

# The OPTIMUM Care Pathway for MS in Cheshire and Merseyside

## Meeting final report

March 2021



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## Contents

Contents.....	2
Introduction .....	3
Multiple sclerosis: key points summary .....	4
Developing an optimal care pathway for MS: Presentation summaries .....	6
The Walton Centre Service The new MS Pathway & services in Cheshire and Merseyside .....	6
The Frimley Health Foundation Trust MS Pathway.....	9
MS Society Focus Groups the new MS pathway & People Living with MS.....	9
Phase 2 Consultation: Identifying the gaps: Psychological well-being services survey ....	10
1. What are the delivery areas of the pathway which participants think are particularly important?.....	11
2. What areas of the pathway are being delivered well?.....	13
3. What are the development areas within the pathway? .....	14
Glossary .....	16
Participants .....	17
Questions and chat facility from event .....	19

Merck provided funding for an original meeting scheduled for March 2020 which was cancelled due to the Covid-19 pandemic and this second meeting virtual meeting. They had no involvement in content development and did not participate in the meeting.

## Introduction

A virtual consultation exercise took place on 4 November 2020 to explore with people who live with multiple sclerosis (MS) and health care professionals the MS pathway across Cheshire and Merseyside (C&M). Around 50 people have contributed so far.

A report of the key points from the meeting were subsequently circulated for comment and this report is the final summary of the areas discussed on the day and evidence submitted during the consultation process for the draft report.

The information gained from this exercise will support the C&M strategic plan for MS services which will enable implementation of the National Neurological Advisory Group Optimum Pathway for MS.

We are most grateful to all those who participated in this consultation, a list of the participants in at the end of this document.

## Multiple sclerosis: key points summary

Overall services were stated to be excellent, but every service has room for improvement. The main areas identified for improvement were:

### Main priorities

- A responsive point of access to deal with all questions in one phone call – ‘a one stop shop’ so that any query could be dealt with immediately or a response time provided – anything from aids and adaptations to new symptoms.
- With NHS changes for Integrated Care Services (ICS’s) and Primary Care Networks (PCNs) integrated multi-disciplinary care teams (MDTs) for neighbourhoods of 30,000-50,000 are being developed. It will be important for MS specialist services to link into these.
- There are currently gaps in service provision to meet emotional support & psychological treatment for MS across the C&M region
- Systems & access criteria under existing specialist services – frequently & commonly not supportive of adequate psychological care
- Clarity around how MS relapse management is provided.
- Provision of more information on what medications are available for MS management.
- Regular patient reviews so that all people with MS receive an annual review.

### Diagnosis priorities

- Development of a community-based rehab model of care including psychological care.
- Signposting patients to Third sector-based support services including MS branches.
- Accessible information i.e. paper form and online formats
- Access to DMTs right from diagnosis

### Education priorities

- Neurology education for GPs, district nurses, and ward staff
- Improved awareness that not .... “Everything down to the MS”, people have general health problems too.
- Education to support psychologically-informed/ biopsychosocial medical care

### Psychological priorities

- Implementation of the Emotional and Psychological Partnership Committee priorities developed following a consultation exercise
  - The development of a multi-disciplinary forum, where complex cases can be discussed and signposted
  - Development of community-based neuropsychological and mental health-based rehab and support
  - Social prescribing and third sector integration (into emotional support provision)
  - Social care and welfare benefits support
  - Support to IAPT services from neuropsychological specialists, to help develop the IAPT offer to MS patients (helping the IAPT offer to become more fit for purpose)

### Therapist issues

- Access to MS specialist nurses.
- Provision of long-term support from specialists that have good therapeutic relationships.
- Availability of speech and language therapists, continence care etc.
- Access to neuro-physiotherapists.
- Accessible exercise classes for all abilities (therapist-led and long term)

### MS management priorities

- Development of specific symptom pathways i.e. for bladder management
- Expansion of intravenous (IV) community service to treat urinary tract infections (UTIs) with IV antibiotics at home to help prevent admissions.
- Pain management for neuropathic pain.
- Access to social activities; accessible swimming, leisure resources, gyms

### Service issues

- Cross-provider agreements to enable partnership working to improve care pathways
- Consideration given to re-alignment of existing workforces, to support the above
- Functional mapping to understand workforce needs: clinical psychologists/ clinical neuropsychologists (with relevant expertise) to support an improved framework of psychological care and rehabilitation
- Care management plans to help avoid admissions.
- Coordination so that services are more joined up.
- Safeguarding patients is a priority – currently overlooked due to capacity issues.

# Developing an optimal care pathway for MS: Presentation summaries

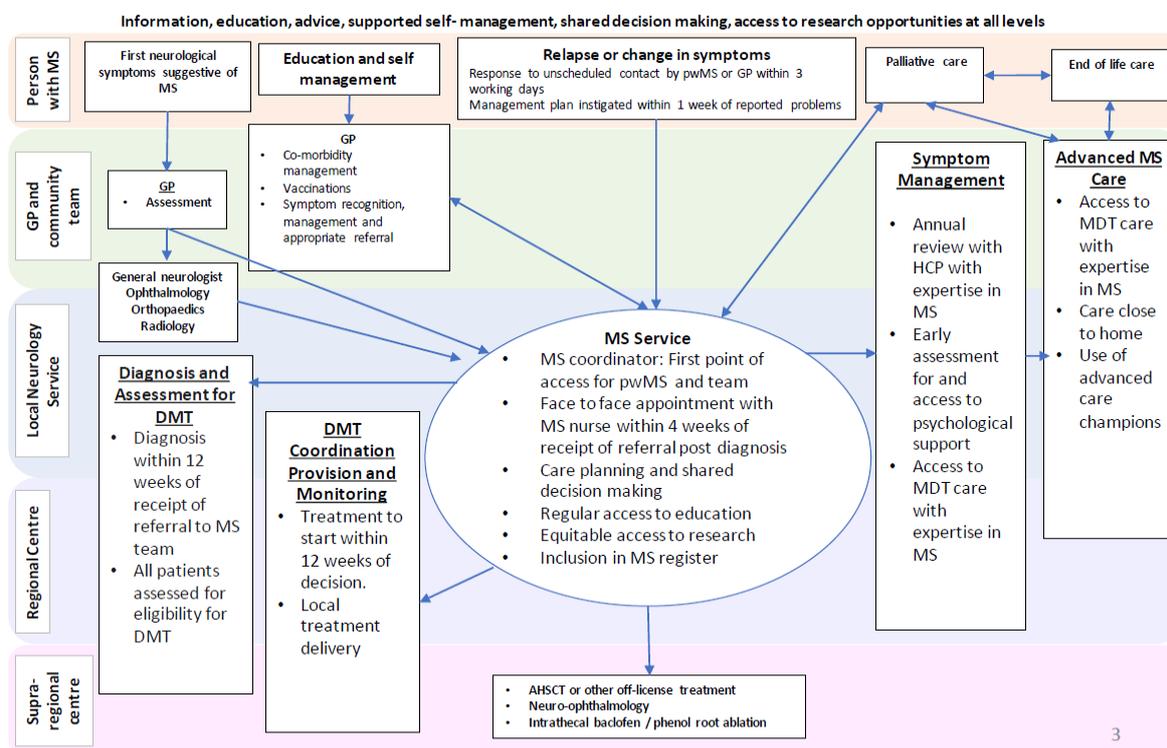
## The Walton Centre Service

### The new MS Pathway & services in Cheshire and Merseyside

Dr Pomeroy outlined the current MS specialist service at the Walton Centre and highlighted the services that were provided, which include multidisciplinary comprehensive MS clinics, individual specialist clinics, advice line, DMT service, newly diagnosed course, transition clinic for physiotherapy and occupational therapy and symptom management clinics and courses.

He also outlined the optimum MS pathway for people with MS that has been developed as part of an NHS England specialised neurology programme (see Figure 1). This pathway is a blueprint for all services in England to aspire to. The pathway outlines quality indicators to support optimum care and identified barriers and provides recommendations around patient flow, information sharing, research and clinical trials.

**Figure 1. MS optimum pathway**



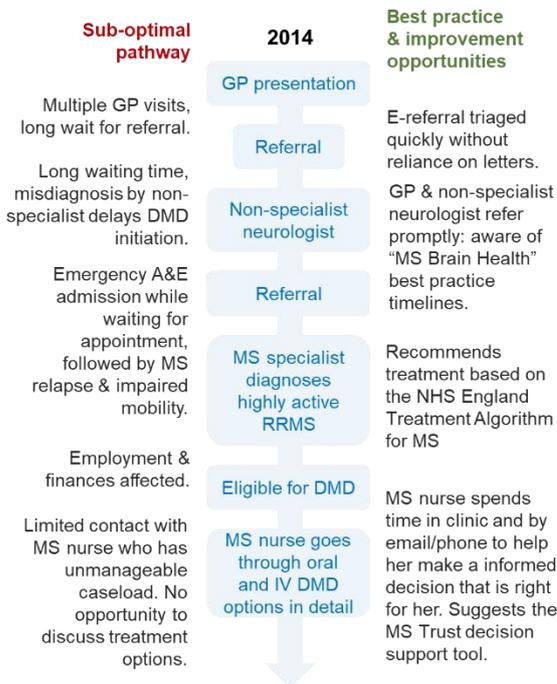
He outlined key statistics from the Walton Centre highlighting that from an audit in March 2020 there were 100 referrals and 70 CAB appointments audited. The median waiting time from referral was 33 days and 92% of patients were seen within 12 weeks of the referral date. There are also good response times from the MS nurses for the proportion of: new patients offered a face-to-face holistic assessment within 30 working days of diagnosis, two-day response times for calls to the nurse advice line, and the proportion of patients with suspected relapse being seen within seven days of contacting the service.

Dr Pomeroy welcomed the chance to ensure the pathway meets need locally and said he wanted aspirational and challenging ideas communicated.

Sue Thomas highlighted two data sets for Cheshire and Merseyside. The first from NHS RightCare which had already been presented to the MS specialist team and revealed opportunities for improvement in the neurology services overall and separately for MS.

Sue spoke about Rachel's story (see Figure 2) – a fictitious but realistic pathway developed using RightCare methodology to highlight opportunities in the pathway for improvement. She stated that the pathway is not just about medical and nursing care but also about the wider issues for people with MS: ability to maintain their lifestyle, family, work, social issues and quality of life. Rachel's story considered her preferences for treatment so she could continue with family and employment but this also had an impact on workforce and capacity within the health care system.

**Figure 2. Rachel's story: An optimal care pathway<sup>1</sup>**



Local data which was then presented showed the numbers of emergency hospital admissions in Cheshire and Merseyside in 2019/20<sup>2</sup>:

- 1,720 spells for patients with MS (6% decrease on previous year).
- Costs of £4,920,615 (10% increase on previous year).
- Cost per patient of £5,200 (10% increase from the previous year).
- Mean length of stay (MLOS) of 7 days (6% increase).

Sue highlighted not only the distress these cause people with MS but also the cost and use of bed days for the hospital. Proactive care management for preventing problems and keeping people well was key and there needed to be closer relationships with community care colleagues to try and prevent some of these admissions.

<sup>1</sup> Wilmington Healthcare (2019) Rachel's story: An optimal care pathway.

<sup>2</sup> Secondary care data is taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital, the new trading name for the Health and Social Care Information Centre (HSCIC) Copyright © 2020, the Health and Social Care Information Centre. Re-used with the permission of the Health and Social Care Information Centre. All rights reserved.

## The Frimley Health Foundation Trust MS Pathway

Dr Matt Craner from Frimley Park Hospital then detailed how the service in Frimley has changed from a local DMT service covering injectables to a tertiary level service offering all DMTs. He said a key part of this had been facilitating transformation:

- Connecting with the team
- Broad engagement
- Commitment to goals: joint planning, equal contribution and allocation to natural strengths
- They had reviewed progress regularly and adjusted to new challenges and opportunities.

A key part of the transformation was developing a supportive and encouraging multidisciplinary team (MDT) meeting with weekly clinical and administrative queries, identification of short-term goals and updates on service development progress.

They also held monthly MDT DMT meetings that were nurse led to review on average 30–35 patients per meeting; this meant management of patients was very focussed and inclusive of the team.

He said MS nurses and MS coordinators are critical to an effective pathway and described how they had empowered their nurses which was reinforced by his MS nurse at the presentation. All nurses were prescribers and had autonomy with appropriate consultant supervision – something the nurses were very comfortable with. The MS coordinators also had non-clinical responsibilities that provided increased capacity for clinicians.

His final words were: work as a team and nothing is impossible to achieve.

## MS Society Focus Groups the new MS pathway & People Living with MS

Ruth Austen-Vincent from the MS Society presented details from structured workshops that had explored perceptions of the pathway by people living with MS (PLWMS). The general view was that the MS pathway was good and covered what people felt they wanted and needed; however, most responses suggest that people are not receiving the pathway currently and there is a big gap in terms of patient experience – not only how people were treated but also that they often didn't feel like partners in their treatment. '*Hold on this is my appointment not yours*'.

Key points raised were:

- The general view was that the MS pathway was good and covered what people felt they wanted and needed.
- Most responses suggest that PLWMS are not receiving the pathway now.
- And a big gap in terms of patient experience – not only how people were treated but also that they often didn't feel like partners in their treatment and a big gap in terms of patient experience
- Services are focused on DMTs and symptom changes tend to get less time.
- Service access for progressive MS was minimal and people were unaware of a range of support services.
- CCG borders and geography impacts provision, as does lack of information on what is available and what you are entitled to.
- The need to access clear information on the treatments available and to have shared decision making with professionals.

- Experiences and outcomes varied even within the same area and sometimes with the same provider. Too much was dependent on the relationship with a professional.
- People often felt they did not want to trouble professionals or services.
- There is a lack of shared patient information; care coordination; good communication.

Separate consultation had taken place on the effects of COVID-19 and the St Helen’s MS Group conducted a survey in August 2020. Sixty-five questionnaires were sent out and 35 were received back. The survey asked:

- How has the lock down changed your activity and exercise levels?
  - 22.9% Not at all
  - 42.8% Severely or very severely
- How has the lockdown affected your emotional wellbeing over the last few months?
  - 16.7% Not at all
  - 41.2% Severely or very severely

The impact of the pandemic and future spikes need to be considered in pathway development due to the additional problems that may present with social isolation and patient reticence to contact MS services or visit in person.

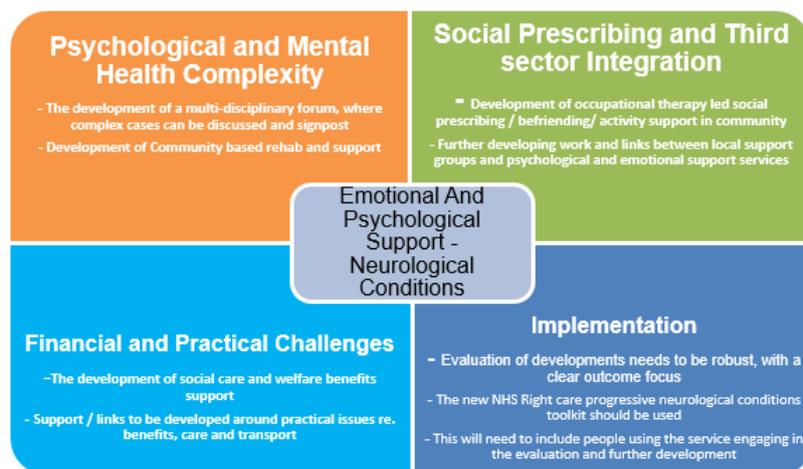
Discussion groups then considered three questions:

- What are the delivery areas of the pathway which participants think are particularly important?
- What areas of the pathway are being delivered well?
- What are the development areas within the pathway?

## Phase 2 Consultation: Identifying the gaps: Psychological well-being services survey

Following the report consultation the report from identifying the gaps in current psychological services was also submitted and is summarised below.

**Figure 3. Summary of actions required in C&M**



## Key points from breakout sessions

### 1. What are the delivery areas of the pathway which participants think are particularly important?

- Multidisciplinary working focused on patient needs.
- Teams need to be upskilled:
  - There needs to be communication between services so that they understand what services are available.
- Almost none of MS care needs to take place in a specialty centre – we need to change patient perceptions that care in specialist centres is superior.
  - Not all patients do want care to always be in centre, there are issues with transport and parking, and they would prefer care closer to home. For patients who have not seen an MS nurse in over 12 months these contacts can have benefit, virtual would seem good solution, or local clinics.
- COVID-19 has provided an opportunity to speed up progress on providing virtual appointments after many failed attempts:
  - Ensure health inequalities are not exacerbated by virtual appointments.
  - Services must be careful not to swing too far towards virtual appointments – consider what is best for patient. Need to be careful not project on to patients that if it can be done virtually, then it is not as important as an in-person appointment.
  - There are massive benefits to be gained from virtual / telephone appointments. The importance of the nurse advice line should not be overlooked as a means to enable contact when appointments are not frequent as might be optimum.
  - In-person appointments are still an important part of care, they allow things to be picked up which could otherwise be missed, e.g. via body language.
- Access to MDTs
- Co-ordination of care.
- Some patients have not even heard of MDT's being used. There are issues around not hearing the results of test/scans – this need to address if patients are to feel part of their care plan.
- The data presented early showed that there are a higher number of admissions and longer length of stays in our region. Although not always in our control, an improvement in our model could also support the community-based services. Two points to consider moving forward in relation to the high admission data: (1) develop improved care plans, and (2) if admitted to hospital, patients should be cohorted to neurology wards and access to specialist teams.
- Access to information:
  - A single point of contact would be better for people to access all the information they need about what services and activities are available. But who would do this, who would maintain it and keep it up-to-date?
  - Historically some of the regional neuro alliances have provided service information/directories across all neurological conditions, but over the years they have lost funding/resources/capacity and are unable to continue with this. A few years ago the national Neurological Alliance funded a project to map all services for Parkinson's which was a big piece of work.
  - The Neuro Therapy Centre also has wide networks and can be a large resource to provide this sort of information, but it requires funding to develop

directory/website and maintain it. The MS specialist nurses in Greater Manchester used to have their own website linked to Salford NHS Trust website, which was full of useful information about services (including voluntary sector services), but unfortunately Salford NHS Trust discontinued the funding of this.

- Developing a directory for MS patients would consume a lot of resources and would be duplicating a lot of information already available for Parkinson's patients. It would be much more efficient to join resources and provide a neurology directory of information. Technology is now so advanced that there should be an easy way to produce such information, but it needs to be credible and up-to-date. Charities can do this work but need to be properly contracted and funded.
- Facebook and other social media channels also useful for sharing information, news and events. Many local MS Society groups have Facebook pages.
- It might be that it is easier to get funding to develop a technical system for a directory and people/organisations and services add their own information into it. Nurses at the Walton Centre do have shared file system where useful information is stored for everyone to access and deleted once out of date or no longer valid. MS Teams and SharePoint already exists and can be used in this way, and it is easy for people to upload information although this is likely to only be information about NHS services.
- Community therapists may be best placed to hold a directory.
- One of the challenges in clinic is that it can be difficult to know where to signpost patients to and find out what is available. It would be good if there was a one-stop shop for people to access all the information.
- There is an access to exercise programme run by the neuro-therapists across Cheshire & Mersey. Clinical staff tell patients about it who can be referred into the programme or self-refer. Details of the programme are on internet pages for local teams to access. Each nurse is responsible for developing knowledge of their local area. Google is also very useful for searching for information but a centralised resource would be better.
- Nurses at the Walton Centre said neuro-MDT meetings which were monthly before the pandemic used to act as a link between hospital and community (they were able to speak to the community neuro-therapist).
- Maybe developing a community network would be a good way to bring everyone together and share information about what services and activities are available. Nurses often are aware of local neurology services.

### **Action points**

- Discussion took place about sativex which currently can be prescribed for spasm, some people with MS are on trials for using cannabis-based products for pain management also. As with other medicines there will be a need to build changes around NICE approval into planning and delivery.
- Optimise co-ordination of care to offer patient choice, making benefit of in person and virtual channels (including helplines).
- Enable/improve communication between services to ensure they know what is available.

## 2. What areas of the pathway are being delivered well?

- Discussion about the value of MDT's that can support access to services closer to home.
- It was discussed that North Wales was a starting point for developing this approach monitoring of bloods etc. are very efficient. It is more than a hub and a spoke model in North Wales, moving the hub to North Wales rather than requiring monthly visits to Liverpool for infusions for example, would further support delivery.
- The nurse advice line works very well, and they get back to 90% of patients within two days. This needs to be developed further as many people are unaware of this service
- Discussed in relation to the above the importance of linking in with current work on social prescribing and ensuring it meets the needs of people with neurological conditions. An example was given of boilers over three years old that can be replaced for appropriate patients, they need to be made aware of this and other relevant initiatives.
- Digital platform delivery has accelerated – but there needs to be a balance between virtual and face-to-face appointments. There is a danger this could increase barriers to accessing services for some people.
- The group also discussed the importance of neuro therapy services which need to be stepped up locally to address the impact of the lockdown on people living with MS – St Helen's was given as an example although this is paid for by the local group. How can this become an NHS service?
- It was commented that the Frimley presentation was very inspiring and shows with some persistence and energy, what can be achieved. But it was noted that there are differences between the Frimley situation and the Walton centre. Frimley is a smaller local service with a smaller catchment area which makes some things easier. Frimley also had different starting point, but the Walton Centre already has a tertiary centre. The Walton Centre covers a much larger area which includes some vulnerable localities and local staffing issues. The real gap is around delivering support between the tertiary centre and community services with people living with MS as a partner in their care

### Action points

- Improve sharing of best practice amongst staff
- Further develop communications and input into the new method of delivery for PLWMS which includes digital offer.
- Look at North Wales and how the strengths of delivery here could be used in England.

### 3. What are the development areas within the pathway?

- Working with and including local community partners.
- Therapy services are not available in all areas – this is a big gap which is crucial to fill as it prevents further injuries from falls etc.
- There are glaring gaps in service provision to meet emotional support & psychological treatment - and psychiatric treatment - needs in NLTCs across the C&M region
- IAPT psychology services are inadequately set up or supported to meet the needs of patients living with neurological LTCs
- Systems & access criteria under existing specialist services – frequently & commonly not supportive of adequate psychological care
- Insufficient collaborative care frameworks locally
- Insufficient specialist staffing levels across the system to enable care and rehab access at rates needed
- Post-code lotteries of access geographically and by type of NLTC
- A holistic approach with local community partners.
- Supporting services such as therapy, exercises, housing with access, etc.
- Services that differentiate between stroke and MS.
- More access to MS Society resource leaflets/links so that newly diagnosed patients are made aware of what is on offer.
- Remote clinics – these carry benefits such as having family with the patient in the comfort of their own home.
- A specialist MDT service is needed but creating more local services may be unrealistic. Services can be organised and governed centrally but delivered locally in novel ways, they do not necessarily need to set up different teams. Services can have a regional network approach but would be good to look at gaps first and how to enhance and build upon existing teams and services.
- Explore what treatments can be delivered outside of the Walton centre (blood monitoring for example).
- It might be unrealistic to expect to have specific MS teams in all locations (perhaps neuro teams?) but better pathways could be developed, including referral processes and documents.
- There are some commonalities between other neurological conditions (Parkinson's and stroke for example) around symptoms and symptom management. It makes sense to provide interventions and services across all neurological conditions rather than focusing on providing fragmented services.
- It was noted that the MS pathway primarily reflects what happens in hospital or other clinical settings. It largely ignores what goes on in community settings. Many voluntary sector organisations provide services and activities neuro wide, some MS specific, but these are not reflected in the pathway.
- Community services are very important in order for pathway to work – community neuro teams are not in place in some areas. Frimley was able to do it because they already had nurses in place in the community.
- An MS specialist nurse talked about the service on Isle of Man. It is a small community with no permanent neurologist which can be difficult (neurologists come over from Walton Centre). There is a MS Working Group which plans study days, newly diagnosed events and have developed a new booklet about available services, including neuro Pilates that the MS Society funds. There are monthly MDT meetings for motor neurone disease patients which includes voluntary sector and health

professionals (but not neurologist) – helps to get to know patients well and provides a joined-up service.

### **Action points**

- Need for the development of an MDT Forum where complex (neurological) cases can be discussed and care arranged/ signposted from
- Development of a community-based rehab model of care including clinical psychology/ clinical neuropsychology input into the MDT
- Supporting improved integrated care access for people living with neurological disorders/ LTCs
- Reducing access inequalities to specialist care
- Look at how to work with and include local community partners.
- Improvement of neurology and local therapy access
- Collaborative working between specialist providers and the third sector, to support third sector-based emotional support services (along similar lines to Aintree's CHP Dept.'s support of Stroke Assoc. and Neurological Alliance support services)
- Support of IAPT care to this population through training & clinical supervision
- Social Prescribing & befriending support services

## Glossary

CAB	Citizens Advice Bureau
CCG	Clinical commissioning group
DMT	Disease-modifying therapy
ICS	Integrated Care Service
IAPT	Improving Access to Psychological Therapy
IV	Intravenous
MDT	Multidisciplinary team
MLOS	Mean length of stay
MS	Multiple sclerosis
PCN	Primary Care Network
UTI	Urinary tract infection
WINS	Worcestershire integrated neurology services

## Participants

Paula Guest	Head of Planning and Delivery, Out of Hospital
Tony McLeod	Commissioning & Transformation Manager/ Senior Project Manager
Lismy Cheripelli	Project Manager, Thriving & Prevention
Jon Dobson	Acting Services Manager
Carole Griffith	Community Therapist
Ian Baddiley	Practice Manager, Adult Healthy Lives
Mark Palmer	Sports Development Manager
James Dixon	Empower Project Coordinator/Holiday Camp Coordinator
Mark Griffiths	Consultant Clinical Psychologist
Jane Johnston-Cree	Centre Director
Dr Joanne Jury	Clinical Psychologist
Lyndsay Atkinson	Specialist Neuro Physiotherapy
Dr Ian Pomeroy	MS Team
Dr Roger Mills	MS Team
Prof Carolyn Young	MS Team
Dr Martin Wilson	Consultant Neurologist
Carolyn Cairns	MS Specialist Nurse
Yvonne Copeland	MS Team
Liene Elson	MS Team
Jenny Thain	MS Clinical Specialist Physiotherapist / LTC PT Team Lead
Michelle Ennis	OT Clinical Lead, Neuro Long-term Conditions Team
Fiona Roberts	MS Specialist Occupational Therapist
Tanya Bennett-Freeman	Integrated Neurology Nurse Specialist
Louise Fasting	Neurology Nurse Specialist
Dr Anita Krishnan	Consultant Neurologist
Julie Riley	Neuro Science Prog
Katy Hancock	
Heidi Morris	Neurology Nurse Specialist
Matthew Craner	
Georgina Carr	CEO Neurological Alliance
Jennifer Dodd	Associate Director of Transformation
Gemma Byrne	Programme Manager Innovation Adoption
Sue Thomas	CEO Wilmington Healthcare Consulting
Ruth Austen-Vincent	Stakeholder Engagement - MS Society
Yvonne Trace	Stakeholder Engagement – MS Society
Sandra Bartolomeu Pires	Research Sister in Neurodegenerative diseases – Southampton Univ.
Saif Huda	Consultant Neurologist
Rob Wright	Person living with or affected by MS
Miranda Forward	Person living with or affected by MS
Allan Trafford	Person living with or affected by MS
Brenda Brockbank	Person living with or affected by MS
Claire Garton	Person living with or affected by MS

Colin Cheeseman	Governor, Walton Centre
Jenny Riddell	Integrated Care Team Care Co-ordinator - Speke and Belle Vale
Jennifer Duffy	Divisional Manager, Neurology
Hannah Butler	Integrated Care Team Care Coordinator, West Derby and Picton
Valerie Trimble	

## Questions and chat facility from event

Really useful walk through the pathway with really useful local info on delivery. Thanks

Thank you so much for that Ian. Just to flag that the draft pathway was published for consultation over the summer - currently running through the comments received. But if you could like a copy, it is available for download here: <https://www.neural.org.uk/consultation-clinical-pathways-on-ms-autoimmune-and-epilepsy/>

Wonderful, thank you for the link

Dr Pomeroy has talked about using local rehab services. Experience of using these services to manage symptoms over the past 10 years tell me that local services struggle to provide basic access to physiotherapy, bowel and bladder services among other things. The provision usually has a woeful understanding of neuro conditions. How does The Walton Centre intend to either track the efficiency of these services for MS clients the use of local services or ensure that clients can access the services they need?

Hi a good and important question we need to discuss in the workshops and feed into work to see how these services can be developed. So please take this point to the workshops.

Central and South Cheshire has a DGH which has no neurology department of its own, but links with Stoke for neurological advice. This often creates big difficulties with non-elective admissions. How can the Walton Centre link more effectively with these clients who have their consultant and in theory their care from this Pathway? Clients do fall out of focus in this situation.

Do you have the OT telehealth data split by first and follow up?

Why is neurology so unpopular amongst medics?

How important was the development of a DMT service at a tertiary level, how do you think that impacted on access?

How do you link community-based therapists to your MDT meetings?

How is psychology embedded into and accessed within your model?

Would using a shared system be useful.? In Liverpool the community Services and primary care use EMIS

Interesting that you have prescribing MS nurses in Frimley as many MS nurses don't seem to prescribe any comments?

There is a drive for closer working with voluntary services who can have a significant impact on lifestyle, physical activity and self-management on people living with MS. Are there any plans to increase activity in this area as it doesn't seem to be included in the pathway?

Re prescribing nurses - absolutely invaluable. the prescribing course is challenging and involves time to support the nurse in it too. we are going to get another of our nurses on the course as inspired by Judith.

Accessible yoga, slimming group and accessible swim. worked very well as enabling self- management

NHSE is funding social link workers for general practices to support patients accessing third sector services. This would be a good

It is intended there will be only one CCG for the whole of Cheshire & Merseyside from April 22; this should support reduction of inequitable commissioning between areas

How much potential is there for Wellness Coordinators to be involved here?

Picking upon the voluntary sector point; support from the voluntary sector should be supported to provide accessible emotional support; within a stepped 'matched' psychological care (including neuropsychological

specialist access); to provide psychological care and support across stages of care. What has been developed within stroke pathways and what is now in stroke national guidance can be learned from, tailoring to MS needs. unmet psychological support needs being a real current gap affecting QoL; as we know regionally, from previous engagement work. We can certainly endeavour to better meet psychological / neuropsychological needs in MS than we currently do

I think the social link workers will need to feel able to link with professionals in with community services so they can get the best out of the social services they are signposting to. the accessible swimming involved lots of partnership working across education, voluntary sector service users and Community physio.

I'm sick of receiving emails from the MS society about grants re drug trials!

The Neuro Therapy Centre tries to address this as part of its core services, but this all costs money, and there appears to be a current lack of recognition of the preventative work that is done in the community. Much more could be achieved outside of the hospital with the right financial support, and would streamline the service and be more responsive to PLWMS needs

The accessible swimming was for a wide range of conditions not just MS as the warm water doesn't always suit people with MS the peer support of other disabled swimming was magic!

Real opportunities here within some wider psychological / neuropsychological care pathway work that certainly needs attention regionally. Such needs should be recognised by funding, care pathway and workforce planning

Many areas (including Liverpool) are developing integrated multi-disciplinary care teams covering neighbourhoods of 30,000-50,000 population. It will be important for specialist services to link into these.

I'm part of one of the Liverpool integrated care teams

We don't have a regional lab system in Cheshire & Merseyside - that is progressing but no simple solution to this until that is in place

Current MS psychology and neuropsychology access - is very piecemeal. We should look to system led solutions in this. No stepped psychological care either; lost opportunities in this so far

NB the brain and spine foundation are developing a directory of support nationally for all neurological conditions - held up due to COVID I believe. Would be helpful to link up

Consider Physiotherapy prescribers re symptom management

The pathway is light on health inequalities, and we haven't really touched on this yet today. Do you have a good understanding of a) if any particular sociodemographic groups of people with MS (or neuro conditions) more broadly aren't accessing care or having a good experience? if so, why? b) how equality, diversity and inclusion underpin the planning and delivery of your services?

The vanguard programme and in particular the neuro nurses did demonstrate improved access to services for people on lower incomes. An important point thanks

Many of the charities link in with local universities and run annual 'neuro days' to medical students and AHP students to engage them in the world of neuro and encourage specialism after qualified

There should be annual reviews with GP like CHD and COPD

Re vanguard - Therapy roles similar to the INNS would enhance links with community integrated teams

Are there any commissioners from Liverpool Sefton or Cheshire here?

There are community social prescribers who have this information and the liv well directory has some information regarding community services