

MS Service Cumbria – Audit

- Covers around 500 000 population
- Over 1047 MS patients, 241 on DMT
- Single referral point
- EMIS electronic patients records
- The team:
 - 1 consultant leading the service countywide
 - 3 MS Specialist Nurses 2 North/1 South
 - 2 Generic Specialist Neurology Nurses supporting infusions service
 - 2 consultant-lead specialist MS clinics per week
- Clinics in 5 areas across Cumbria ‘Close to Home’ delivery
- Weekly rapid access/relapse MDT clinics

DMT North and South Cumbria

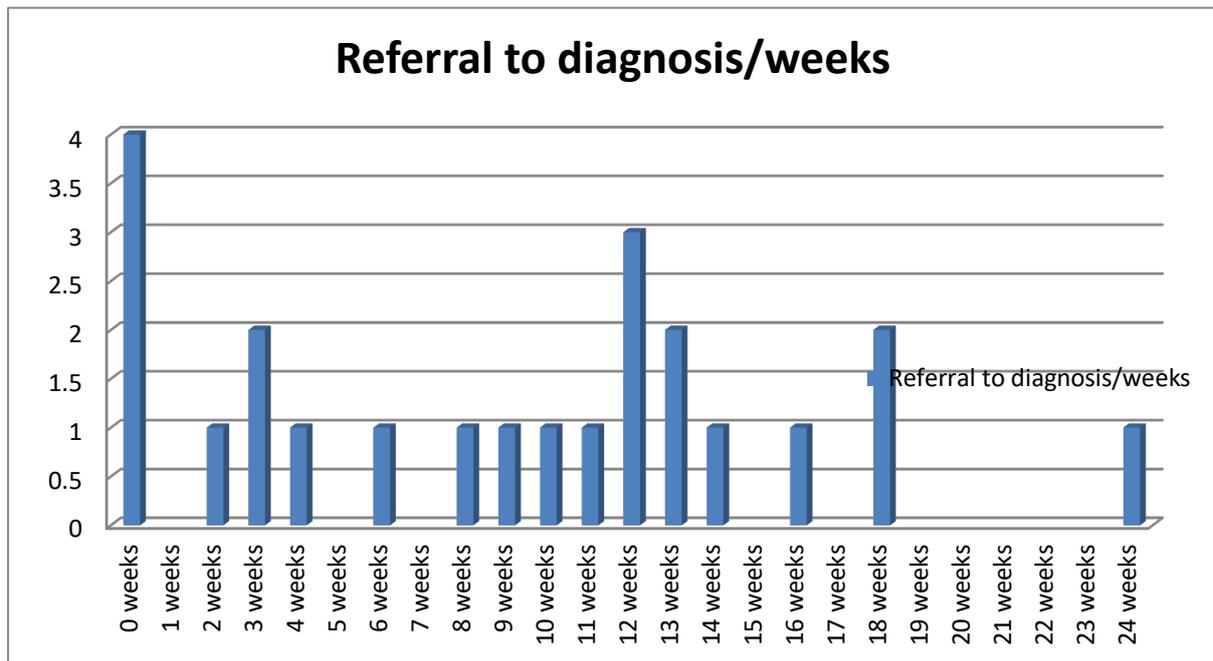
Summary (without patient’s names) Appendix 1 excel spreadsheet with the service info

DMT NORTH PATIENT TOTAL					DMT SOUTH PATIENT TOTAL			
	SH	JG	Total	RVI			Bluteq Done	
Aubagio	20	8	28	5			7	
Avonex	7	3	10	5			2	
Copaxone	12	4	16	6			4	
Fampyra	5	4	9	0			0	
Fingolimod	9	14	23	9			11	
Lemtrada	6	9	15	8			6	
Plegridy	1	1	2	0			0	
Rebif	4	10	14	1			2	
Tecfidera	10	15	25	6			11	
Tysabri	27	22	49	10			14	

RVI	50			50			
TOTAL DMT (DF)	101	90	191		TOTAL DMT (DF)	57	
DMT All Caseload	241						

Time from referral to diagnosis

Appendix 2 (MS patients list excel spreadsheet)



MS Interview questionnaire summary – cumulative narrative

7 questionnaires returned (1 manager, 2 nurses, 2 consultants, 1 service users, 1 MS society)

Participant

Consultant Nurse Manager other non-medical (please pick)

Q1

Do you think our MS service is better or worse than most services?

A/ **Better** B/ Worse C/Not sure

Why?

Q2

What elements of MS service do you value and we should keep as a part of the future service design.

Q3

What are the main current issues /problems which need addressing?

Q4

Would you expect that after introduction of the new revised diagnostic McDonalds MS criteria *, we will encounter new issues?

A/ Yes B/ No C/ Not sure

Why?

**The following changes were made: in patients with a typical clinically isolated syndrome and clinical or MRI demonstration of dissemination in space, the presence of CSF-specific oligoclonal bands allows a diagnosis of multiple sclerosis; symptomatic lesions can be used to demonstrate dissemination in space or time in patients with supratentorial, infratentorial, or spinal cord syndrome; and cortical lesions can be used to demonstrate dissemination in space.*

Q1

Better 2

Worse 0

Not sure 1

Why? Offer a broader service than other services other services tend to focus mainly on DMT but we cover more broad issues sometimes this can be seen as a positive, but it can also be a negative as it ends up creating significantly increased workloads.

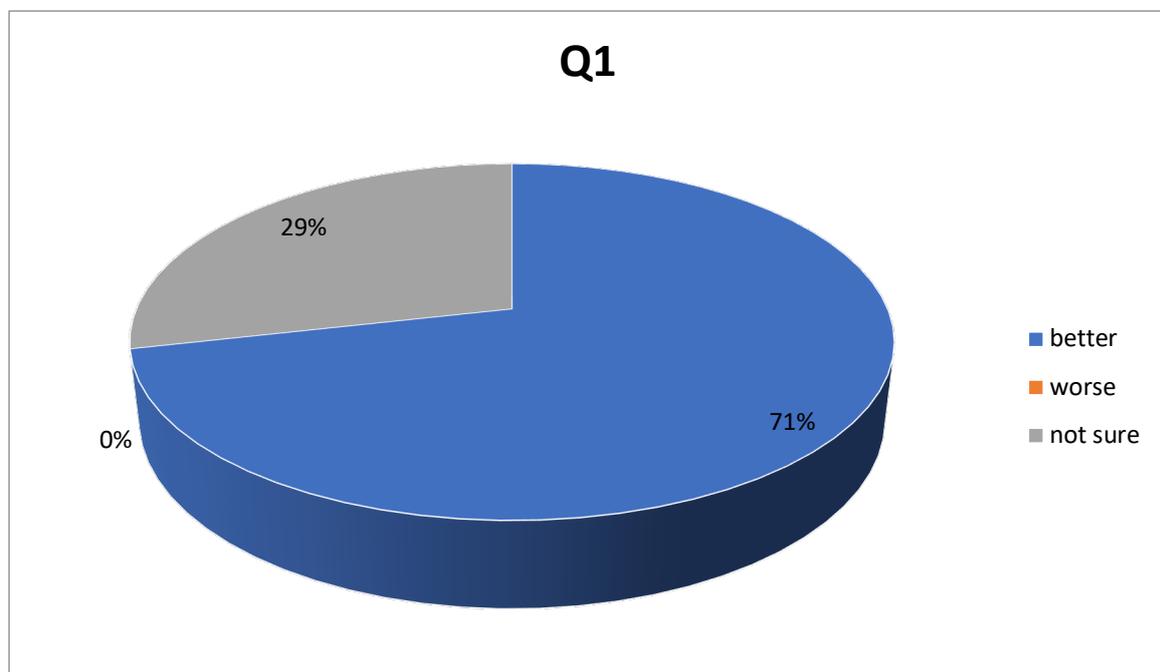
Underfunded, missing out on tariff means we have not got the funding to provide the service our patients deserve.

Links with rehabilitation much weaker

More robust system in place for quality and safety

Patient choice re clinic location

As this service provides everything that people affected by MS need, which is hugely beneficial for patients, but leads to concerns about sustainability. Difficult to do a comparison with other specialist services in Cumbria as we are not familiar with them.



Q2

DMT, DMT

Newly Diagnosed support

Annual Review

Accessibility, but this is a double-edged sword as often overwhelmed!

We provide our patients with high standard holistic care throughout the disease process

Infusion service

The MS Specialist Nurses are a huge value to people affected by MS in Cumbria. People who require to access the neurological services on a more emergency basis, value the ease with which they can contact the MS Nurses, with the opportunity to telephone and email greatly appreciated. The quick response to requests for help, especially when that help requires a consultation with a neurologist or MS nurse is hugely beneficial. Regular check ups with a neurologist are valued and the ability for the MS Nurses to signpost to other services when help is needed.

Prompt diagnosis with information and ongoing support around treatment options, including DMTs. Effective service design, which allows for treatments to be taken and monitored efficiently and safely. Flexibility for the MS Nurses to offer holistic community support (especially for people who have progressive MS) and be a persons key point of contact, at the centre of their multi-disciplinary team. The service seems to manage the rurality of Cumbria as well as it possibly can within the resources available. Having such specialist clinical knowledge of MS and its impact, is invaluable not just for people who have MS, but also over generic practitioners in the county, who need to be upskilled and supported.

Q3

Work load due to picking up broader issues

Lack of neuro Rehab Nurse to pick up and support patients who come to this part of their pathway

Lack of input from rehab consultant for same group listed above

Number of DMT Drugs and time required to manage these patients

Lack of suitable accommodation for infusion services

Resilience – we only have one Consultant who specialised in MS

Workload is relentless

Access to rooms, clinics, sustainable staffing, equipment storage

Problems with MS nurse availability recently, which are probably due to the very large workload. Also, some people have described that they are experiencing difficulty in seeing a consultant. There is a huge need for more clerical support, so the MS Nurses can spend more time supporting patients and less on paper work. Process's need to be addressed, which aim to prevent 'MS Nurse Burn-out'.

There are questions about how to contact the MS Nurse or Neurologist at present at times of relapse or support needed. We need to make sure that the people of Cumbria can maintain their treatment, care and support when the MS Nurse Service workforce changes significantly over the coming months and we don't get left behind with new developments in treatments.

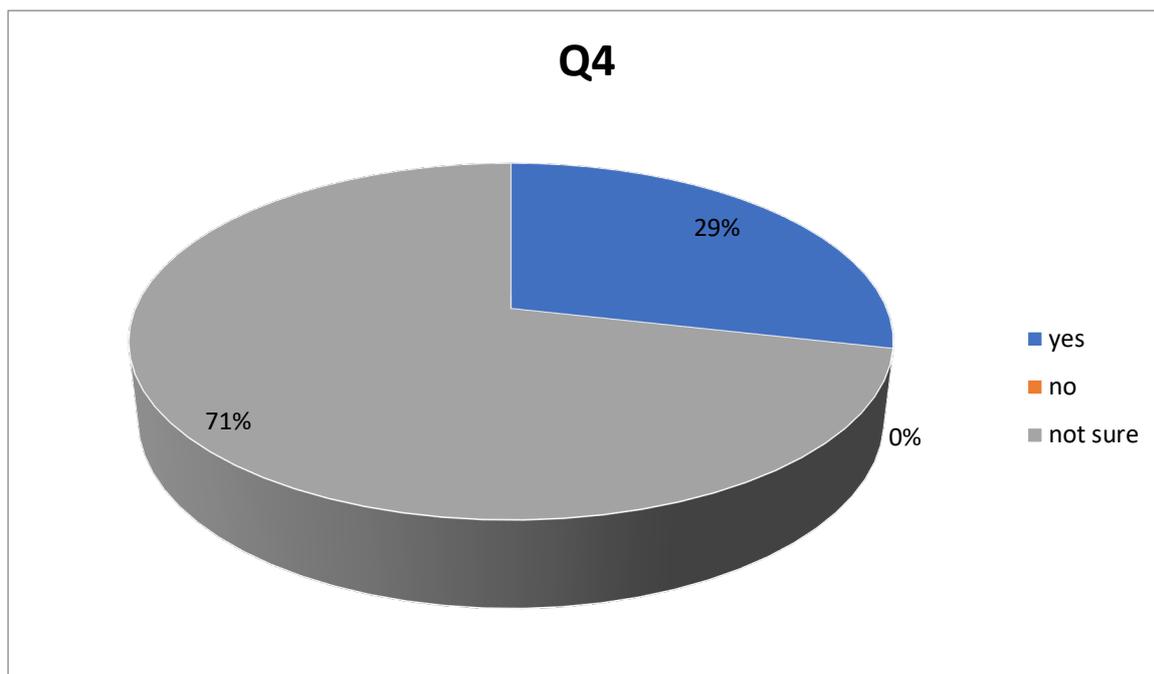
Facilities are not always suitable for wheelchair users. Patients with MS may also need to attend other clinics i.e. diabetes, podiatry. There should be good disabled access and parking for all clinics. Integration of social care, housing, finance and medical care, continues to be a difficulty as does equity in service across the county.

Q4

Yes 2

No 0

Not sure 5



Increased eligibility for Disease modifying therapy will increase demand and pressure on the service with no extra money to match a further increase in workload. (there will also be a further increase with the new drugs which are going to target patients with progressive disease – these patients previously did not meet criteria for DMT's either but again no more money for us to match increases in demand).

2 service users 1 MS society 1pt

Q1 - Do you think our MS service is better or worse than most services?

Better – As this service provides everything that people affected by MS need, which is hugely beneficial for patients, but leads to concerns about sustainability. Difficult to do a comparison with other specialist services in Cumbria as we are not familiar with them.

Q2 - What elements of MS service do you value and we should keep as a part of the future service design.

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Q3 - What are the main current issues /problems which need addressing?

Problems with MS nurse availability recently, which are probably due to the very large workload. Also, some people have described that they are experiencing difficulty in seeing a consultant. There is a huge need for more clerical support, so the MS Nurses can spend more time supporting patients and less on paper work. Process's need to be addressed, which aim to prevent 'MS Nurse Burn-out'.

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Summary Q2

- Newly diagnosed support group (educational platform)
- Prompt diagnosis with information and ongoing support around treatment options, including DMTs.
- Annual Review
- Excellent service accessibility, MS nurses point of contact (urgent app., telephone, e-mail...)
- Effective service design, which allows for treatments to be taken and monitored efficiently and safely
- MS Nurses offer holistic community support throughout the disease process
- Service is well designed able to manage rurality of Cumbria within the resources available

Summary Q3

- Lack of Neuro Rehab Nurse support
- Lack of input from Rehab Consultant
- Non-existence of sustainable staffing levels, resilience (1 consultant specialised in MS, 3 MS nurses/500 000)
- Workload is relentless, risk of 'MS Nurse Burn-out'
- Problem with access to accommodation, clinic rooms, equipment storage
- Telecare and skype not utilised for assessments and follow ups
- Facilities not always suitable for wheelchair users, lack of disabled access and parking in some clinics
- There is a need for more clerical support, so the MS Nurses can spend more time supporting patients
- Integration of social care, housing, finance and medical care, continues to be a difficulty
- Lack of equity in service provision across the county
- We need clarity from commissioners about the service future

Benchmarking

HES data Appendix 3

- Non-elective admissions and re-admissions /100 000 pop.
- Non-elective admissions and re-admissions /100 000 pop. Rural
- Non-elective admissions UTI

Benchmarking Summary

- Cumbria has less non-elective re-admissions/100 000 pop. compared to most services
- Cumbria has less non-elective re-admissions/100 000 pop. compared with similar rural regions
- Cumbria compared to Devon has less non-elective admissions with UTI

Recommendations

- Invest in Neuro-rehabilitation equitable service provision in Cumbria
- Increase staffing levels:
 - Appoint another consultant with MS speciality interest
 - Ensure of appropriate level of MS nurses staffing and contingency planning
 - Additional clerical support
- Improve links with community nurses and support to unburden MS nurses
- Utilise telehealth options
- Improve access to accomodation (clinic rooms, office space, car park) incl. disabled and wheelchair access
- Ensure that Changing Places/toilets at key community clinics between West Cumbria to the Cumbria border on route to Newcastle
- Better integration of social care, housing, finance and medical care
- Ensure of equity of the service provision across Cumbria
- Engage commissioners re future of the service provision

Dr Jitka Vanderpol

Consultant Neurologist Cumbria

4th June 2018