

The following data has been collected by the 14 MS specialist nurse teams who took part in the GEMSS project over the year April 2014-March 2015.

1. Activity data (numbers collected monthly via Excel sheet, some items can be populated with data through a hospital information system request)

- New referrals received by the service
- Patients removed from caseload (died, discharged)
- Outpatient consultations carried out, by location
- Outpatient DNAs by location
- Home visits
- Home visit DNAs /patient not in
- Patients visited on wards
- Patients started or switched on Disease Modifying Therapies
- Attendees at group sessions (e.g. new patient or fatigue management courses)
- Phone calls received (inbound or callback patient/carer)
- Phone calls received (inbound or callback from healthcare professionals and other professionals working with MS patients)
- Phone calls made - outbound to patient/carer
- Phone calls made - outbound to healthcare professionals and other professionals working with MS patients
- Number of patients with acute deteriorating symptoms (including suspected relapses) presenting to service

2. Process measures / KPI data (numbers collected monthly for I-III. Each team set a stretching but realistic local target in working days and then assessed the % met)

- I. % of newly referred patients¹ seen by the service for a holistic assessment by the MSSN within x working days of receipt of the referral (*most teams chose to measure against 10, 15 or 20 working days*)
- II. % of incoming phone calls from patients responded to within x working days (*most teams chose to measure against 2 or 3 working days*)
- III. % patients with acute deteriorating symptoms (including suspected relapses) contacted for assessment and appropriate management² within x working

¹ In practice this is mainly newly diagnosed patients, but also includes those new to the service (e.g. moved into the area).

² 'Assessment and appropriate management' may constitute telephone based assessment and putting in place a treatment plan, for example by making a prescribing recommendation to the GP by fax, in line with a relapse protocol. It may also include booking the patient into an MS clinic for face to face examination.

day(s) of alerting the service (*most teams chose to measure against 1 or 2 working days*)

- IV. Proportion of patients on the caseload who have had a face to face review with an MSSN in the past year (measured once each year, either through an information request or, if this is not possible, via the patient survey with a representative sample of the caseload).

3. Caseload data - for each patient on caseload (continuously updated) (Excel sheet, but many teams use their own databases instead)

- First name*
- Last name*
- Gender
- Postcode*
- Named MSSN within team (if applicable)*
- Date of birth* (which automatically calculates age)
- Ethnicity (standard NHS categories provided)
- Hospital number* and/or NHS number* and/or CHI number (Scotland)w*
- Type of MS³
- Date of diagnosis (exact or to nearest year)
- Level of disability⁴ (defined as mild, moderate, severe)
- Current DMT treatment (list of licensed and common DMTs is provided, custom ones can be added to the list)
- Date DMT treatment started*
- Date last seen by MSSNs*
- Planned date of next review*
- Planned review frequency (SOS, 1m, 3m, 6m, 12m or custom)*

*These data items were not collated centrally by the MS Trust as part of GEMSS evaluation but included in the database to make it more operationally useful. Teams could add additional fields locally if they wished.

³ Defined as CIS, relapsing remitting, primary progressive, secondary progressive, progressive – not known, not known.

⁴ This is defined as:

Minimal - EDSS 5.5 or below (walking without aid to 100m)

Moderate - EDSS 6 - 7.5 (needs stick, frame or chair to get about but largely self-caring)

Severe - EDSS 8 or above (limited use of upper body, immobile, possibly bed bound)

4. Patient service utilisation and experience measures (collected once during the year via patient survey of a representative sample of the caseload)

Questions are all MCQ or closed ended except where stated.

Patients' use of services

- Number of times seen different health professionals (from tick list) about MS in the past year
- Whether pt has attended a self management or 'understanding MS' course, and whether they would like to
- Admissions in the past year, number of nights, reasons (MS related or not, free text for detail)
- Use of MSSN services in past year (OP appts, HVs, phone calls)

Experience of MSSN service (those marked ** were used for performance comparison across teams)

- Views on whether MSSN support was too little/about right / too much**
- Benefits of having access to an MSSN in past year (tick list of options, 'It's made no difference' option, free text field for examples)
- Difference it would have made if there hadn't been an MSSN in the past year (tick list)
- Time to return of call last time you phoned the MSSN service**
- General ease of getting hold of the MSSN service – easy enough all of the time, most of the time or not easy enough.
- Whether they know when they will see their MSSN next
- Extent of involvement in decisions about care by MSSNs**
- Extent of being treated with dignity and respect by MSSNs**
- Trust and confidence in the MSSN service**
- Best things and suggestions for improvement on the MSSN service (free text fields)
- 'Friends and family' test (Would you recommend the MSSN service...?)

Background demographics (for comparison with utilisation and experience data)

- Time since diagnosis
- Type of MS
- DMTs taken now (none / self-injected / oral / IV)
- Disability (defined as mild, moderate, severe)
- Postcode (first part only)
- Gender
- Age
- Employment status

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