

Update from the MS Trust

Geraldine Mynors – GEMSS Programme Manager, MS Trust

Shona Flucker – MS Specialist Nurse, Tayside and North Fife

MS Register Meeting, Edinburgh

8 September 2015

The MS Trust



We provide the information you trust and support the health professionals you need.

- A UK wide charity which works to make life better today for people with MS.
- Key priorities:
 - A personalised information service to help people better understand their MS
 - Supporting MS specialist services across the UK
 - Educating MS professionals

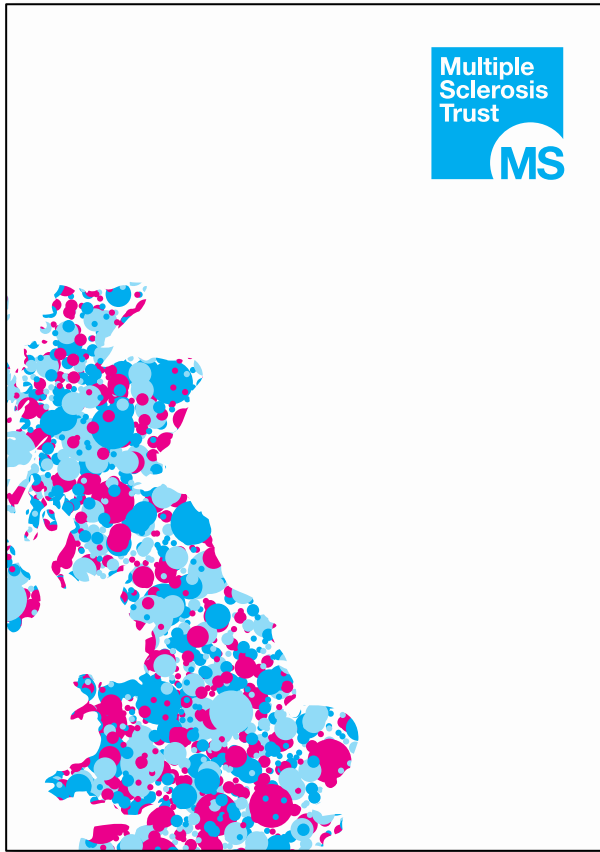
Topics

- Overview of the MS Trust GEMSS project
- The GEMSS experience in Tayside
- MS Forward View
- Other projects and support for MS specialists

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- **Overview of the MS Trust GEMSS project**
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In 2012, the MS Trust published *Defining the Value of MS Specialist Nurses*



- Strong anecdotal evidence for the value of the MS nursing role
- But robust data on impact and cost effectiveness thin on the ground
- Nurses were not collecting evaluation data due to lack of time, tools and evaluation skills



The result was the GEMSS project, launched in 2012

Objectives:

1. To support the evaluation of MS specialist nurse services over a year [and, in GEMSS II, services including Allied Health Professionals]
2. To identify general Quality Indicators for MSSN services
3. To develop tools for data collection on activity, caseload and outcomes
4. To identify and build, in the nurses, the skills and resources needed to undertake service evaluation
5. To produce local reports on MSSN services for managers and commissioners [and, in GEMSS II, a meta-evaluation of MS specialist nurse services]



Two phases of GEMSS

GEMSS I	GEMSS II
2012 – 13	2014 - 15
5 teams	11 teams in two learning sets 4 GEMSS I teams continued to collect data
Specialist nurses only	Includes two multi disciplinary teams of nurses and Allied Health Professionals

GEMSS teams collecting service evaluation data in 2014/15 – covering nearly 15,000 people with MS

England

- Calderdale and Huddersfield NHS FT
- Leeds Teaching Hospitals NHS Trust
- Mid Essex Hospital NHS Trust
- Northern Devon Healthcare NHS Trust
- Royal Devon and Exeter NHS FT
- Salford Royal NHS FT
- Shrewsbury and Telford Hospital NHS Trust
- University Hospitals of Leicester NHS Trust
- The Walton Centre FT#
- Dudley Hospitals NHS FT**
- Northumbria Healthcare NHS Trust**
- Poole Hospital NHS Trust **

Scotland

- Tayside and North Fife Regional MS Service#
- NHS Western Isles

Multi-disciplinary team including AHPs

** GEMSS 1 teams repeating data collection in 2014/15



GEMSS teams have collected data on

- Activity
- Caseload and casemix
- Key Process Indicators on responsiveness
- Patient experience and reported outcomes (postal survey)
- Views of other health professionals working with the MSSN team (online survey)
- Case studies
- Topics covered in consultations (Dorset Specialist Neurological Intervention Audit Tool)*
- Capacity vs activity *

The MS Trust provided...

- Training on practical evaluation skills
- Simple evaluation tools (activity, caseload, patient survey)
- Facilitator support for data collection, analysis and report writing



Individual team and overall reports in GEMSS II

Individual team reports

x 11

- Produced locally by each team with facilitator support
- Completed June 2015
- Written for local management audiences

MS Trust overall report

- Based on anonymised data from each team
- To be published November 2015
- Written for national audiences and to support MS services across the UK

Early outputs from GEMSS already published

SERVICE DEVELOPMENT

Modelling sustainable caseloads for MS specialist nurses

Report on a consensus process led by the MS Trust

Geraldine Mynors and Amy Bowen

1. Introduction and objectives

Multiple Sclerosis (MS) specialist nurses (MSSNs) are highly valued by people with MS. There are currently around 245 (216 whole time equivalent) MSSNs in the UK (MS Trust, 2014). They work across the whole disease trajectory, providing proactive case management to respond to acute deteriorations and relapses and to prevent secondary complications which can be disabling or life-threatening and result in unscheduled care.

The MS Trust has been at the forefront of supporting, developing and mapping MSSN services across the UK. We published an overview of MS nurse coverage by commissioning organisation in 2012 (Mynors et al, 2012) and an updated report in November 2014, the light of recent changes to the NHS landscape (Mynors and Bowen, 2014). This shows widely varying caseloads of MSSNs in different parts of the country.

In order to assess the magnitude of any shortfalls in the provision of MSSN services, it is essential to agree on what constitutes an acceptable caseload for an MSSN. The MS Trust has therefore developed, as part of the GEMSS (Generating Evidence in MS Services) programme, a capacity planning and caseload model and, in September 2014, convened a consensus group of experts and practitioners (listed at the end of this paper) to test the model and develop robust assumptions to put into it. This briefing reports on the results of that process. The objectives of the work were:

- To quantify a sustainable caseload for a whole-time MSSN
- To identify the conditions under which this might need to be varied, for example based on how rural the area covered is
- To identify what conditions need to be present for services to be effective with this level of caseload.

2. Background and approach

Modelling an 'optimum' caseload for any specialist nurse service is challenging for a number of reasons. Approaches which start with the needs of patients, encounter the challenge that 'need' is a complex and subjective concept: normative (professionally-defined) need may differ from the needs 'felt' by people living with a condition, which will also differ from the needs

ABSTRACT

Background: There are 245 Multiple Sclerosis (MS) specialist nurses across the UK, with variable caseloads, suggesting inequitable and, where caseloads are particularly high, inadequate provision.

Aim: The MS Trust set out to establish a 'sustainable' caseload for an MS specialist nurse providing a high quality, proactive service to patients with MS throughout the disease trajectory.

Method: An expert consensus group agreed standards for MS specialist nurse services and assumptions about their working patterns and practices; this process was informed by 'real world' data from 40 MS specialist nurses taking part in the MS Trust GEMSS programme. A simple model was then used to determine the sustainable number of cases an MS specialist nurse can manage.

Results: The model showed that a caseload of 358 people with MS per whole time specialist nurse is sustainable.

Conclusions: A number of conditions must be met, including well-planned job plans, sufficient administrative support, an effective home visit policy and a high level of utilisation of clinic capacity.

Key Words: Specialist nursing, clinical nurse specialists, multiple sclerosis (MS), caseload, equitable provision

Author: Geraldine Mynors, GEMSS programme manager; Amy Bowen, Director of service development, MS Trust, UK

Correspondence: amysbowen@msstrust.org.uk

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they express and the services they might demand (Bradshaw, 1994). Clear, evidence-based guidelines are therefore essential to define the needs which services should meet, and such guidelines are not always available (as discussed below). Approaches which start by benchmarking existing services and their caseloads also encounter challenges. The definition of specialist nurse roles is highly variable across geographies and specialisms (Vidall et al, 2011), making comparison problematic. Many clinical nurse specialists report that they leave work undone (Leary et al, 2014), and services which appear to be performing well, may be doing so only because nurse specialists are working significant amounts of unpaid overtime to sustain them (Frontier Economics, 2010). Perhaps because of these challeng-

Discussion Paper Briefing Reports Consensus



MS Specialist Nursing in the UK 2014: The case for equitable provision November 2014

Authors: Geraldine Mynors*, Amy Bowen†

Executive Summary

- This report by the MS Trust follows up on its report, *MS specialist nursing in the UK - 2014*, which gives an overview of numbers of MS specialist nurses (MSSNs) in the UK. It offers a more detailed picture of provision and states the case for MS specialist nursing care for everyone with a diagnosis of MS.
- MS is a disease of the central nervous system, commonly diagnosed between the ages of 20 and 40, giving rise to a range of symptoms and disabilities with an often unpredictable course. People with MS require access to disease modifying and symptomatic treatments, including medicines and expert multidisciplinary care.
- MS specialist nurses are highly valued by people with MS. They work across the whole disease trajectory, providing proactive case management to respond to acute deteriorations and relapses and to prevent secondary complications which can be disabling or life threatening and result in unscheduled care.
- Based on a sustainable caseload of 358 people with MS per whole time specialist nurse, there is currently a shortfall of 62 MSSNs across the UK, with significant shortfalls in England and Scotland and overall sufficient provision in Northern Ireland and Wales. 28% of people with MS, nearly 30,000, live in areas where MSSN caseloads are more than twice the level that is sustainable.
- In some areas, despite adequate provision, people with MS may still have to travel significant distances to reach services. This is notable in areas such as central Wales and Northern Ireland.
- The MS Trust GEMSS programme has worked with MSSNs to reach consensus on the patient outcomes they achieve through their interventions and is supporting them to evaluate their services against these. The results will be published in 2015.
- Whilst MSSN numbers overall are holding up, the current NHS context poses challenges including evidence of down-banding of posts in England, restrictions on maternity leave cover and on time available for training in all countries except Northern Ireland.
- There is a need for constructive dialogue between Commissioners/Health Boards, Providers and MSSNs, in consultation with people living with MS, to ensure that everyone with MS has access to an MSSN with a sustainable caseload.

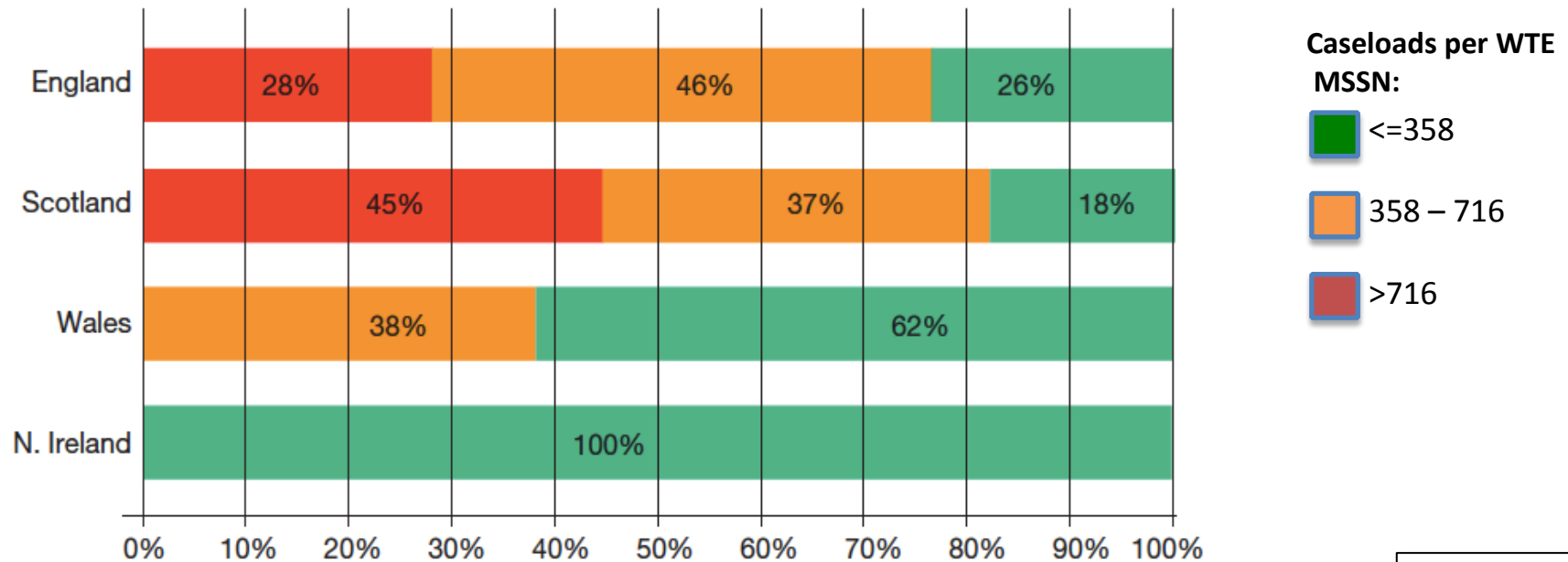
* GEMSS Programme Manager, MS Trust

† Director of Service Development, MS Trust



In Scotland, 82% of PwMS live in Health Boards where the caseload per MS specialist nurse is more than 358 people

Figure 11 - Proportion of people with MS in each country by level of provision in their local CCG/Health Board



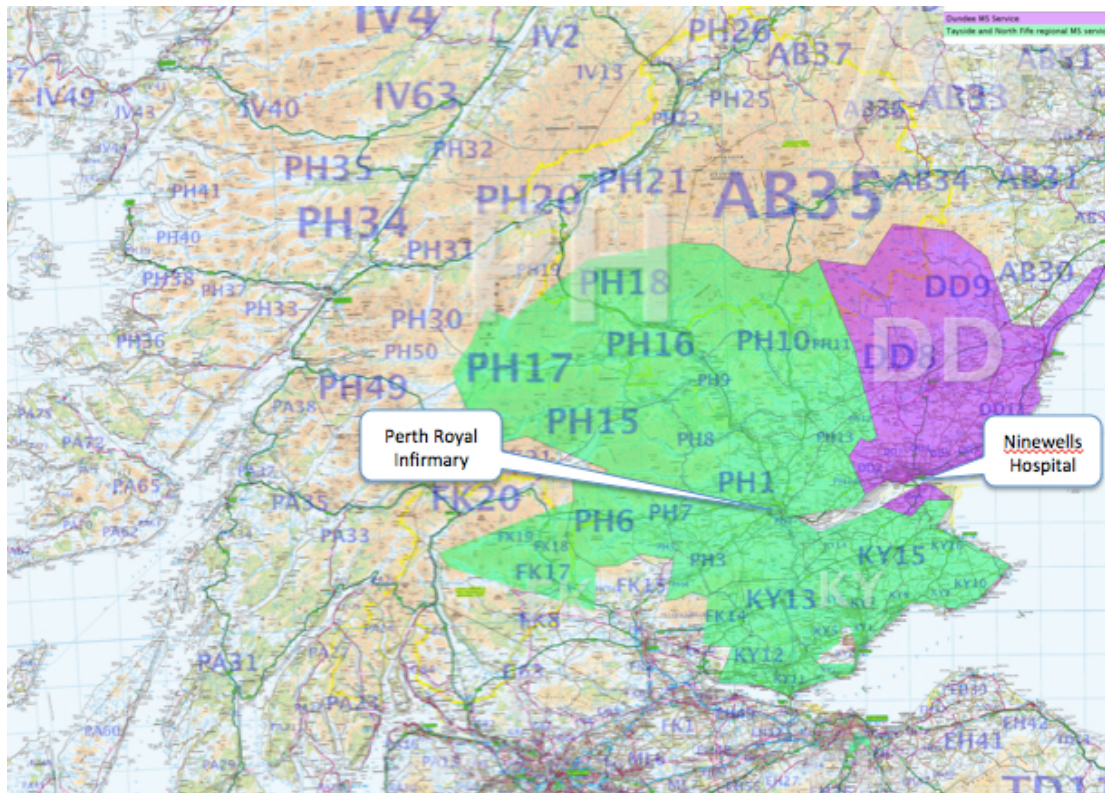
The GEMSS patient survey service

- Available to any MS specialist nurse or therapist team
- Helps you to find out about patients' experiences of your service and build evidence for your role
- MS Trust provides:
 - Validated survey tool (postal and online)
 - Data entry and analysis
 - Report comparing your service with GEMSS benchmarks

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The Tayside and North Fife MS service team

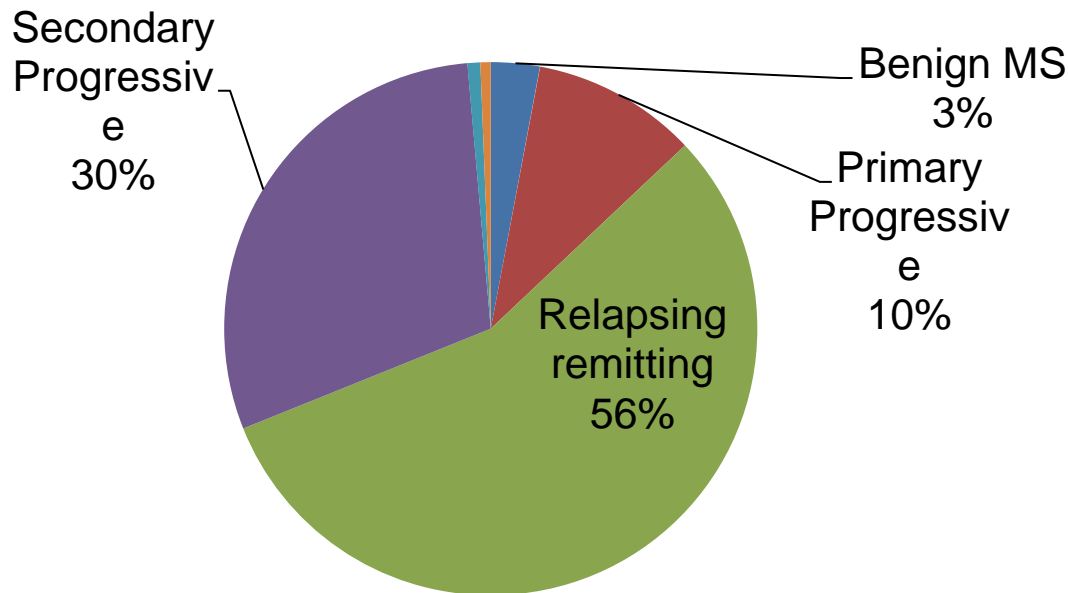


The GEMSS evaluation encompassed:

- 3 MS specialist nurses
- MS specialist physiotherapist
- MS specialist social worker

We were able to look in depth at caseload vs. capacity

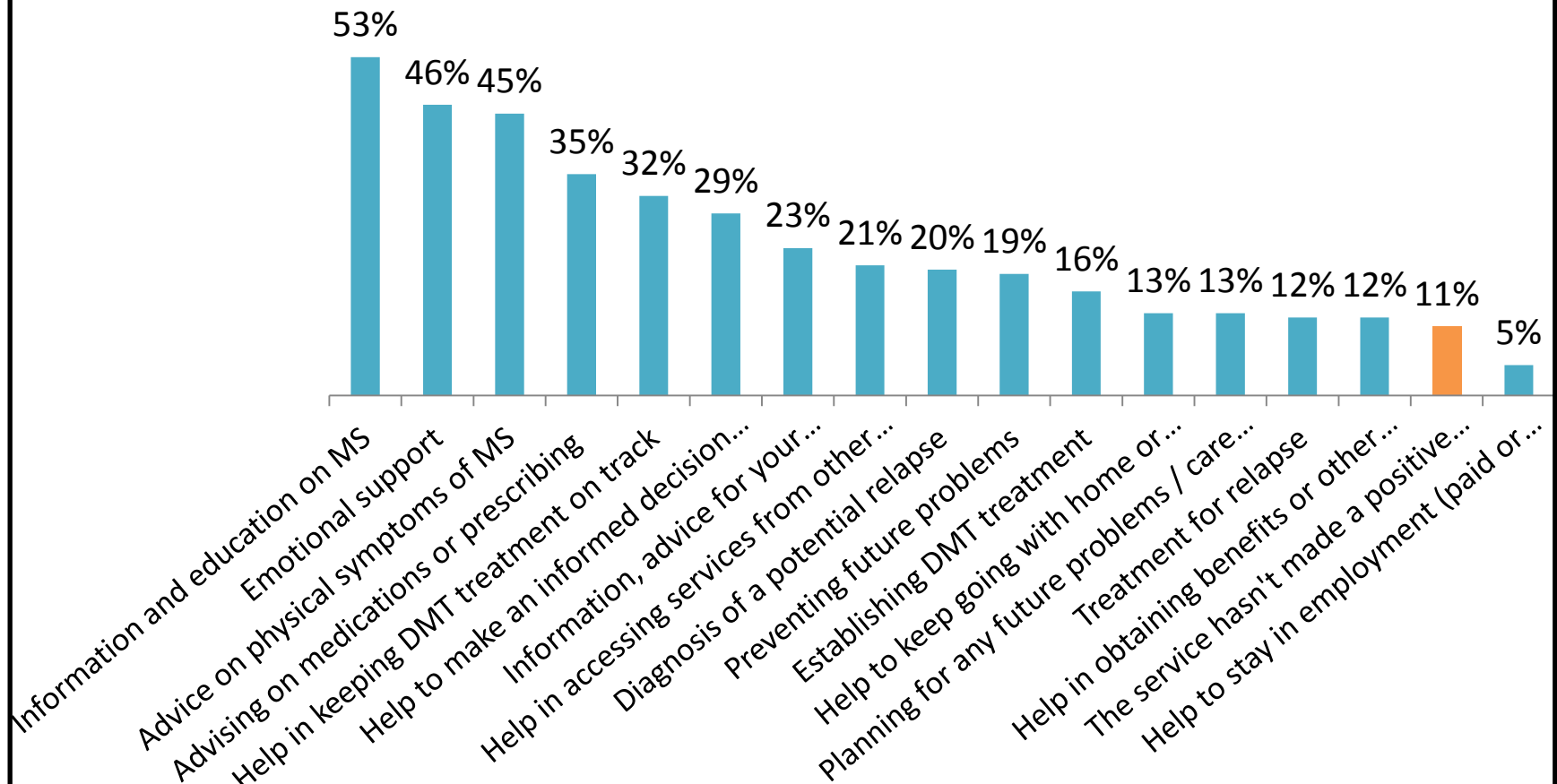
Tayside and North Fife MS Caseload - Total 1280 pwMS



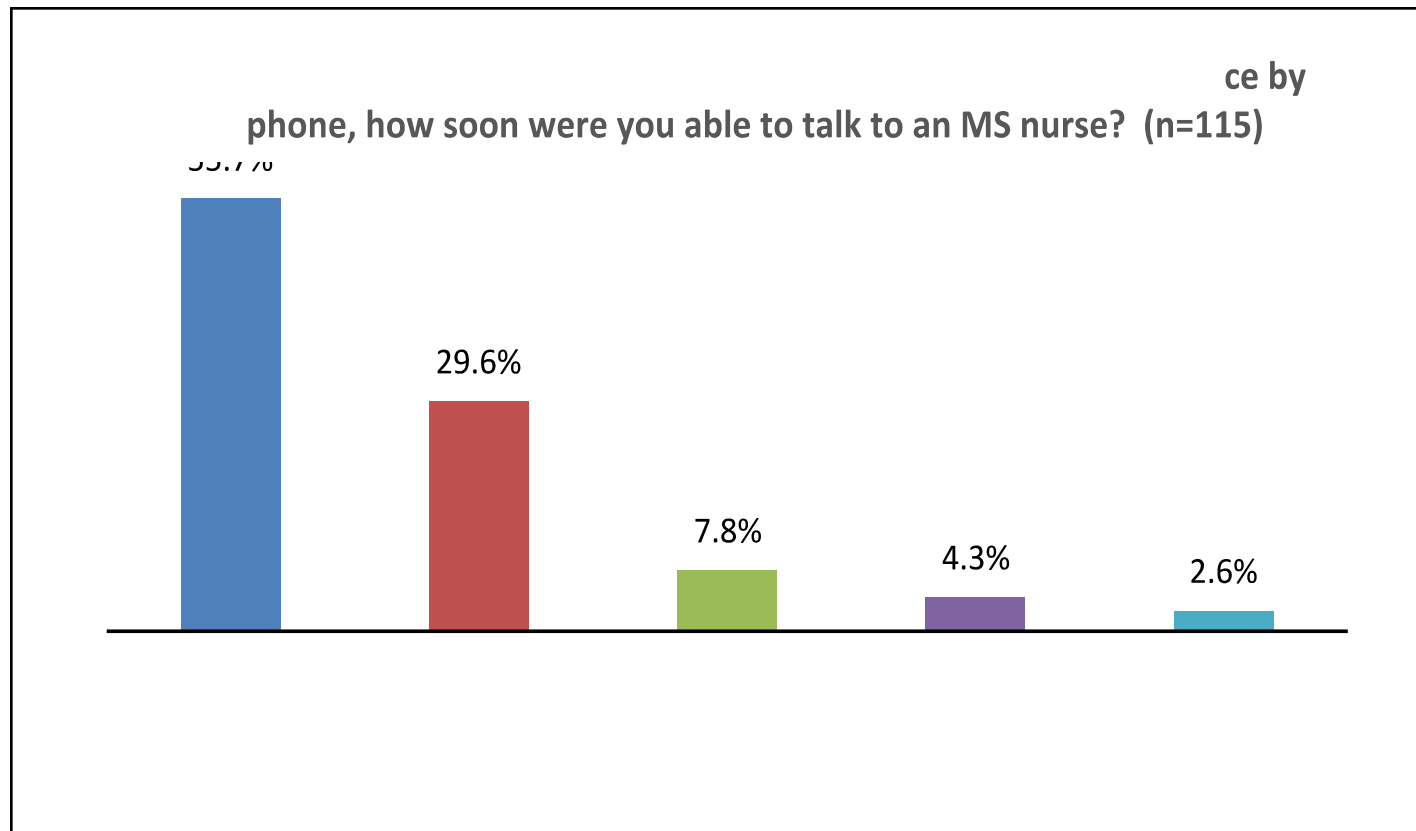
- We have capacity as MSSNs to see each pwMS on the caseload 1.7 times per year
- 85% of our caseload had a face to face contact in 2014/5

The GEMSS patient survey showed 89% of patients said the service had made a positive difference

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? (n=146)



86% of people calling the service spoke with a nurse the same or next day



Data collected highlighted recommendations for improvement – examples:

- Review the 15% of patients on the caseload who have not seen an MSSN in the past year
- Re-establishing patient self-management programmes
- Review use of capacity for acupuncture
- Look to employ a support worker to assist with non-specialist tasks and triaging calls

Reflections - benefits of doing evaluation

- An enlightening journey
- Establishes what you are doing well
- Shows areas where the service can change and develop to respond better to the needs of patients in Tayside and North Fife

The national GEMSS report will be published at the MS Trust conference in November



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Why *MS Forward View*?

- New treatment paradigms
- DMT initiation, switching and monitoring increasing
- Shortage of MS neurologists and MS specialist nurses
- Potential for inequity:
 - Between those who benefit from DMTs and those who don't
 - Between those seen at major neuroscience centres and those not



MS Forward View (launching November 2015) will:

- Map and quantify MS MSSNs and neurologists across the UK
- Define different service models currently operating
- Identify skills and competencies needed to prescribe and monitor DMTs
- Appraise options for new models of care using skills differently or re-configuring services
- Define metrics for monitoring access to care, service quality and equity across whole trajectory
- Produce a final report and multi-stakeholder action plan / pilots

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Other news



- **MS Decisions** relaunch
- New MS Trust website
- MS Trust annual conference – November 2015
- Relapse guide
- Competency framework for neuro-specialist AHPs
- Input to NICE quality standard on MS (England)

Questions?