly selected patients. It indicates the high level of involvement required when reviewing patients who have NOT had specialists support for a long period of time. It shows that there is a large number of contacts required in a short period of time, with most contacts then requiring other service liaison (an average 4). This requires extra time and resources. For patients there was also a greatly increased level of reported physical or mental health problems, therefore all patients required onward referrals for further interventions. As a matter of course, patients were also asked if they would like to report the findings and participate in the service questionnaire. 100% of patients were very keen to participate in feedback and wanted to support their MS service. As this sample group of patients is very small, further information and data review will be collected to substantiate findings further.

Conclusions

The future can be bright for people with MS (pwMS) and their service, but requires further investment to enable this. Patients greatly appreciate the MS Specialist support received and are willing to participate in developing or moulding resources in the local area. From the feedback received during this project, patients find that Specialist interventions enhances their ability to navigate and negotiate the changes encountered throughout their journey. They want their voice to be heard, but many have little energy or ability to speak out, especially as the disease progresses and they transition into advanced stages. The impact on families can also be extremely challenging with strains on relationships and difficult decisions for carers and their future prospects.

As an advocate for patients with multiple sclerosis and their families, the specialist clinicians have a duty to keep up-to-date with the changing NHS and MS landscapes. They need to work in collaboration with other social or voluntary sector, so that clinicians are ready to engage with decision makers and budget holders. The result could mean that pwMS are not left without specialist support at difficult periods in their journey and when they feel their need is greatest. Logically, emergency NHS future plans should be formulated by reviewing the lessons learnt from this recent pandemic. By using evidence to avoid unnecessary service disruption further distress imposed on vulnerable patient groups, can be avoided.

By listening to the patient's voice and engaging them directly in planning services, future service provision can be more focused to support their unique and challenging needs. Working collaboratively across organisations in health and social care services as well as voluntary and charity organisations, can also lead to utilising resources in a more effective and efficient way, thereby reducing financial and emotional costs for pwMS and help protect the services they require and highly value.