

## Your views about your MS Nurse

This questionnaire is about the service you have received from your MS nurse over the past 12 months. Your MS nurse team is using this questionnaire to find out what patients think about their service.

The questionnaire should take around 10-20 minutes to complete. By completing it, you will help us to develop and improve our service. The questionnaire is totally anonymous and we will not be able to identify you.

Once completed, please return by **xxxxxxx** using the envelope provided.

If you need help to fill in this questionnaire, please feel free to ask a relative or carer to help.

### Section A - About you and MS

#### 1. How long ago did you receive a definite diagnosis of MS?

	<i>Tick one</i>
Less than 1 year ago	
1-2 years ago	
3-4 years ago	
5-10 years ago	
10-20 years ago	
More than 20 years ago	
I have not been given a definite diagnosis	

#### 2. What type of MS do you currently have?

	<i>Tick one</i>
Relapsing remitting	
Secondary Progressive	
Primary Progressive	
Clinically Isolated Syndrome (CIS)	
Don't know / can't say	

### 3. Do you currently take disease modifying therapies / DMT's?

Note:- By this, we mean drugs which are used to reduce the frequency of relapses, not medicines for MS symptoms such as pain relief, steroids for relapses etc.

	<i>Tick one</i>
I don't take any disease modifying drugs	
Injectable disease modifying drugs (e.g. beta interferon, glatiramer acetate)	
Oral (tablet form) disease modifying drugs (e.g. fingolimod)	
Disease modifying drugs given through IV infusion in hospital (e.g. natalizumab)	

### 4. How would you rate your level of disability?

	<i>Tick one</i>
I can walk without help for 100 metres	
I need a stick, frame or wheelchair to get about but largely look after myself	
I am dependent on a wheelchair or in bed, and need a great deal of help with daily activities	

Draft for illustrative purposes only

## Section B - Your use of health services for your MS in the last 12 months

5. Who have you had a consultation with (face to face or over the phone) about your MS in the last 12 months?

<i>Tick all that apply</i>			
Neurologist	<input type="checkbox"/>	Physiotherapist	<input type="checkbox"/>
MS specialist nurse	<input type="checkbox"/>	Psychologist / counsellor	<input type="checkbox"/>
Other specialist nurse	<input type="checkbox"/>	Occupational therapist	<input type="checkbox"/>
GP	<input type="checkbox"/>	Speech and language therapist	<input type="checkbox"/>
Community / district nurse	<input type="checkbox"/>	Dietician	<input type="checkbox"/>
Palliative care specialist	<input type="checkbox"/>	I have not seen a health professional about my MS in the last 12 months	<input type="checkbox"/>
Rehabilitation medicine doctor	<input type="checkbox"/>	Other (please state): _____	<input type="checkbox"/>

6. In the last 12 months, have you been admitted to hospital for one or more nights?

	<i>Tick one</i>
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

7. If you answered 'Yes' to the previous question (question 6), what was the total number of nights you spent in hospital over the past 12 months?

(If you cannot remember, please estimate).

\_\_\_\_\_ nights

8. If you answered 'Yes' to question 6, what was/were the reason(s) that you were admitted to hospital? Please say whether you think this was linked to your MS or not.

## Section C – your experience of the MS nurse service

### 9. How many times have you had a consultation with an MS specialist nurse over the past year?

(If you can't remember how many times, please just give an estimate – please enter a whole number, if none enter '0').

Outpatient clinic consultation with MS nurse	No. of times _____
Home visit from MS nurse	No. of times _____
Consultation over the phone with MS nurse	No. of times _____
Visit from MS nurse whilst an inpatient in hospital	No. of times _____

### 10. What do you think about the amount of contact you have had with the MS specialist nurse over the past 12 months?

	<i>Tick one</i>
It was too much contact	
It was about right	
It wasn't enough – I would have liked more	

**11. Thinking about the care you have received from an MS specialist nurse over the past 12 months, which types of support have made a *positive difference* to you?**

(Tick all that apply. If the service hasn't made a positive difference to you please tick the option which is at the end).

<i>Tick all that apply</i>			
Emotional support	<input type="checkbox"/>	Diagnosis of a potential relapse	<input type="checkbox"/>
Information and education on MS	<input type="checkbox"/>	Starting treatment for a relapse (e.g. issuing prescription, advising your GP on treatment for a relapse)	<input type="checkbox"/>
Help to stay in employment	<input type="checkbox"/>	Advice on MS symptoms	<input type="checkbox"/>
Help to keep going with home or leisure activities	<input type="checkbox"/>	Support to identify issues caused by MS that could lead onto problems such as falls, infections, anxiety or depression	<input type="checkbox"/>
Information, advice and guidance for your family and carers	<input type="checkbox"/>	Help in obtaining benefits or other funding	<input type="checkbox"/>
Help to make an informed decision about treatment options with disease modifying drugs ( <i>see question A3 for what these are</i> )	<input type="checkbox"/>	Planning for any future problems / care planning	<input type="checkbox"/>
Help in getting disease modifying drug treatment established (e.g. injection training)	<input type="checkbox"/>	Help in accessing services from other health or care professionals	<input type="checkbox"/>
The service hasn't made a positive difference to me	<input type="checkbox"/>	Help in keeping disease modifying drug treatment on track (e.g. monitoring bloods, recommending changes to treatment, helping with using treatment correctly)	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>		<input type="checkbox"/>

**12. Please use this box to provide any examples of the positive difference your MS nurse team has made to you in the past 12 months.**

**13. If you hadn't had access to an MS nurse service over the past 12 months, what difference do you think it would have made to you?**

	<i>Tick all that apply</i>
It would have made no difference	
I would have struggled on my own	
I would have seen my GP more	
I would have seen my neurologist more	
I would have had to go to Accident and Emergency	
Other	

**14. Thinking back to the last time that you contacted your MS nurse service by phone, how soon were you able to talk to an MS nurse?**

	<i>Tick one</i>
I spoke with an MS nurse the same working day	
I spoke with an MS nurse the next working day	
I spoke with an MS nurse after 3–5 working days	
I spoke with an MS nurse more than 5 working days later	
I wasn't able to speak with a nurse at all	
I haven't phoned my MS nurse service in the last 12 months.	

**15. Is it easy enough to get hold of your MS nurse team when you need to?**

	<i>Tick one</i>
Easy enough all or most of the time	
Easy enough some of the time	
Not easy enough	
Don't know / can't say	

**16. Do you know when you will have your next consultation (by phone or in person) with your MS nurse?**

	<i>Tick one</i>
Yes to the nearest month	
Yes I have a specific date	
No, but I am happy with that. I know I can contact my MS Nurse if I need them	
No, but I would rather know when I am going to see my MS Nurse next	

**17. Are you as involved as you would like to be in making decisions with MS nurses about your care?**

	<i>Tick one</i>
Yes, definitely	
Yes, to some extent	
No	
Don't know / can't say	

**18. Have you been treated with dignity and respect by MS nurses you've had contact with during the past 12 months?**

	<i>Tick one</i>
Yes, definitely	
Yes, to some extent	
No	
Don't know / can't say	

**19. Do you have trust and confidence in the team of MS nurses that you have had contact with during the past 12 months?**

	<i>Tick one</i>
Yes, definitely	
Yes, to some extent	
No	
Don't know / can't say	

**20. Do you think that having an MS nurse has improved the co-ordination of your care or treatment during the past 12 months?**

	<i>Tick one</i>
Yes, definitely	
Yes, to some extent	
No	
Don't know / can't say	

**21. Is there anything that the MS nurse service has done particularly well over the past 12 months?**

**22. Is there anything that the MS nurse service could have done better or done more of over the past 12 months?**



## Section D - About you

23. Please tell us the first part of your postcode. (This will not identify you but will help us to map who uses our services).

\_\_\_\_\_

24. What is your gender?

	<i>Tick one</i>
Male	
Female	

25. What is your age? \_\_\_\_\_ years

26. What is your employment status?

<i>Tick one</i>			
Full-time paid employment (including self-employment)		Early retirement (on grounds of ill health)	
Part-time paid employment (including self-employment)		Early retirement (for other reasons)	
Not in paid employment		Retired	
Unemployed/seeking work			

Other (please specify)

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Thank you very much for your help. Now please return the questionnaire in the envelope provided. No stamp is needed.

Endorsed by:

