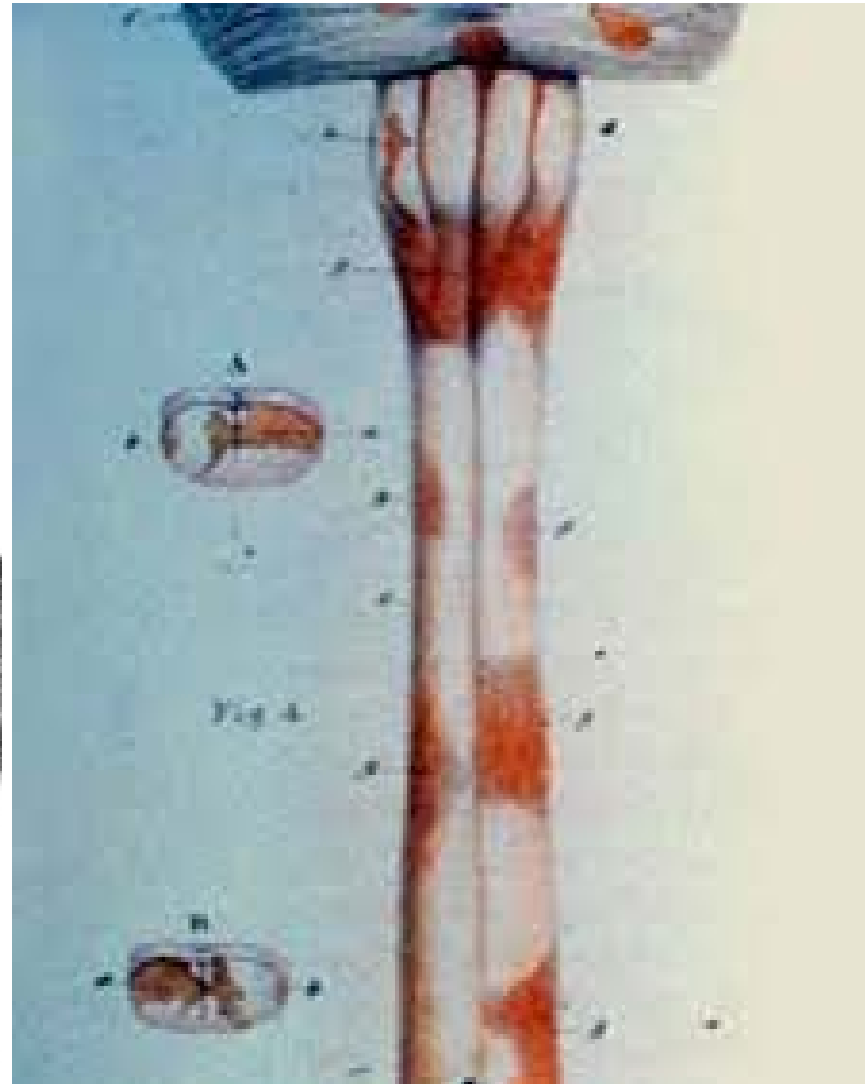
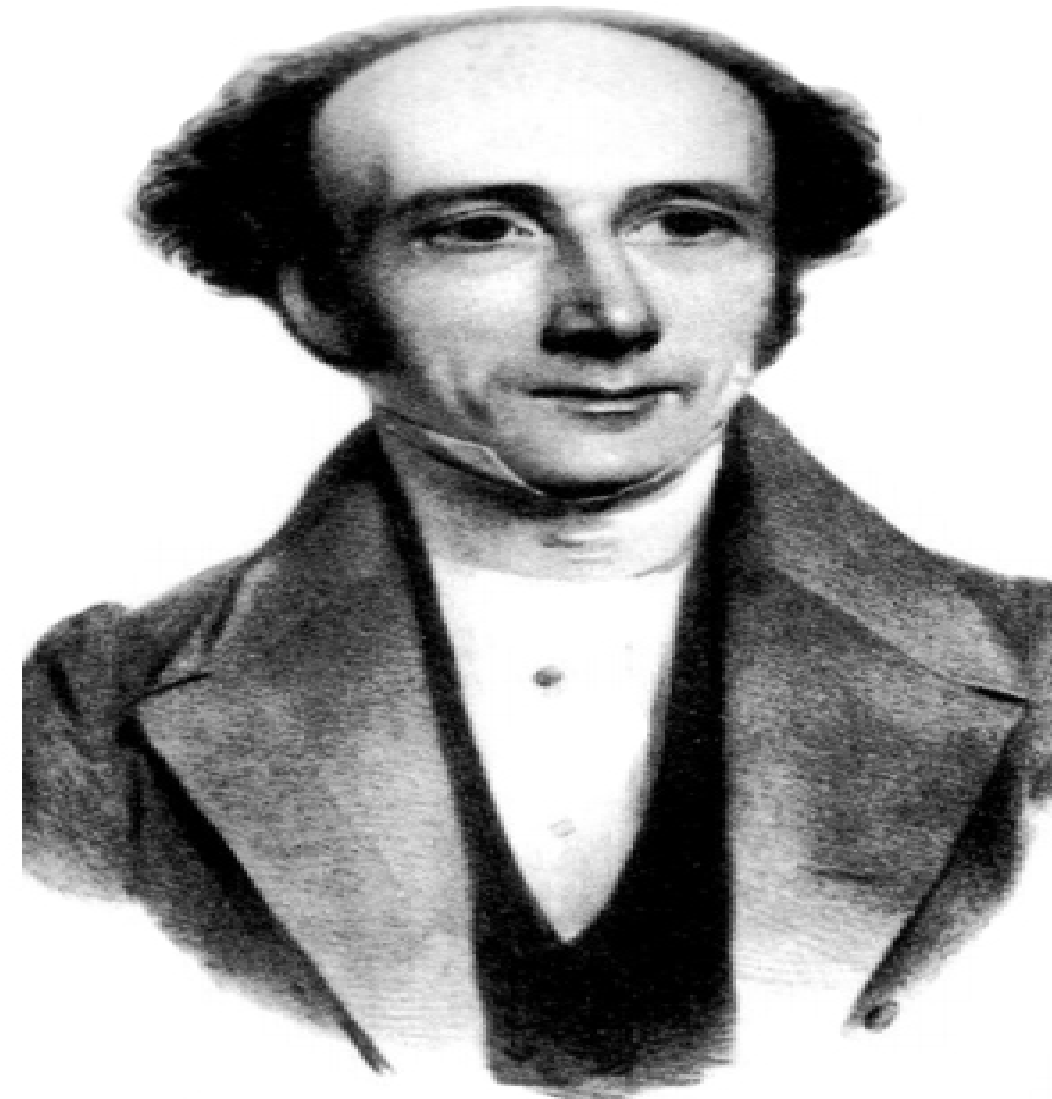


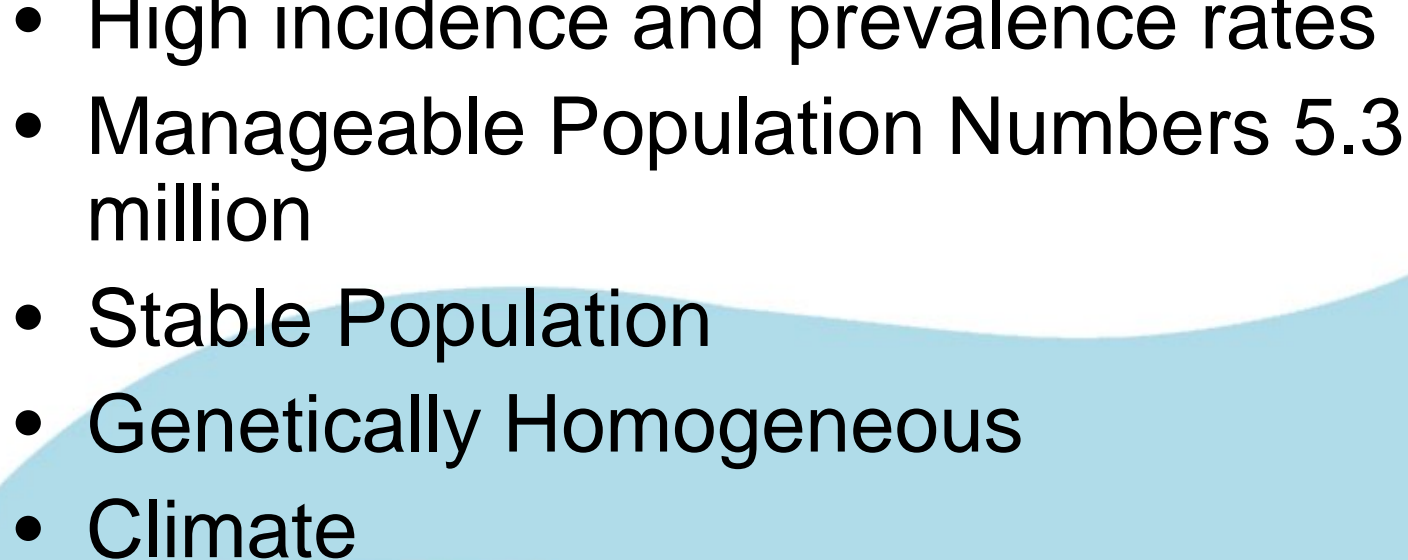
# Scottish National MS Incidence Register: Lessons From the First Five Years

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On behalf of the Scottish MS Register  
Steering Committee  
8 September 2015



## Why Scotland?

- High incidence and prevalence rates
  - Manageable Population Numbers 5.3 million
  - Stable Population
  - Genetically Homogeneous
  - Climate
- 
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## Development of the Register

- Originally proposed by Scottish MS Society in 2005
- Steering Group Formed in 2006
- Administration of Register by ISD from 2009
- First report 2010

## Aims

- To establish accurate incidence rates of MS in Scotland
- To inform Service Planning
- To audit standards of care against published Scottish Government Guidelines
- To develop a database of newly diagnosed PwMS to facilitate epidemiological and clinical research

## Inclusion Criteria

All newly diagnosed patients with MS living in a Scottish Health Board area

Diagnosis made by Consultant Neurologist using revised McDonald criteria

# Exclusion Criteria

Clinically isolated Syndromes

“Possible” MS

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# MS Register Incidence Form v2



Person who confirms diagnosis of MS, please complete grey area and send form to MS Team

Hospital: \_\_\_\_\_

Completed By: \_\_\_\_\_

**1. Personal details** Place patient label here (or write details).

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_

**Postcode:**

**DOB / CHI No:**

**Hospital No:**

**SEX:**  Male=1, Female=2

**2. Investigations** No=0, Yes=1, Not known=9

**Was a brain MRI carried out?**

**Was a spinal cord MRI carried out?**

**Was a lumbar puncture carried out?**

**Were Evoked Potentials carried out?**

**3. Date of diagnosis:**   /   /

**Particular form of MS:**  Relapsing-remitting=1, Primary progressive=2, Secondary progressive=3, Not known=9

**4. MS Team contact**

**Date of 1<sup>st</sup> contact with MS team:**   /   /

**Date of referral to MS nurse:**   /   /

**Date referral received by MS nurse:**   /   /

**Date of first 1<sup>st</sup> contact:**   /   /

**Type of contact:**  Phone=1, Letter=2, Clinic=3, New diagnosis group=4, Declined=5, Ward=6, Not known=9 Other=8 (please specify) \_\_\_\_\_

**5. Optional Information**

**Date of 1<sup>st</sup> onset of symptoms:**   /   /

**Does any 1<sup>st</sup> degree family member have a diagnosis of MS?**  No=0, Yes=1, Not known=9

**If yes, (please specify)** \_\_\_\_\_

**Country of Birth:** \_\_\_\_\_

**Domestic Status at time of diagnosis:** \_\_\_\_\_

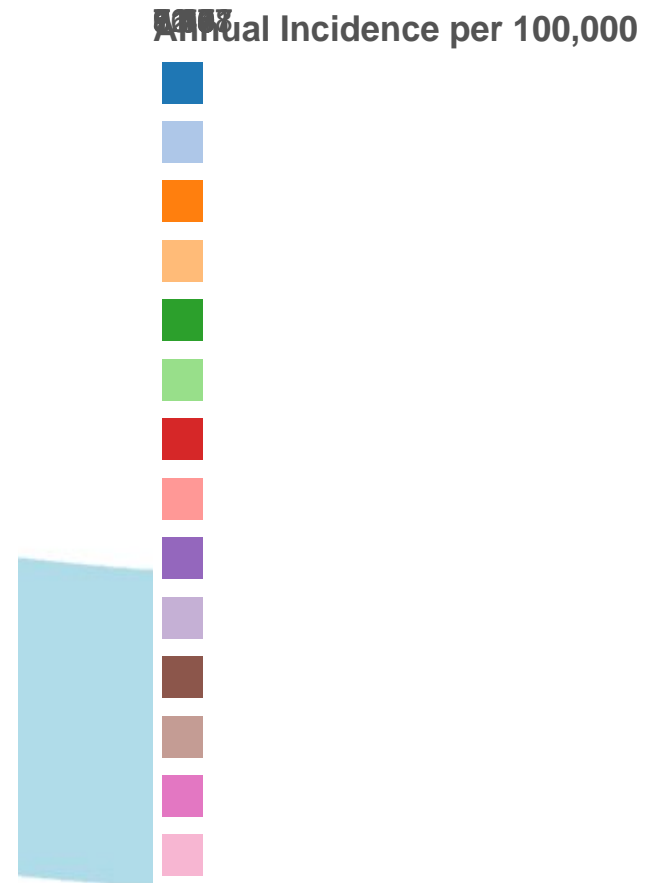
**Employment Status at time of diagnosis:** \_\_\_\_\_



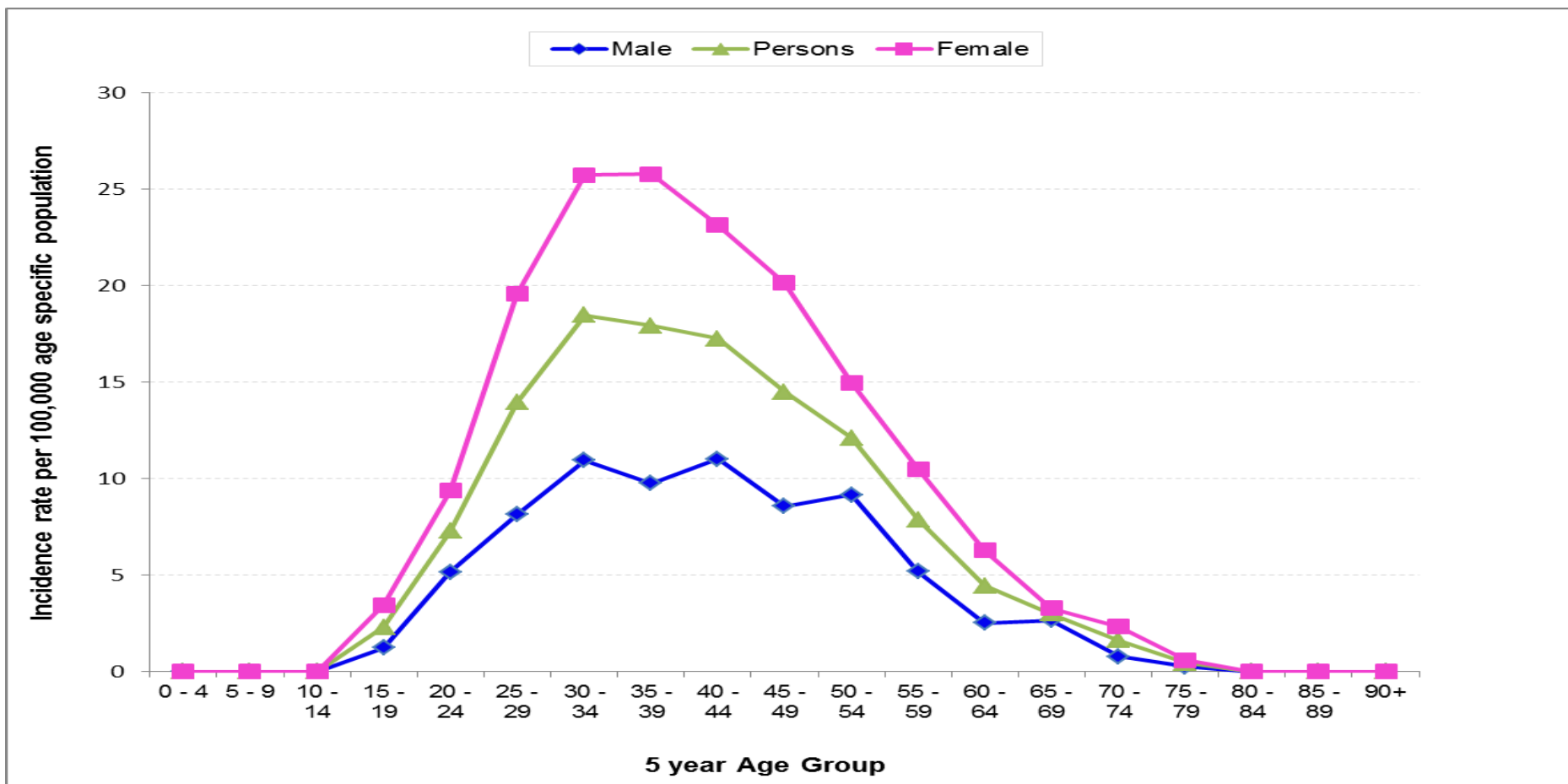
# Number of people newly diagnosed in Scotland 2010-2014

Health Board	Year of Diagnosis				
	2010	2011	2012	2013	2014
NHS A&A	16	27	34	35	29
NHS Borders	8	7	7	7	6
NHS Dumfries & Galloway	12	16	15	25	15
NHS Fife	29	27	34	38	31
NHS Forth Valley	17	23	25	26	29
NHS GG&C	95	83	82	83	75
NHS Grampian	54	49	60	65	50
NHS Highland	27	19	27	35	38
NHS Lanarkshire	48	30	46	29	22
NHS Lothian	60	54	50	73	66
NHS Orkney	5	5	5	3	0
NHS Shetland	4	6	1	1	2
NHS Tayside	41	42	56	49	56
NHS Western Isles	5	2	3	3	0
<b>Total</b>	<b>421</b>	<b>390</b>	<b>445</b>	<b>472</b>	<b>419</b>

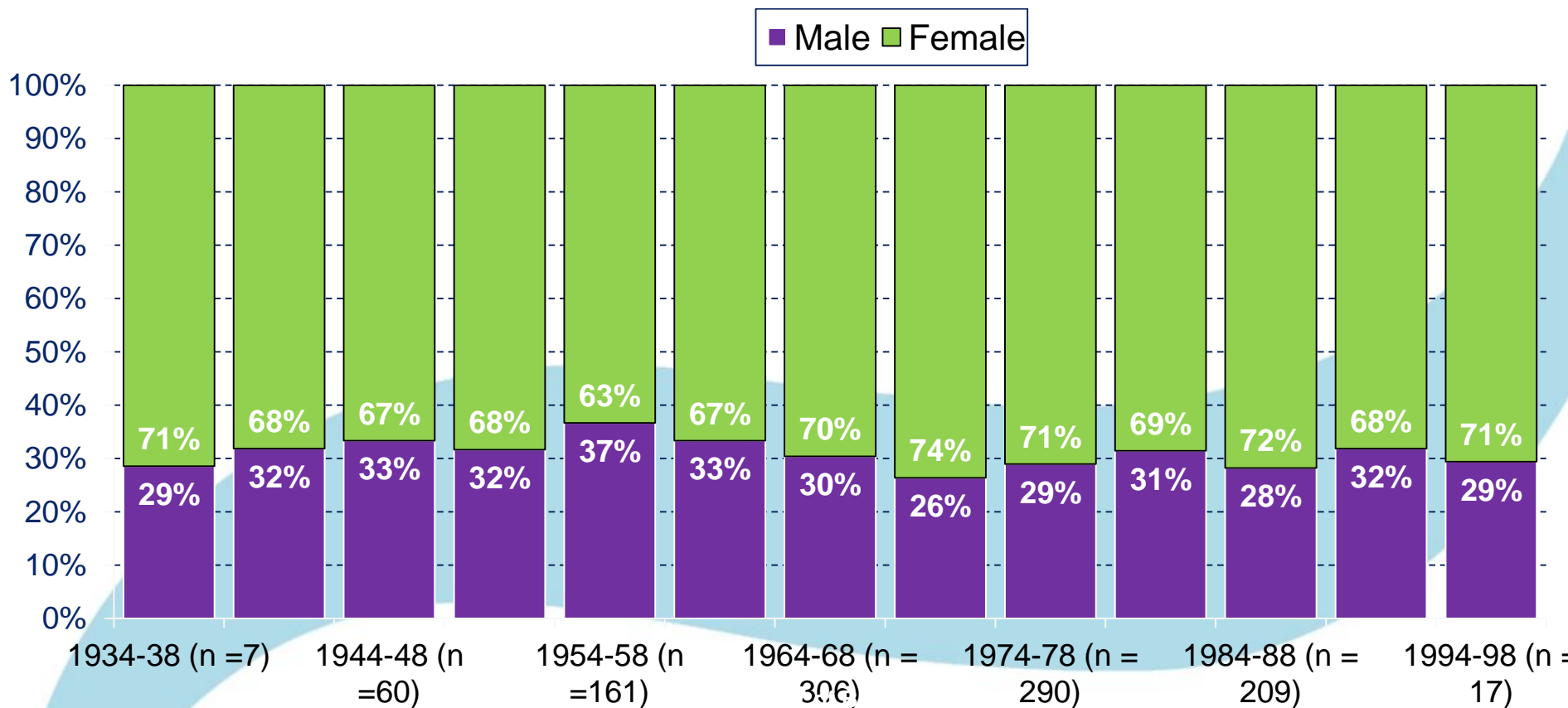
## Average annual incidence rates by health board 2010-2014



Average annual age specific incidence of people newly diagnosed with MS in Scotland per 100,000 population, 2010-2014



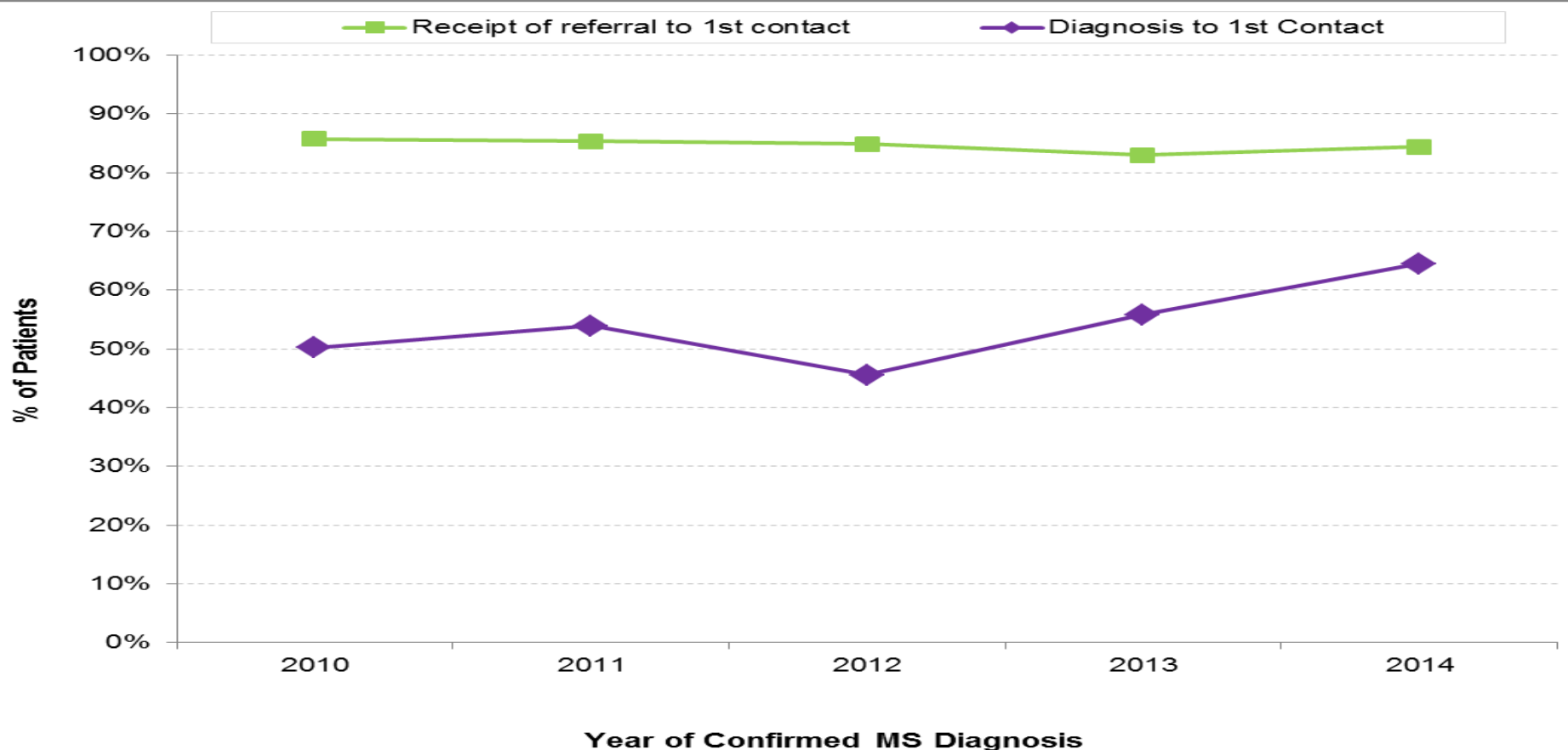
Percentage of people newly diagnosed with MS in Scotland, 01.01.2010 - 31.12.2014 data (by gender and year of birth).



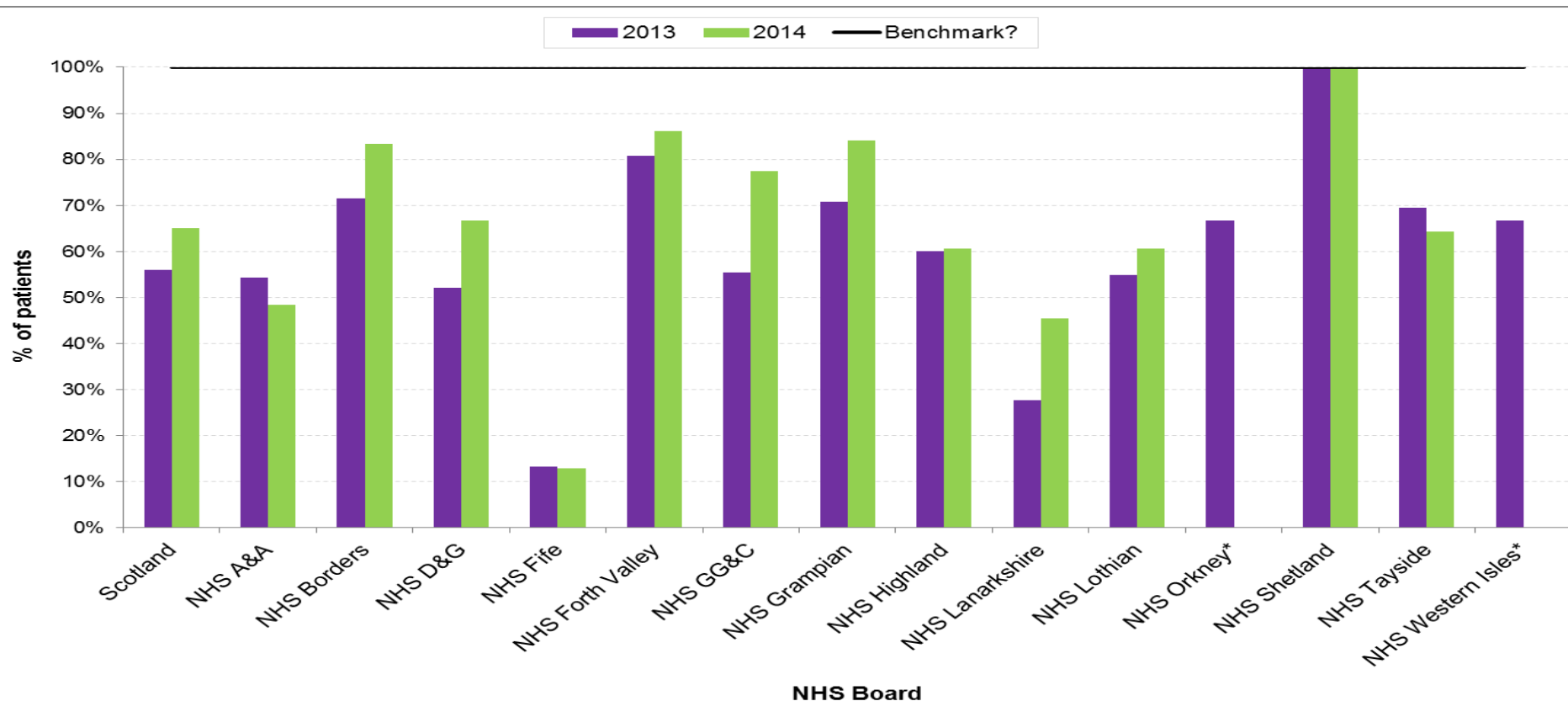
## Snapshot Demographics

- 84% Scottish Born
- 56% Married or Living with Partner
- 68% in Employment
- 12% Family History of MS
- No Obvious Season of Birth Effect

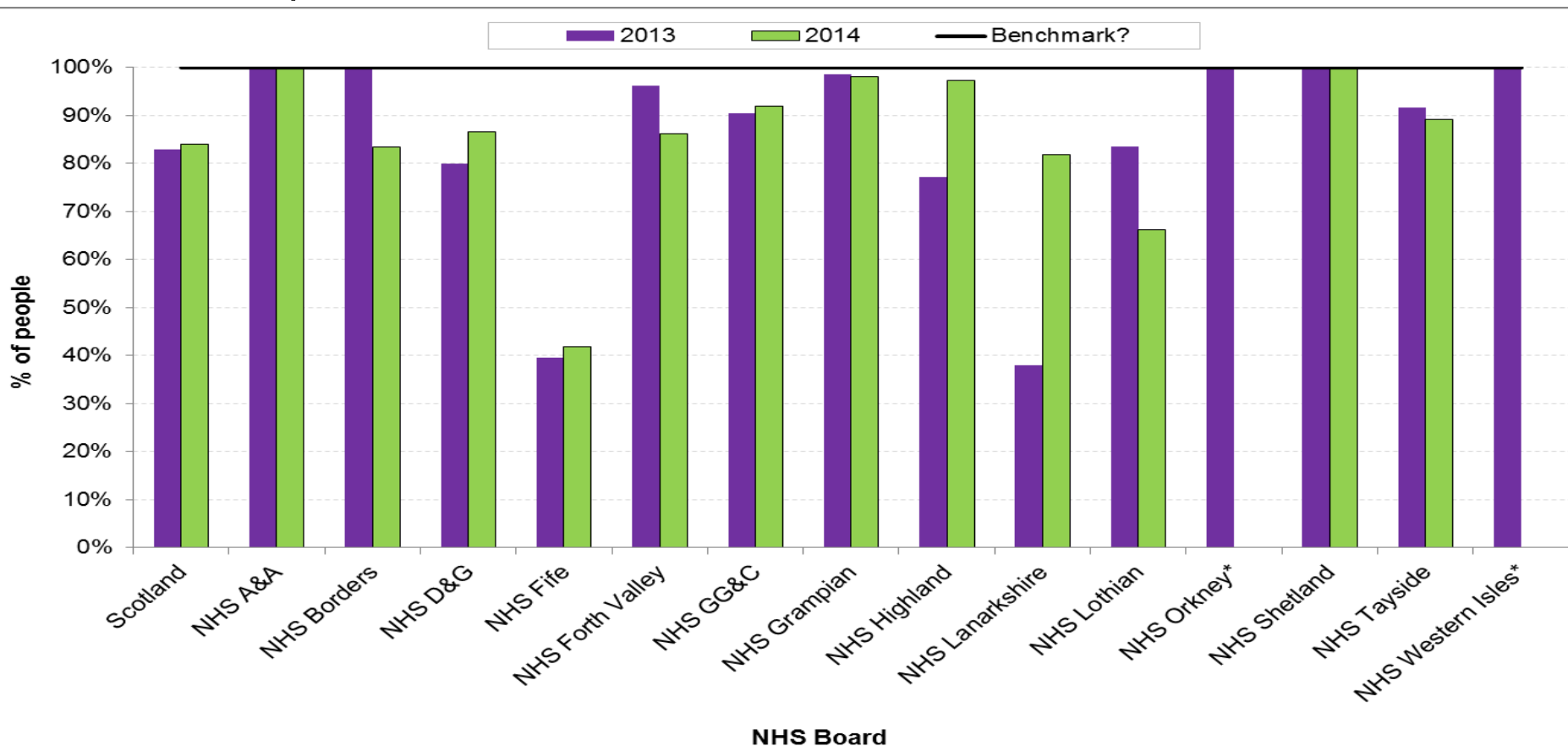
Percentage of people with a new diagnosis of MS contacted by a MS Nurse within two weeks of confirmed diagnosis Vs percentage contacted within two weeks from receipt of referral



Percentage of people with a new diagnosis of MS contacted by a MS Nurse within two weeks of confirmed diagnosis, 2013 and 2014 data.

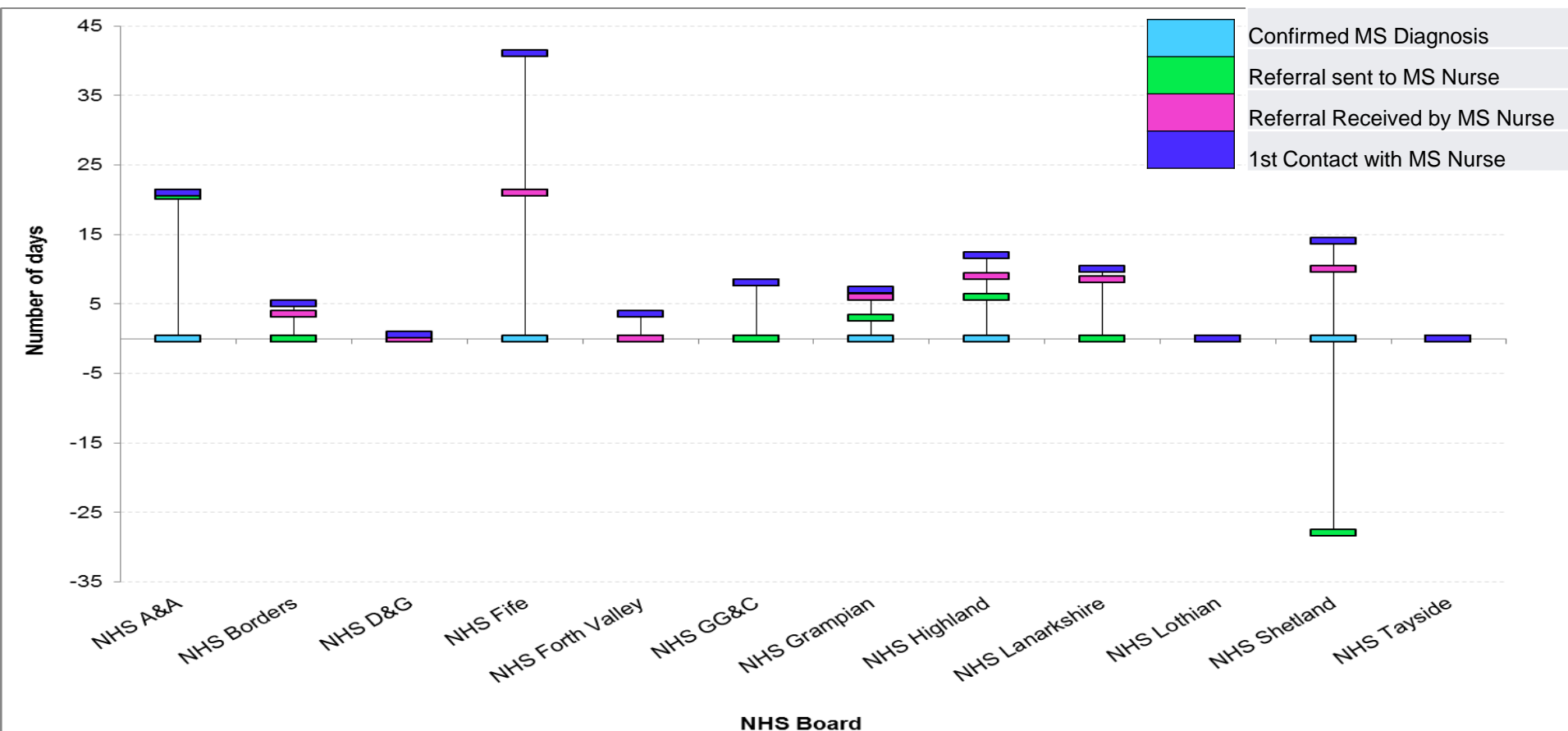


Percentage of people with a new diagnosis of MS contacted by a MS Nurse within two weeks of receipt of referral

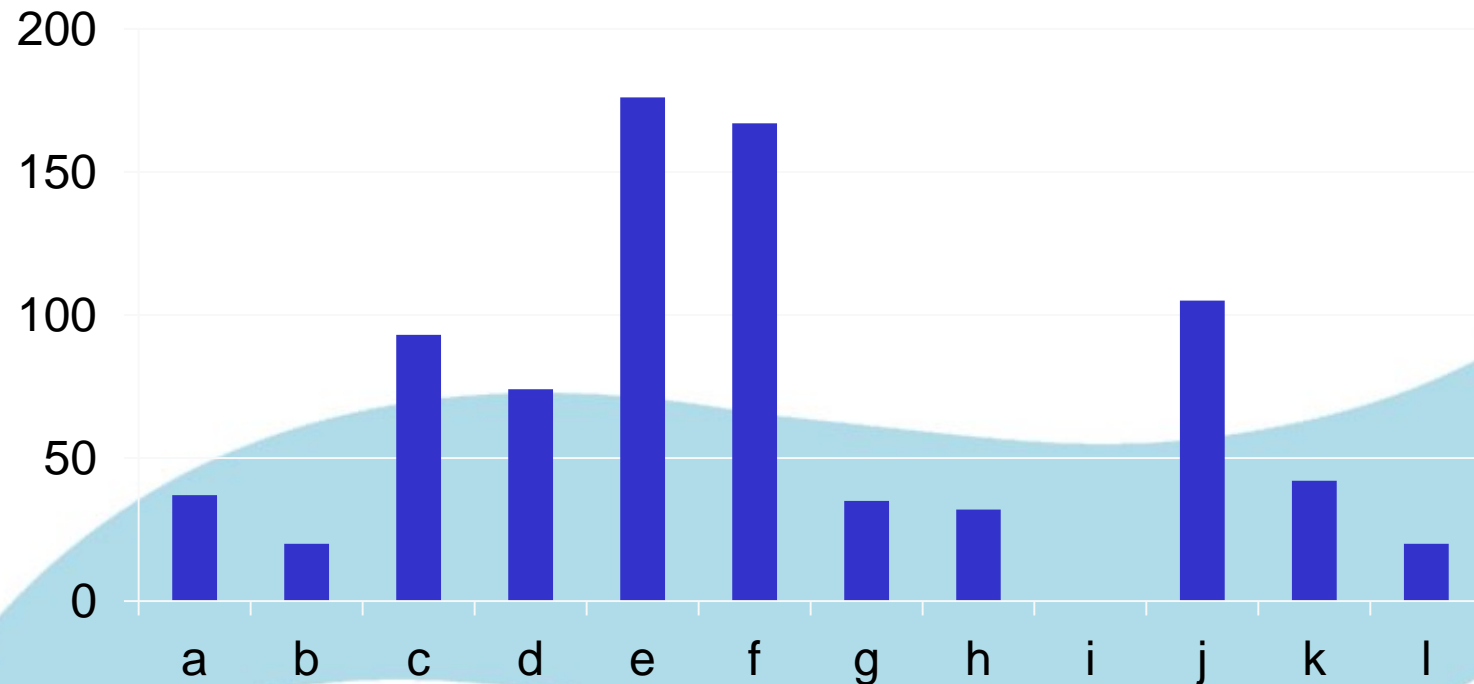




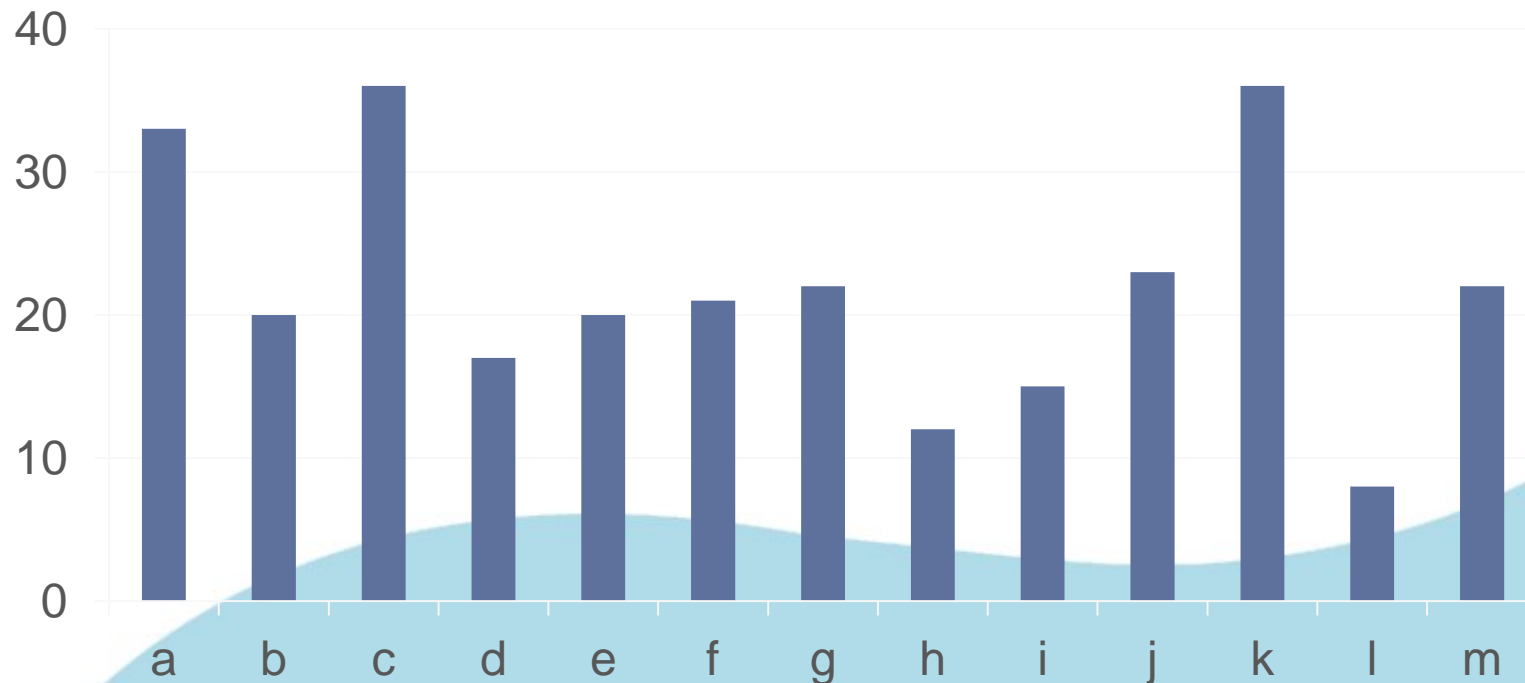
## Average number of days between each stage in the referral process from diagnosis to first contact by a MS Nurse, 2014 data

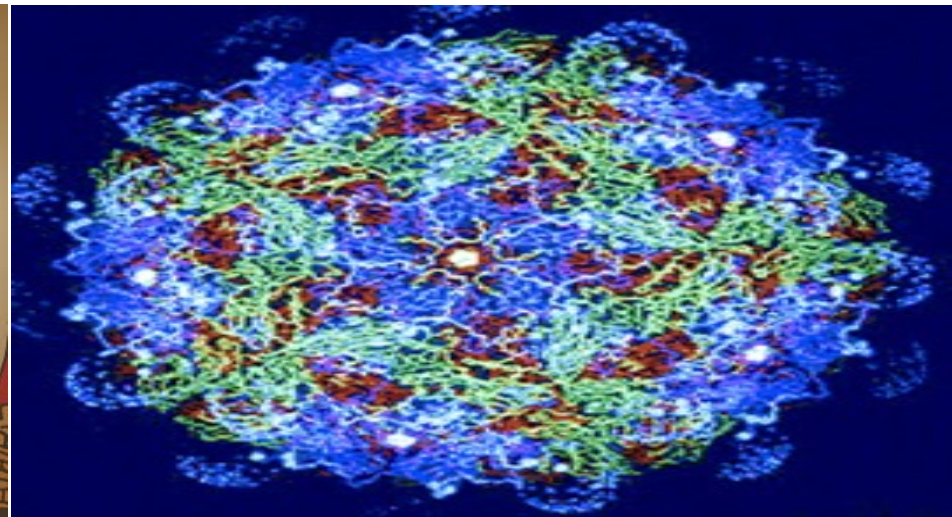


## Percentage increase in DMT prescribing by Health Board 2010-2014

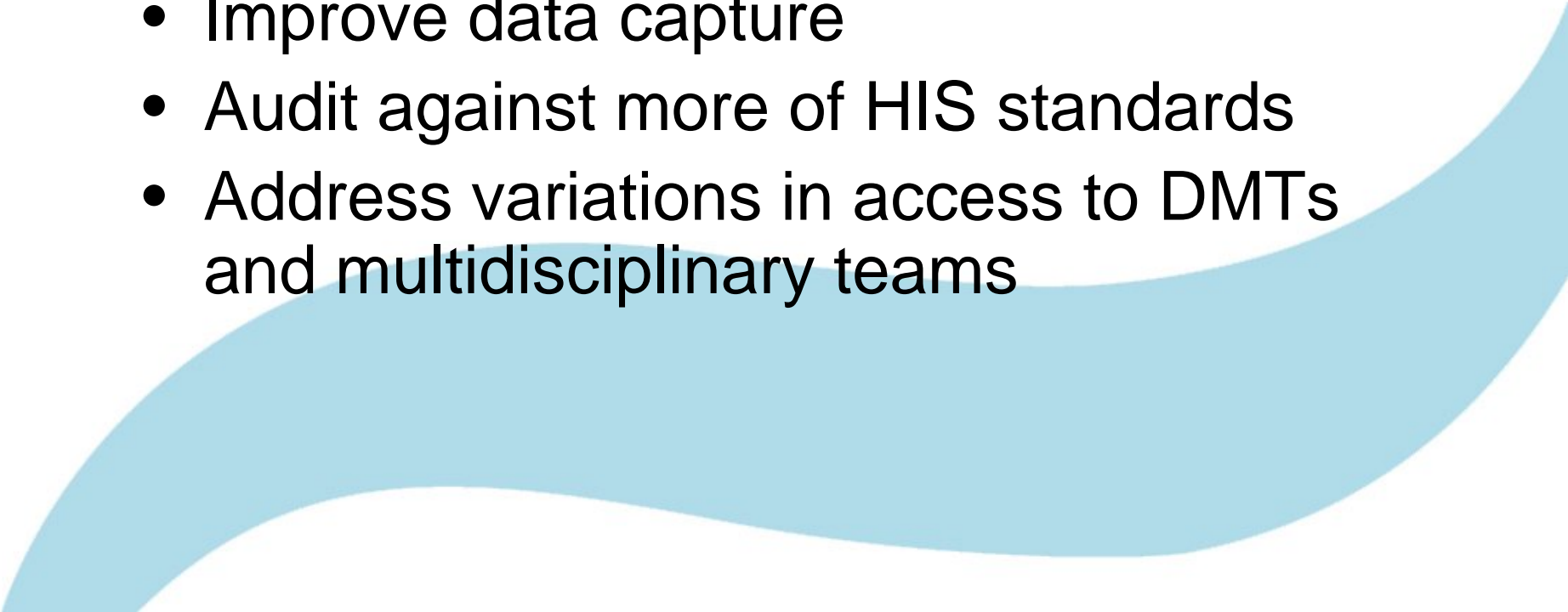


## Percentage of total MS patients receiving disease modifying treatment by health board 2014





## Future Challenges

- Improve data capture
  - Audit against more of HIS standards
  - Address variations in access to DMTs and multidisciplinary teams
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“What we see depends  
mainly upon what we look  
for”

John Lubbock