



Atlas: Multiple Sclerosis **A Questionnaire on Country Resources** **Cover Sheet**

Further explanation and definition of all words and phrases marked with an (asterisk)* can be found in the attached glossary.

Country Name:

Sent by:

Full Name:							
Title:							
Current position:							
Organization:							
Involvement with MS:							
Address:							
Telephone:							
Fax:							
E-mail:							
Date:	<table style="width: 100%; border-collapse: collapse; margin: 0 auto;"> <tr> <td style="width: 15%; border: 1px solid black;">Day</td> <td style="width: 15%; border: 1px solid black;"></td> <td style="width: 15%; border: 1px solid black;">Month</td> <td style="width: 15%; border: 1px solid black;"></td> <td style="width: 15%; border: 1px solid black;">Year</td> <td style="width: 15%; border: 1px solid black;"></td> </tr> </table>	Day		Month		Year	
Day		Month		Year			

Person(s) with MS (Full Name and E-mail address):

Full Name:	
E-mail:	
Full Name:	
E-mail:	
Full Name:	
E-mail:	

Please return a copy of the completed questionnaire by Wednesday 30 November 2005 via e-mail, fax or mail to:

Dr Tarun Dua
Office 6159
World Health Organization
1211 Geneva 27, Switzerland
Phone: + 41 22 791 3059
Fax: +41 22 791 4160
E-mail: duat@who.int

Mr Paul Rompani
Multiple Sclerosis International Federation
3rd Floor, Skyline House, 200 Union Street,
London SE1 0LX, United Kingdom
Phone: +44 20 7620 1911
Fax: +44 20 7620 1922
Email: paul@msif.org

Please do not hesitate to contact Tarun Dua or Paul Rompani with any questions.



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section A

1. Epidemiology of MS in the country

1.1 What is the estimated total number of people with MS in the country?

1.2 Please indicate the *source(s) of information**.

1.3 What is the estimated *prevalence** of MS in the country? /100,000

1.4 Please indicate the *source(s) of information**.

1.5 What is the estimated *incidence** of MS in the country? /100,000

1.6 Please indicate the *source(s) of information**.

1.7 What is the estimated mean *age of onset** (in years) of people with MS in the country?

1.8 Please indicate the *source(s) of information**.

1.9 What is the estimated male/female ratio of people with MS in the country? :

1.10 Please indicate the *source(s) of information**.

2. Multiple Sclerosis (MS) Groups and Organizations*

2.1 Is there a national or local patient group or organization involved in MS in the country?

Yes No

If yes, please indicate the following details for the three most prominent local or national patient groups or organizations involved in MS the country.

2.2 Please confirm the name of patient groups or organizations (NOT chapters or branches) and name and contact details of the key person.

a	
b	
c	

2.3 Please confirm the number of local centres, offices, chapters or branches of the patient group(s) or organization(s) listed in 2.2

a (as in 2.2)	
b (as in 2.2)	
c (as in 2.2)	

2.4 Please confirm the type of group(s) or organization(s) listed in 2.2 (with a tick '✓')

	<i>Non profit*</i>	<i>For profit*</i>	<i>Public*</i>
a (as in 2.2)			
b (as in 2.2)			
c (as in 2.2)			

2.5 Please confirm the approximate number of members of the patient group(s) or organization(s) listed in 2.2

a (as in 2.2)	
b (as in 2.2)	
c (as in 2.2)	

We understand that the estimated prevalence of MS in the country may be very low and there may be no local or national groups or organizations involved in MS. However, we would be grateful if you could try to complete all Sections.

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section B

1. Support available to people affected by MS

1.1 Please indicate who provides the following services and support to people affected by MS in the country (tick '✓' all that apply):

	Not Provided	MS Group or Organization*	Health Professionals*	Pharmaceutical Companies
1.1.1 Telephone Helpline				
1.1.2 Printed information* material				
1.1.3 Audio-visual material*				
1.1.4 Newsletter				
1.1.5 Website				
1.1.6 Other (please specify below):				

1.2 What are the most common/popular topics/titles of the printed information material provided?

1.2.1 General Information	<input type="checkbox"/>	1.2.7 Family issues (children, pregnancy)	<input type="checkbox"/>
1.2.2 Symptoms	<input type="checkbox"/>	1.2.8 Employment	<input type="checkbox"/>
1.2.3 Treatment	<input type="checkbox"/>	1.2.9 Research	<input type="checkbox"/>
1.2.4 <i>Alternative/Complementary therapy*</i>	<input type="checkbox"/>	1.2.10 Communication (hearing/speech)	<input type="checkbox"/>
1.2.5 Rehabilitation	<input type="checkbox"/>	1.2.11 Other (please specify below):	<input type="checkbox"/>
1.2.6 Lifestyle (diet, exercise, daily living)	<input type="checkbox"/>		

1.3 Does one group or organization in the country provide all the above listed printed information material on MS?

Yes No

1.4 If answer to question 1.3 is yes, please indicate which group or organization provides this service

1.5 Please indicate (with a tick '✓') who provides the following services and support in the country:

	Not Provided	MS Group or Organization*	Health Professionals*	Pharmaceutical Companies
Advice and advocacy* on MS issues				
1.5.1 Meetings, conferences and seminars				
1.5.2 Advising Government				
1.5.3 Lobbying/Campaigning Government				
1.5.4 General legal advice to people affected by MS				
1.5.5 Employment advice to people affected by MS				
1.5.6 Education advice to people affected by MS				
1.5.7 Other (please specify):				
Education and training*				
1.5.8 Training of health professionals on MS				
1.5.9 Courses for people with MS and their families				
1.5.10 Other (please specify):				
Personal support for people with MS				
1.5.11 Home Visits to people with MS				
1.5.12 <i>Self Help/Mutual Support Groups*</i>				
1.5.13 Transport				
1.5.14 Adaptations/Living aids/technical support				
1.5.15 Other (please specify):				
Support for family and carers				
1.5.16 <i>Respite Care*</i>				
1.5.17 Financial or work benefits				
1.5.18 Information for family and carers				

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section C

C1 Diagnosis of MS in the country

1.1 Please estimate (as a percentage) the frequency of the following presenting symptoms of MS recognised in the country?

1.1.1 Sensory	<input type="text"/> %	1.1.6 Pain	<input type="text"/> %
1.1.2 Visual	<input type="text"/> %	1.1.7 Urinary	<input type="text"/> %
1.1.3 Balance	<input type="text"/> %	1.1.8 Sexual dysfunction	<input type="text"/> %
1.1.4 Motor	<input type="text"/> %	1.1.9 Fatigue	<input type="text"/> %
1.1.5 Cognitive and/or behavioral	<input type="text"/> %	1.1.10 Other (please specify below)	<input type="text"/> %

1.2 What is the approximate time from initial presentation to diagnosis?

Between weeks/months and weeks/months (delete as necessary)

1.3 Which of the following diagnostic procedures are available in the country (tick '✓' all that apply)?

1.3.1 Magnetic Resonance Imaging (MRI)	<input type="checkbox"/>	1.3.3 Evoked potentials	<input type="checkbox"/>
1.3.2 Spinal tap/lumbar puncture	<input type="checkbox"/>	1.3.4 Other (please specify below)	<input type="checkbox"/>

1.4 If available, what is the estimated number of MRI machines in the country?

1.5.1 What percentage of the cost of an MRI test is covered by the Government (0-100%)?: %

1.5.2 What is the cost of an MRI test (in local currency)?
In Government /insurance covered facilities
In private clinics

1.6 If available, what is the approximate time from initial presentation to get an MRI?

Between weeks/months and weeks/months (delete as necessary)

1.7 Which *diagnostic criteria** are used (please tick '✓' all that apply)?

	Used
1.7.1 McDonald criteria	<input type="checkbox"/>
1.7.2 Poser criteria	<input type="checkbox"/>
1.7.3 Schumacher criteria	<input type="checkbox"/>

1.8 Which *diagnostic criteria** is the commonest diagnostic criteria used?

	Commonest
1.8.1 McDonald criteria	<input type="checkbox"/>
1.8.2 Poser criteria	<input type="checkbox"/>
1.8.3 Schumacher criteria	<input type="checkbox"/>

1.9 Does MS get diagnosed without MRI in the country? Yes No

1.10 At the time of diagnosis which of the following topics/titles of printed information material does the person with MS receive (you can tick more than one choice)?

1.10.1 What is MS	<input type="checkbox"/>	1.10.4 Counselling	<input type="checkbox"/>
1.10.2 Disease course & symptoms	<input type="checkbox"/>	1.10.5 Courses and education	<input type="checkbox"/>
1.10.3 Therapy options	<input type="checkbox"/>	1.10.6 MS organization	<input type="checkbox"/>

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section D

D1. Management of MS in the country

1.1 What is the estimated number of neurologists in the country?

1.2 Are there any *MS neurologists** in the country? Yes No

1.2.1 If yes, please confirm the number of MS neurologists

1.3 Are there any *MS nurses** in the country? Yes No

1.3.1 If yes, please confirm the number of MS nurses

1.4 What level of education/training do MS nurses in the country receive?

- | | | | | |
|--|-----|--------------------------|----|--------------------------|
| 1.4.1 None | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 1.4.2 Nursing diploma/degree/masters/PhD | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 1.4.3 MS specific education/training | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |
| 1.4.4 International accredited MS nursing exam | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> |

1.5 Are there any hospital based *interdisciplinary teams** involved in MS in the country? Yes No

1.6 If the answer to question 1.5 is yes, please indicate from the list below which health professionals are members of the hospital based interdisciplinary teams?

- | | | | |
|---------------------------------|--------------------------|--------------------------------------|--------------------------|
| 1.6.1 Neurologist | <input type="checkbox"/> | 1.6.6 Speech Therapist | <input type="checkbox"/> |
| 1.6.2 Physiotherapist | <input type="checkbox"/> | 1.6.7 MS Nurse | <input type="checkbox"/> |
| 1.6.3 Occupational Therapist | <input type="checkbox"/> | 1.6.8 Urologist | <input type="checkbox"/> |
| 1.6.4 Psychologist/Psychiatrist | <input type="checkbox"/> | 1.6.9 Gynaecologist | <input type="checkbox"/> |
| 1.6.5 Social Worker | <input type="checkbox"/> | 1.6.10 Other (please specify below): | <input type="checkbox"/> |

1.7 Are there any community based interdisciplinary teams involved in MS in the country? Yes No

1.8 If the answer to question 1.7 is yes, please indicate which health professionals are members of the community based interdisciplinary teams?

- | | | | |
|---------------------------------|--------------------------|--------------------------------------|--------------------------|
| 1.8.1 Neurologist | <input type="checkbox"/> | 1.8.6 Speech therapist | <input type="checkbox"/> |
| 1.8.2 Physiotherapist | <input type="checkbox"/> | 1.8.7 MS Nurse | <input type="checkbox"/> |
| 1.8.3 Occupational therapist | <input type="checkbox"/> | 1.8.8 Urologist | <input type="checkbox"/> |
| 1.8.4 Psychologist/Psychiatrist | <input type="checkbox"/> | 1.8.9 Gynaecologist | <input type="checkbox"/> |
| 1.8.5 Social worker | <input type="checkbox"/> | 1.8.10 Other (please specify below): | <input type="checkbox"/> |

1.9 Is there one place where all members of the interdisciplinary team are available? Yes No

1.10 If the answer to question 1.9 is yes, how many such places are there in the country?

1.11 If the answer to question 1.9 is yes, what is the approximate average time a person with MS has to wait to be seen for consultation by the interdisciplinary team?

Between weeks/months and weeks/months (delete as necessary)

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section E

E1. Treatment of MS in the country

1.1 Are the following disease modifying treatments available in the country?

1.1.1 Inteferon beta-1a (intramuscular)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
1.1.2 Inteferon beta-1a (subcutaneous)	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
1.1.3 Interferon beta-1b	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
1.1.4 Glatiramer acetate	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
1.1.5 Mitoxantrone	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
1.1.6 Other (please specify)				

1.2 Please explain the standard *clinical prescription criteria** for disease modifying treatments:

1.2.1 Please explain any differences in the clinical prescription criteria for the disease modifying treatments:

1.2.1 Inteferon beta-1a (intramuscular)	
1.2.2 Inteferon beta-1a (subcutaneous)	
1.2.3 Interferon beta-1b	
1.2.4 Glatiramer acetate	
1.2.5 Mitoxantrone	
1.2.6 Other (please specify)	

1.3 Please confirm the approximate cost (in local currency) per month and corresponding strength/dosage (in milligrams):

	Cost	Dosage
1.3.1 Inteferon beta-1a (intramuscular)		
1.3.2 Inteferon beta-1a (subcutaneous)		
1.3.3 Interferon beta-1b		
1.3.4 Glatiramer acetate		
1.3.5 Mitoxantrone		
1.3.6 Other (please specify)		

1.4 What percentage of people with MS who fulfil/meet the clinical prescription criteria for disease modifying drugs receive treatment?

%

1.5 If the answer to 1.4 is not 100% please tick the reason(s) why:

- 1.5.1 Access to neurologist
- 1.5.2 General national clinical practice
- 1.5.3 Funding policy
- 1.5.4 Patient choice
- 1.5.5 Other (please specify):

1.6 What is the *source of financing** of disease modifying drugs (Indicate percentage paid)

- 1.6.1 Out-of- pocket %
- 1.6.2 Insurance %
- 1.6.3 Government %

1.7 Which of the following drugs are used for treating *exacerbations*/relapses*?

- | | Oral | IV |
|----------------------------------|--|--------------------------|
| 1.7.1 Dexamethasone | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.7.2 Prednisolone/Prednisone | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.7.3 Methylprednisolone | <input type="checkbox"/> | <input type="checkbox"/> |
| 1.7.4 Plasmapheresis | | <input type="checkbox"/> |
| 1.7.5 Intravenous immunoglobulin | | <input type="checkbox"/> |
| 1.7.6 Other (specify) | <input style="width: 450px;" type="text"/> | |

1.8 Please indicate if drugs are available to treat the following symptoms of MS (tick '✓' all that apply):

- | | | | |
|-----------------------------------|--------------------------|--------------------------|--------------------------|
| 1.8.1 Sensory | <input type="checkbox"/> | 1.8.6 Pain | <input type="checkbox"/> |
| 1.8.2 Visual | <input type="checkbox"/> | 1.8.7 Urinary | <input type="checkbox"/> |
| 1.8.3 Balance | <input type="checkbox"/> | 1.8.8 Sexual dysfunction | <input type="checkbox"/> |
| 1.8.4 Motor | <input type="checkbox"/> | 1.8.9 Fatigue | <input type="checkbox"/> |
| 1.8.5 Cognitive and/or behavioral | <input type="checkbox"/> | 1.8.10 Other symptoms | <input type="checkbox"/> |

1.9 What of the following *various complementary/alternative therapies** are used by people with MS in the country (tick '✓' all that apply)?

- | | | | |
|-------------------------------------|--------------------------|-------------------|--------------------------|
| Acupuncture | <input type="checkbox"/> | Homeopathy | <input type="checkbox"/> |
| Aromatherapy | <input type="checkbox"/> | Hypnosis | <input type="checkbox"/> |
| Ayurvedic Medicine | <input type="checkbox"/> | Hypnotherapy | <input type="checkbox"/> |
| Biofeedback | <input type="checkbox"/> | Hyperbaric oxygen | <input type="checkbox"/> |
| Cannabis | <input type="checkbox"/> | Iridology | <input type="checkbox"/> |
| Chiropractic/Osteopathy | <input type="checkbox"/> | Macrobiotics | <input type="checkbox"/> |
| Dentistry (replacement of fillings) | <input type="checkbox"/> | Massage | <input type="checkbox"/> |
| Diet/Nutrition | <input type="checkbox"/> | Naturopathy | <input type="checkbox"/> |
| Herbal Medicine | <input type="checkbox"/> | Pilates Method | <input type="checkbox"/> |
| Others (please specify) | <input type="checkbox"/> | | |

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section F

F1. Quality of life of people with MS

1.1 Is private health insurance available to people with MS in the country? Yes No

1.1.1 If yes, what are the legal issues regarding provision of private health insurance to people with MS?

1.2 Is travel insurance available to people with MS in the country? Yes No

1.2.1 What are the legal issues regarding provision of travel insurance to people with MS?

1.3 Is MS mentioned in the legislation for driving in the country? Yes No

1.3.1 If yes, what does the legislation mention regarding driving for people with MS?

1.4 Is there a mention of MS related issues in the legislation for employment in the country? Yes No

1.4.1 If yes, what does the legislation mention regarding employment for people with MS?

1.5 Is it possible for a person with MS to lose their job because he/she has MS? Yes No

1.6 Is there a mention of MS related issues in the legislation for education in the country?

Yes No

1.6.1 If yes, what does the legislation mention regarding education for people with MS?

1.7 Is there a mention of MS in the legislation for *disability entitlements** in the country?

Yes No

1.7.1 If answer to question 1.7 is yes, what does the legislation mention regarding disability entitlements for people with MS?

1.7.2 If answer to question 1.7 is yes, what are the main disability entitlements that are available to people with MS (tick '✓' all that apply)?

1.7.2.1 Money compensation (pension/allowance)

1.7.2.2 Tax benefits

1.7.2.3 Rehabilitation and health benefits

1.7.2.4 Benefits in the work place (e.g. relocation, early retirement etc)

1.7.2.5 Benefits in the home

1.7.2.6 Other benefits (e.g. housing, transport, education, discounts etc)

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

1.7.3 If the answer to 1.7 is NO are there disability entitlements available to people with MS as part of general legislation?

Yes No

This Section was completed by:

Full Name:

E-mail:



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Section G

G1. Issues in MS care

1.1 What are the five major issues for people living with MS in the country?

1.1.1

1.1.2

1.1.3

1.1.4

1.1.5

1.2 What are the five major issues for health professionals involved in MS care in the country?

1.2.1

1.2.2

1.2.3

1.2.4

1.2.5

1.3 What are the five major changes that you would suggest to improve MS care in the country?

1.3 .1

1.3 .2

1.3 .3

1.3 .4

1.3 .5

1.4 Any other additional comments?:

This Section was completed by:

Full Name:

E-mail: