Scotland has an unenviable number of people affected by Multiple Sclerosis (MS). Some of the highest reported rates of MS, both incidence and prevalence in the world. However accurate recording of definitive numbers has not been possible, most of the reported rates relying upon retrospective data which may contain inherent flaws due to the uncertainty of accuracy of case ascertainment.

The Scottish MS Register was created in 2010 in order to provide for the first time a valid and reliable information. It contributes to service improvements for those with MS in Scotland. To achieve this goal, the Register collects information on the person’s journey, from symptoms to a definitive diagnosis of MS, to referral to a MS Nurse Specialist.

Why is the Scottish MS Register important?

Results

- In 2014, 431 new patients were reported to the MS Register. This brings the total number of people reported over the five year period to 2164. (Figure 1)
- The average annual incidence over the five year time period shows that more than twice as many women as men were diagnosed with MS. (Figure 2)
- In 2014, 63% had contact with a MS Nurse Specialist within two weeks of diagnosis. This is a 7% improvement on 2013 (56%) though performance does vary. (Figure 3)
- Delays in MS Nurse Specialists receiving referrals from Neurologists continue to be problematic.
- In 2014, once the referral was received by the MS Nurse Specialist, contact within two weeks was achieved for 85% of the patients. (Figure 3)

Aim

MS is the most common disabling neurological condition among young adults in Scotland. The Scottish MS Register was created in 2010 in order to provide for the first time a valid assessment of the numbers of people with a new diagnosis of MS. The purpose of collecting reliable and valid information is that it contributes to service improvements for those with MS in Scotland. To achieve this goal, the Collect registers information on the person’s journey, from symptoms to a definitive diagnosis of MS, to referral to a MS Nurse Specialist.

Methodology

Data recording each new case of confirmed MS made by a Consultant Neurologist since 1st January 2010 have been collected primarily by the MS Nurse Specialists using an agreed proforma. Data are validated and analysed providing the clinical teams with quarterly reports containing local data and an annual National Report.

Outcomes and benefits

1. To improve the quality of health care services and so ultimately the health of those with MS in Scotland.
2. To allow clinical teams to prioritise areas of service improvement through the use of valid and reliable information.
3. To allow comparison of clinical services at local and national levels against published national Neurological Standards relating to MS.
4. To initiate and manage research to provide evidence to substantiate change in practice.

Conclusion

There continues to be a great opportunity for Scotland to develop this unique Register of those newly diagnosed with MS. These data provide a picture of the potential of the Register in its ability to provide a benchmark against which clinicians can raise standards and drive improvements in MS management across Scotland.

Notes:
1. Analysis above is calculated using cases for which contact with a MS Nurse Specialist was not declined. Cases for which contact was declined (Nbr < 36) have been excluded.
2. Two patients have been excluded from the calculation pertaining to the number of weeks between confirmed diagnosis and 1st contact as they both received a confirmed diagnosis from Consultant neurologists out with Scotland (Wales and Australia).
3. One patient has been excluded from the above analysis due to incomplete/missing date of confirmed diagnosis.

Figure 1

Number of people newly diagnosed with MS in Scotland, 2010-2014 data (by Health Board)

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Year of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2010</td>
</tr>
<tr>
<td>NHS Ayrshire &amp; Arran</td>
<td>16</td>
</tr>
<tr>
<td>NHS Borders</td>
<td>8</td>
</tr>
<tr>
<td>NHS Dumfries &amp; Galloway</td>
<td>12</td>
</tr>
<tr>
<td>NHS Fife</td>
<td>29</td>
</tr>
<tr>
<td>NHS Forth Valley</td>
<td>17</td>
</tr>
<tr>
<td>NHS Grampian</td>
<td>34</td>
</tr>
<tr>
<td>NHS Greater Glasgow &amp; Clyde</td>
<td>95</td>
</tr>
<tr>
<td>NHS Highland</td>
<td>27</td>
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<tr>
<td>NHS Lanarkshire</td>
<td>48</td>
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<tr>
<td>NHS Lothian</td>
<td>60</td>
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<td>NHS Orkney</td>
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<tr>
<td>NHS Shetland</td>
<td>4</td>
</tr>
<tr>
<td>NHS Tayside</td>
<td>42</td>
</tr>
<tr>
<td>NHS Western Isles</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>422</td>
</tr>
</tbody>
</table>

Notes:
1. One patient residing in NHS Lanarkshire Board area, did not have a year of confirmed diagnosis recorded and consequently has been removed from the above table.
2. 2014 data for NHS Lothian denoted * are incomplete due to data collection issues.
3. Data for NHS Shetland denoted ** are incomplete due to data collection issues.

Figure 2

Average annual incidence of people newly diagnosed with MS in Scotland per 100,000 population, 2010-2014 data (by gender)

Figure 3

Percentage of people with a new diagnosis of MS contacted by a MS nurse within two weeks of confirmed diagnosis Vs percentage contacted within two weeks from receipt of referral, 2010-2014 data

Notes:
1. Arithmetic mean of mid-year gender population estimates for 2010-2014 have been used for the above analysis, and the arithmetic mean incidence for each gender across the 5 year time period has been taken.
2. Arithmetic mean age for each gender is calculated using patients date of birth quoted at time of confirmed diagnosis.
3. Three males and five females were excluded from the above analysis as their date of confirmed MS diagnosis was unknown.

Reference


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