Evidence for MS Specialist Services

Report on the process and impact of delivering an evaluation programme with specialist nurses and therapists

Multiple Sclerosis Trust

MS

GEMSS

Generating Evidence in
Multiple Sclerosis Services

Contents

1. Introduction

Generating Evidence in Multiple Sclerosis Services (GEMSS) is a programme of work funded and led by the MS Trust to develop an evidence base for high quality specialist MS services. The GEMSS evaluation project was the first major project undertaken within GEMSS. In GEMSS I, five teams of MS Specialist Nurses (MSSNs) (including one multidisciplinary team) were supported to evaluate their services over 12 months, April 2012 to March 2013. A further eleven teams (including two multi disciplinary teams) were recruited in Autumn 2013 to take part in GEMSS II in 2014/15. Four of the five GEMSS I teams continued to participate in data collection and service evaluation in 2014/15.

This report documents the approach used in GEMSS to undertake meaningful service evaluation and reflects on the experience of the 16 teams that took part and the contribution that GEMSS has made to their work. A separate report[1] presents the findings of the GEMSS project.

This report begins by setting out the rationale for and objectives of GEMSS, the methodology and how this evolved across phases I and II of the project. Following a section on the main achievements in GEMSS, the report sets out the impact on participating team and services. Evidence for this comes from a series of online questionnaires completed by both GEMSS I and II team leads over the course of the project, and an independent impact study of GEMSS I, two years after the end of the project for the GEMSS I teams[2]. The report concludes with a section that reflects on what the GEMSS project tells us about how a third sector organisation like the MS Trust can engage with the NHS to evaluate and improve services, for the benefit of those who use them.

2. Rationale and objectives for GEMSS

The impetus for GEMSS came from a scoping study undertaken for the MS Trust to assess the evidence for the value of MS specialist nurses, in early 2011. The output of the study was a report, **Defining the Value of MS Specialist Nurses**, which summarised the evidence, both in MS and in other specialties, and pointed to further work which would enable MS specialist nurses to make the case for maintaining and developing their services.

The report found that, in general, MS nurses are short on robust evidence to show that their services are cost-effective. There was a great deal of anecdotal evidence that they are highly valued, not only by patients, but also neurologists, GPs and other members of the health and social care community. However, no rigorous studies had been done to demonstrate their worth since the work commissioned by the MS Trust from Jane Johnson at Southbank University in 2000[3].

Managers and commissioners of services are increasingly looking for information that articulates the complexity of the MS specialist nurse role and shows how this translates into value – for the MS patient and the wider health service. However, not all MS specialist nurses have the skills and experience required to gather, analyse and communicate data about their service. The GEMSS project aimed to address this gap.

In deciding on the model for the GEMSS project, two alternative options were considered but rejected:

- The MS Trust could have produced a 'toolkit' to guide MSSNs on how to collect, analyse and present evidence on their services. However, past experience with the numerous toolkits which are available on websites and elsewhere suggest that, without proper training, support and incentives, nurses would struggle to implement such guidance and uptake would be poor.

- The MS Trust could have commissioned an external academic study to assess the impact of MS nurses. Two problems were identified with this approach. First, a robust study would have been very costly and difficult to set up, not least because of the difficulties of establishing a control group. The 'before and after' approach adopted in the earlier study by Johnson et al is no longer possible because the entire country is now broadly covered by MSSNs (although some MSSNs have unacceptably high caseloads). Secondly, an external study of this nature would have provided no opportunity for nurses to build the skills required to evaluate services locally, communicate the results to local audiences, on an ongoing basis, and crucially, use the results of their evaluations to improve services.

The approach adopted in GEMSS I and continued in GEMSS II was therefore one of hands-on support for teams to undertake their own evaluation. The project had a professional development component, building the skills and capabilities of the nurses involved, and a service development component, developing an improvement culture in the services evaluated. In addition, the project aimed to leave a lasting legacy for MS nurse services more generally by developing a set of common quality standards and tools by which they can be measured.

2.1   Objectives of GEMSS

GEMSS I and GEMSS II shared broadly the same objectives, but with an emphasis in GEMSS II of building on what had been learnt and the gaps identified in GEMSS I. The objectives of GEMSS I were:

1. To provide support for the evaluation of four MS specialist nurse services over a one year period up to March 2013.

2. To identify the organisational and individual skills and resources required to undertake service evaluation and to seek to build these in the nurse teams involved.

3. To produce reports on MSSN services for key commissioning and management audiences in each of the four locations.

4. To explore the feasibility of identifying general Quality Indicators and KPIs for MSSN services drawing on the experience and views of MS nurse team together with documents such as the NICE MS Guideline, the National Service Framework for Long Term Conditions (acknowledging that both of these documents are to some extent outdated) and the MS Trust Commissioning Pathway.

5. To explore the feasibility of developing general tools for data collection for MSSN service evaluation, including a patient experience survey (building on the CRIMSON tool developed by the UK MS Specialist Nurses Association (MSSNA) and a simple framework for capturing activity and outcome data.

These objectives were rearticulated for GEMSS II to reflect what had been achieved GEMSS I, and three further objectives were set.

6. To aggregate the results from all GEMSS teams into an overall report on the value of MS specialist nursing which can be published by the MS Trust as the response to the gap in evidence outlined in 'Defining the Value of MS Specialist Nurses'.

7. To explore the feasibility of evaluating integrated teams of MS specialist nurses and Allied Health Professionals using a single set of evaluation tools, by including at least two integrated teams within the cohort.

8. To identify and develop the support mechanisms needed for teams to continue to evaluate and improve their services beyond the year of intensive GEMSS support.

The addition of AHPs in GEMSS II reflected the fact that the MS Trust recognises that MS specialist nurses cannot be effective in isolation and need to work with a wider multi-disciplinary team to manage the symptoms and issues faced by people with MS. AHPs expressed interest at an early stage in participating in GEMSS, but a number of possible barriers to using the GEMSS approach and tools with AHPs were identified through discussions with them.

•   Relatively few AHPs work exclusively with people with MS. Most neuro-specialist AHPs work across multiple conditions, and hence to evaluate just the MS part of their work could be impractical.*

•   AHPs tend to work on a more episodic basis with people with MS over short

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* The MS Trust's charitable objects preclude it investing in work covering other conditions than MS.

courses of treatment for specific problems, rather than managing an ongoing caseload.* AHPs already use a range of outcome measurement tools to track improvements in MS-related problems within their daily work, and hence already potentially have access to data that could help them to evidence the value of their input. It was not immediately apparent what the evaluation tools of the GEMSS project would add.

• It was also identified that AHPs in general have a greater level of confidence and knowledge around service evaluation than their nursing counterparts.

Nevertheless, the GEMSS approach was piloted with three multi-disciplinary teams, adapting the tools for AHP use, with a view to understanding whether they were applicable and enhancing understanding of multi-disciplinary team working.

* There are notable exceptions to this, such as the Dorset Community Neurology Service (which took part in GEMSS) and the East Staffordshire Neurology Service, where AHPs do carry a caseload as part of a neuro-practitioner approach.

3. Overview of the process

3.1 The GEMSS approach

The distinctive features that have driven the GEMSS project forward are summarised below. Appendix 1 describes the timetable for the GEMSS project and the activities which took place at each stage.

3.1.1 Selection process

The teams selected to take part in GEMSS were chosen through a national, competitive selection process to represent a cross-section of MS services, rural and urban, large and small, community and hospital based. All teams in the UK were invited to apply and 31 applications to take part were received (across GEMSS I and II). In the event, two teams selected were in Scotland (both in GEMSS II), the rest in England. A demonstrable willingness and enthusiasm to engage with the process was the primary criterion for participating in GEMSS; in GEMSS II, support from the host organisation for the project and a willingness to share data with the MS Trust for the meta-analysis were essential requirements. Successful teams were asked to nominate 'GEMSS leads' to drive their team's engagement in the project, and each team put forward between one and three individuals.

3.1.2 Facilitator support

GEMSS was designed to offer hands-on practical support for teams from start to completion of the project. This was delivered by two GEMSS facilitators, Geraldine Mynors and Jane Suppiah, evaluation consultants with experience of working in the NHS. They were commissioned by the MS Trust but worked very collaboratively with the MS Trust team on both the design and delivery of the project. Each participating team received around nine days of individually tailored facilitator input. This ensured that they established their data collection systems, offered analysis and reflection on monitoring and survey data as it became available, and supported teams to produce their individual final reports. Facilitation was delivered through a mixture of site visits two per team in most cases) and work over the phone and email.

3.1.3 Training programme

The primary objective of training the GEMSS leads was to build into the teams involved the evaluation skills and mindset necessary to evaluate their services. GEMSS started with a two-day residential training followed by a programme of conference calls (or webinars) and two further training workshops integrated into the MS Trust's residential MS Specialist Nurse Meeting, run annually in March, and Annual Conference in November. This allowed the introduction of data collection tools to be paced throughout the year and for the theory of evaluation to be revisited as teams started to experience the practical application of concepts that had been introduced. A further element of training was the peer support and peer review promoted through regular meetings and training activities designed to promote collaboration. Thirty MS specialists (27 MSSNs, 2 physiotherapists and 1 research coordinator) took part in GEMSS training.

3.1.4   Co-production

The GEMSS model was highly collaborative, involving GEMSS teams not only in collecting data, but as partners in the design of the evaluation logic and tools underpinning GEMSS. The evaluation framework, Key Process Indicators (KPIs) and surveys used with pwMS and stakeholders were all jointly developed with GEMSS I teams.

3.1.5   Guidance from an expert Advisory Group

An advisory group met at regular intervals over the four years of the project. Its broad membership, including representatives of other professions and specialties as well as national policy makers and service users, enabled it to deliver critical feedback and analysis on the scope, development and findings of the project throughout.

3.1.6   Relationships with senior managers in Trusts and hospitals

Buy-in and support from managers within the GEMSS teams was an important component of GEMSS, needed to facilitate the practical support required for activities such as the patient survey and also to ensure that the findings presented by teams in their local reports were disseminated and acted upon. A feature of GEMSS II was a local launch of GEMSS in each Trust/Health Board, whereby the GEMSS lead(s) and MS Trust facilitator jointly presented the project to other team members, neurologists, managers, service users, commissioners and wider stakeholders.

3.1.7   Central support for survey activities and report writing

In recognition of the limited time that GEMSS leads would have, efforts were made to remove, in so far as possible, the administrative burden of administering surveys and the technical analysis associated with GEMSS data and reporting. This was particularly the case with teams' local final reports. GEMSS leads were required to provide case studies and a description of their service, but the facilitators populated individual GEMSS teams' reports with data. This allowed GEMSS leads to concentrate their time on working collaboratively with facilitators to develop conclusions, recommendations and narrative for the body of the reports.

Although the same model was broadly followed in phase I and II of the GEMSS project, there were some important differences and these are summarised in figure 1.

Figure 1 Summary of the main differences in GEMSS I and GEMSS II

GEMSS I	GEMSS II
• 5 teams covered by both GEMSS facilitators	• 11 teams splits in two 'learning sets' each led by a GEMSS facilitator
• Focus on specialist nurses (although one multi-disciplinary team did take part)	• Included two multi disciplinary teams of nurses and Allied Health professionals plus one MS Social Worker. Specific tools developed to capture data relevant to AHPs
• Local management support 'desirable'	• Local management support essential – Memorandum of Understanding between MS Trust and NHS Trusts about data sharing
• Evaluation reports for local audiences only	• Evaluation reports for individual teams produced for local audiences plus a summative report authored by the MS Trust drawing on combined GEMSS data
• Light on economics	• More focus on economics, with patient survey data used to analyse costs saved elsewhere in the health system through MSSN input

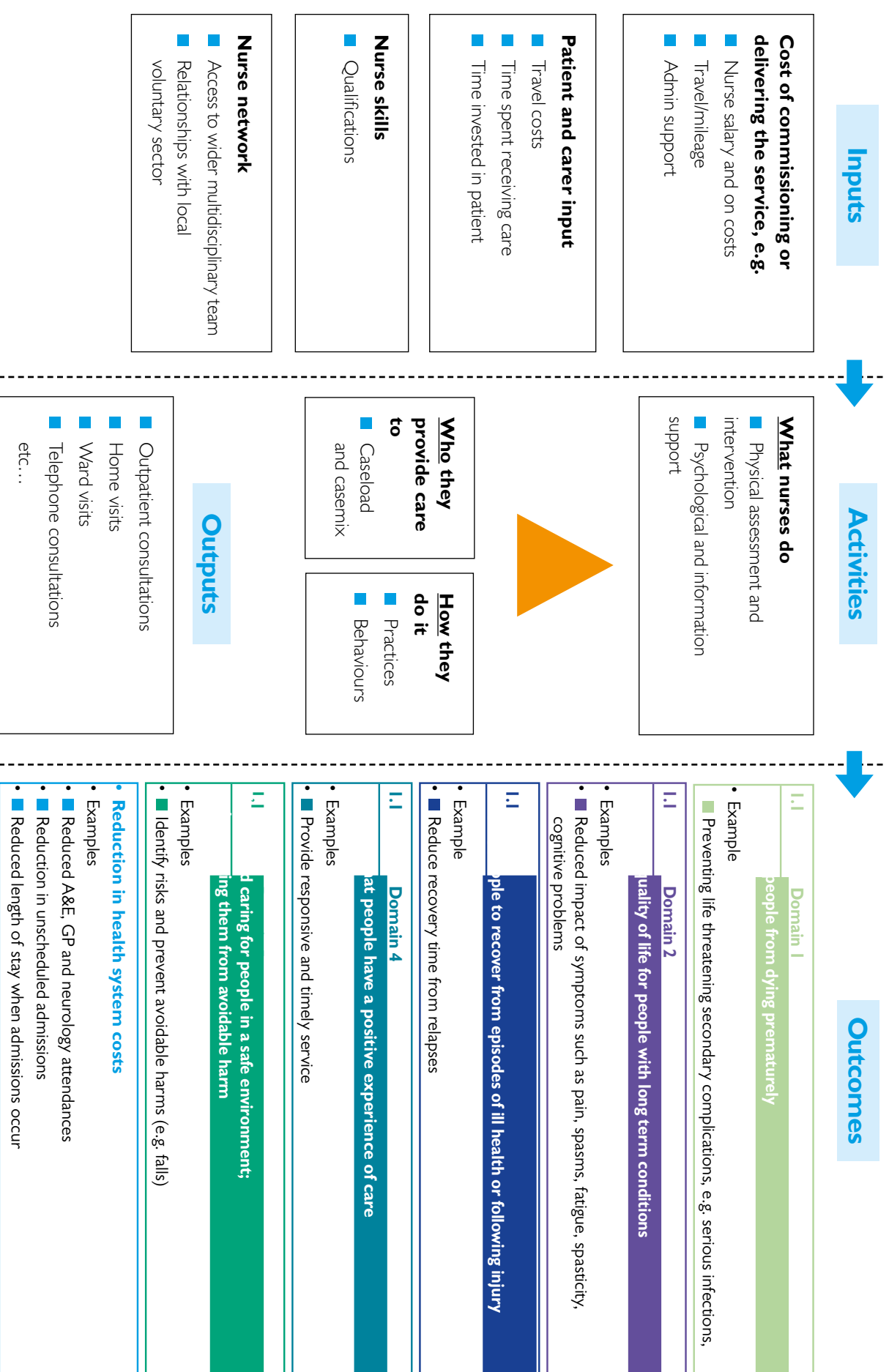## 3.2   The participating GEMSS teams

Appendix 2 lists the participants in GEMSS. Across GEMSS I and II, 30 MS specialists (27 MS specialist nurses, 2 physiotherapists and 1 research coordinator) worked collaboratively with the GEMSS facilitators to implement the project in their role as 'GEMSS leads'. A total of 40 MSSNs, four physiotherapists, two occupational therapists, one orthoptist and one MS social worker collected data about the specialist services they deliver through GEMSS.

The sixteen GEMSS teams reflected the diversity of contexts in which MS specialist service are delivered ranging from:

- Services covering mainly urban conurbations with caseloads in excess of 3,000 pwMS, in contrast with other services operating across sparsely populated rural areas with caseloads as low as 92 pwMS.

- Acute based services co-located with neurologists specialising in MS, to services based in district general hospitals providing access to neurologists via satellite clinics or a regional neuroscience centre.

- Services with a focus on meeting the complex care needs people with progressive MS, undertaking a high proportion of consultations as home visits, in contrast with services for focused on enabling people with Relapsing Remitting MS to self-manage, as well as make choices and manage Disease Modifying Drugs.

- Multidisciplinary teams in which MSSNs work alongside Allied Health Professionals (AHPs), and in one instance an MS specialist social worker, to deliver continuity of specialist care versus teams of MSSNs that refer on to therapist services.

Inputs

Cost of commissioning or delivering the service, e.g.
- Nurse salary and on costs
- Travel/mileage
- Admin support

Patient and carer input
- Travel costs
- Time spent receiving care
- Time invested in patient

Nurse skills
- Qualifications

Nurse network
- Access to wider multidisciplinary team
- Relationships with local voluntary sector

Activities

What nurses do
- Physical assessment and intervention
- Psychological and information support

Who they provide care to
- Caseload and casemix

How they do it
- Practices
- Behaviours

Outputs

- Outpatient consultations
- Home visits
- Ward visits
- Telephone consultations
- etc…

Outcomes

Domain 1
...people from dying prematurely
- Example
  - Preventing life threatening secondary complications, e.g. serious infections,

Domain 2
...uality of life for people with long term conditions
- Examples
  - Reduced impact of symptoms such as pain, spasms, fatigue, spasticity, cognitive problems

I.I
...ple to recover from episodes of ill health or following injury
- Example
  - Reduce recovery time from relapses

Domain 4
...at people have a positive experience of care
- Examples
  - Provide responsive and timely service

I.I
...d caring for people in a safe environment; ...ing them from avoidable harm
- Examples
  - Identify risks and prevent avoidable harms (e.g. falls)

Reduction in health system costs
- Examples
  - Reduced A&E, GP and neurology attendances
  - Reduction in unscheduled admissions
  - Reduced length of stay when admissions occur

3.3 The GEMSS evaluation framework

The evaluation framework for MS specialist nursing (summarised in figure 2) was developed jointly with teams taking part in GEMSS I and the GEMSS Advisory Group. It was informed by a literature review by the GEMSS facilitators to identify previous descriptions of the MSSN role and relevant standards and frameworks for MS services in the UK. The framework identifies the activities which MSSNs undertake, the ways of working which define MSSN activity and the outcomes which MSSNs seek to achieve for their patients, mapped to the five domains of the NHS Outcomes Framework for England. Outcomes were also mapped to the three Quality Ambitions for Scotland for GEMSS II.

3.4 The GEMSS data collection tools

Monitoring and evaluation tools were developed in collaboration with participating MSSNs to enable teams to collect data about their services to demonstrate whether, and how, their services delivered the evaluation framework activities and outcomes. Information was collected about the follows aspects of services, using the tools described below. Where teams had existing caseload databases in place, these were used in preference to the GEMSS tools to avoid duplication, but nearly all teams used the GEMSS tools.

3.4.1 Caseload and casemix

Data on date of birth/age, type of MS, disease modifying drug (DMD) use, disability (in three broad categories based on the Expanded Disability Status Scale) and ethnicity (some teams only) was recorded by teams on an Excel database. A caseload dashboard provided teams with quick reference charts and tables summarising caseload data. The spreadsheet was enhanced in GEMSS II to allow teams to record the planned review frequently of individuals and the date of their last consultation.

3.4.2 Service activity

Teams collected monthly data on their clinic consultations, DNAs, home visits, education sessions delivered and phone calls received and made, as well as recording the number of pwMS new to the service, those known to have left and people commencing treatment with DMDs. In GEMSS II the option to record other locally valued data was added to the Excel tool. Teams used this to record information on phone clinics, cancelled appointments and the number of clinic letters sent to patients, for example.

3.4.3 Key Process Indicators

During the GEMSS I training workshop teams worked collaboratively with the facilitators and the MS Trust team to come up with a set of Key Process Indicators (KPIs) which would be measurable markers of a high performing service. Importantly, these were designed to apply equally to a service focused on people newly diagnosed with MS as to a service with a greater caseload of patients with complex needs and progressive MS. Teams were given the freedom to decide, for each KPI, where they would set their own standard, based on what they were currently achieving and aspired to achieve. In GEMSS I the following four KPIs were agreed on.

- **KPI 1**. % of patients new to the service that are offered a face to face holistic assessment (comprehensive initial assessment) by an MS nurse to take place within X working day

- **KPI 2**. % of calls about specific patients responded to within X working days

- **KPI 3**. % of patients with acute deteriorating symptoms (including suspected relapses) contacted for assessment and appropriate treatment/management within X working days of alerting the service

- **KPI 4.** % of patients with progressive forms of MS who have a review appointment with a nurse planned in (to the nearest month).

KPIs 1 to 3 remained the same in GEMSS II, but KPI 4 was changed to a more practical measure that many teams could extract from the hospital systems by making a data request.

- **KPI 4** (GEMSS II). % of all patients on the caseload who had an annual review within the past year.

3.4.4   Patient experience and patient reported outcomes.

A patient survey was developed by the GEMSS facilitators with input from GEMSS I team, using questions drawn from national and validated surveys where possible. It was piloted with a group of people with MS (recruited through the MS Trust), and refined as a result. Teams sent out the surveys, with replies coming back to the MS Trust (anonymously) for data entry and analysis, and the facilitators fed back the survey findings to teams via a short report (GEMSS I) or PowerPoint presentation (GEMSS II).

3.4.5   Stakeholder and professional colleagues' views of the service

An online survey was developed by the facilitators and two GEMSS I teams and, as with the patient survey, this was jointly administered by GEMSS leads and the MS Trust.

3.4.6   Case studies about individual patients' interactions with MSSNs

GEMSS leads received guidance on writing case studies, took part a case study writing master class via a conference call and peer reviewed each others' work at a training workshop.

3.4.7   Audit of activities undertaken

Teams in GEMSS I used an audit tool, Cassandra, developed by Professor Alison Leary to audit all their activity (both clinical and non-clinical) over a three week period in early 2013. The tool was adapted in collaboration with Professor Leary for use in MS, and a user manual developed for those taking part. The results were subsequently published[4].

In GEMSS II, teams had the choice to opt in to an audit of consultations, again over three weeks, using The Dorset Specialist Neurological Intervention Tool (SNIAT).

This tool was developed by members of the Dorset Community Neurology Service and Poole Hospital MS Service in order to capture data on the proactive role played by MS specialists and to provide insight into the range of specific areas covered and interventions undertaken during consultations with pwMS. Six GEMSS II teams carried out this activity, and the results are available separately[5].

3.4.8   Use of service capacity

GEMSS II teams also had the option of analysing their use of service capacity. Facilitators developed a simple capacity planning spreadsheet that allowed teams to quantify their capacity to deliver face to face consultations based on their job plans and compare this to actual activity for the year. Facilitator support was given to interpret and review findings following the approach used by the MS Trust to model MS nurses workload[6]. Eight teams opted into this activity.

4. The achievements of GEMSS

4.1 Maintaining engagement throughout the evaluation project

The following have been notable achievements of the project.

- All the participating GEMSS I and GEMSS II teams stayed the course throughout the project and implemented the entire suite of data collection tools. This in itself is a significant achievement, not least because nearly all of the teams underwent managerial change and, in some cases, Trust re-organisations or mergers during the course of the project. Other teams had vacancies or staff sickness at various points in the project, leading to additional pressures.

- Participating services, many for the first time, have data as a result of GEMSS that allows them accurately to describe the people on their caseload, the volume of activity they deliver together and patient and stakeholder perspectives on their service, allowing analysis of the service and its delivery model in the round.

- The project led to the development of an evaluation framework and Key Process Indicators that were agreed upon by the 16 GEMSS teams and felt to reflect the broad range of MS specialist services represented in GEMSS.

- All 16 teams completed a local evaluation report at the end of GEMSS and have shared this with their managers and professional colleagues.

- Four of the five GEMSS I teams were continuing to collect data on their activity and caseload two years after completing the project, and this has been integrated with GEMSS II data to enable analysis of the caseload and activity of 15 services representing approximately 12-15% of the population of people with MS across England and Scotland.

4.2 Development of the wider GEMSS programme

The GEMSS project has resulted in other initiatives and publications that now sit within a wider GEMSS programme. GEMSS data has been used to generate a series of reports aiming to influence national policy and the provision of specialist MS services locally.

For example, using the first six months of GEMSS data collected in 2014/15, the MS Trust developed and published a 'sustainable caseload' model for MSSNs that quantifies an optimal caseload number and the conditions that need to be present for services to be effective with this caseload[6]. In parallel to this, using the findings of a national survey of MS specialist nurses, the sustainable caseload model was also used in the MS Trust report 'the case for equitable provision' to identify estimated caseloads for MSSNs serving each Clinical Commissioning Group and Health Board in the UK.

The report on the findings of GEMSS1 draws on the combined data sets of GEMSS I and GEMSS II teams to provide a robust and detailed review of MS specialist nursing and the multi-disciplinary context in which it is delivered. Data on the characteristics of over 15,000 pwMS, the activity of 15 services and the views of 1,254 pwMS who responded to the GEMSS survey are synthesised into a discussion on the activity and

productivity of teams and outcomes and economic effectiveness of MS specialist services.

The GEMSS project has also generated a repertoire of tools that the MS Trust are now starting to use to support MS specialist services UK-wide.

- The GEMSS patient survey has been developed into a service offer which the MS Trust has made available to MS teams nationally with nurse, therapist and MDT versions available. By the end of 2015, nine teams outside of GEMSS will have used the survey and five GEMSS teams will have used it for a second time, generating valuable benchmarking data.

- The capacity planning tool used by GEMSS teams has been refined and integrated into a workshop that looks more broadly at productivity. This was run twice at the MS Trust conference in 2014 and can be delivered as required.

- The use of GEMSS data and facilitator support for business case development is being trialled by one GEMSS team and will lead to web-based guidance for teams on producing credible evidence-based business cases.

- The MS Trust and GEMSS facilitators now offer brief, tailored 'consultancy' support for teams needing help to develop, improve or defend their services, using the expertise and tools developed through GEMSS. During 2014 and 2015, twelve teams (including two GEMSS teams) have been supported on issues as diverse as carrying out an audit to identify people with MS out of contact with specialist services[8], undertaking a survey to identify unmet therapy needs, creating a business case for a service expansion, making the case against the proposed de-specialisation of a neurology therapy team and exploring ways to improve throughput.

4.3   Use of the GEMSS approach beyond MS

The GEMSS project has generated significant wider interest amongst the specialist nursing community, beyond MS. Launching in late 2015, Dementia UK will be adopting the GEMSS approach and making use of many of the tools developed in GEMSS (with the MS Trust's permission) to launch GEANS – Getting Evidence into Admiral Nursing Services. This will evaluate the role of Admiral Nurses, specialist nurses who support carers and train up staff working with people with dementia.
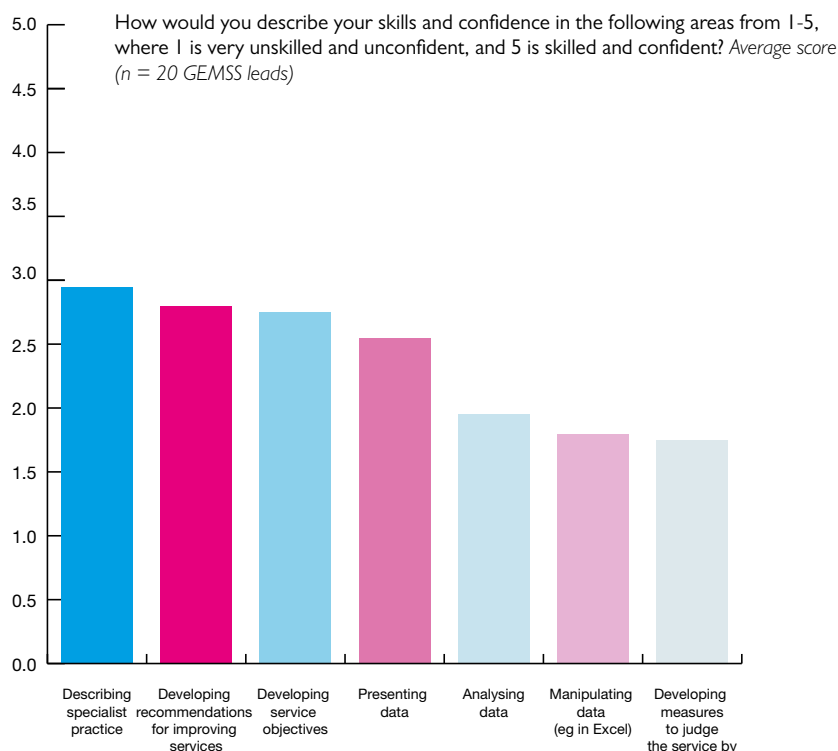
5. The impact of GEMSS

This section of the report looks at the impact of GEMSS on those that directly participated in the project, the GEMSS leads, and then discusses how useful teams found the GEMSS tools and consequently their plans for data collection going forward. The section concludes by presenting the evidence we have of the impact of GEMSS on how MS specialist services operate and therefore seek to meet the needs of people with MS more effectively. The section draws on quantitative evidence and illustrative quotes gathered through surveys with participants before and after their involvement in GEMSS, and qualitative evidence collected from GEMSS I teams during an independent impact assessment two years on from their completion of GEMSS[2].

5.1　　Impact on MS specialists who participated in GEMSS

5.1.1　　Participants' attitudes, beliefs and competence in evaluation

The GEMSS project was established to address the gap in evaluation skills so it comes as no surprise that 90% of GEMSS II participants told us in a survey prior to the start of the project that they had no previous training or coaching in evaluation or service development methodologies. Figure 3 shows that they also reported relatively low levels of skills and confidence in tasks needed for service evaluation and improvement, and rated their ability to develop measures to judge their service by, and analyse and manipulate data as particularly low.

Figure 3: GEMSS II leads' skills and confidence in evaluation at the start of GEMSS

How would you describe your skills and confidence in the following areas from 1-5, where 1 is very unskilled and unconfident, and 5 is skilled and confident? *Average score (n = 20 GEMSS leads)*

Getting to grips with the practical application of evaluation logic was an essential element of GEMSS. Although the concept of service evaluation was not new to GEMSS I and II leads, the language and logic of evaluation was challenging for many. As one GEMSS II lead commented following the project's initial training:

"In learning about evaluation I feel like I've learnt a whole new language".

In GEMSS II training participants mapped case studies they had written about care they had delivered to individual patients onto the GEMSS evaluation framework.

"I liked the case studies and deciding what aspect of the case study fitted into which category of the evaluation logic. This helped me get these categories organised in my head."

This exercise was identified by GEMSS II leads as the most useful of the training. But even so, only two thirds said that they had a clear understanding of the GEMSS evaluation framework and basics of the theory sitting behind on completion of the training. For facilitators this meant that the constant revisiting of evaluation logic was essential, but for many GEMSS leads, the real breakthrough in understanding was achieved once they acquired confidence in using the GEMSS tools and started to study the data these generated.

Feedback from GEMSS I and II leads identified the following aspects that contributed to embedding a culture of evaluation and growing competency in their teams.

- The discipline of collecting monthly data on activity and performance and its relevance and meaning for the service; so not just about what is needed for financial reporting.

- A growing confidence in using Excel to record and analyse data - this was the most common answer by GEMSS II leads in response to a question about what they had personally learnt from GEMSS.

- The final service evaluation report bringing together all the elements of GEMSS and setting out the outcomes and areas of improvement of the service. Participants often mentioned that they had benefited from constructive challenge from facilitators in order to reach strong conclusions and recommendations.

On completion of their final report all GEMSS II leads reported that the project had resulted in a positive impact on their confidence to evaluate their service and their knowledge and understanding of evaluation (see figure 5).

Experience from GEMSS I

The independent impact assessment of GEMSS I in early 2015 collected the views of GEMSS leads almost two years on from the completion of the project[2]. They reported that their involvement in the project had reinforced their belief in the value of evaluation, a strong motivating factor from the outset, but the greatest benefit has been influencing the attitudes and beliefs of more skeptical team members. As one GEMSS lead described:
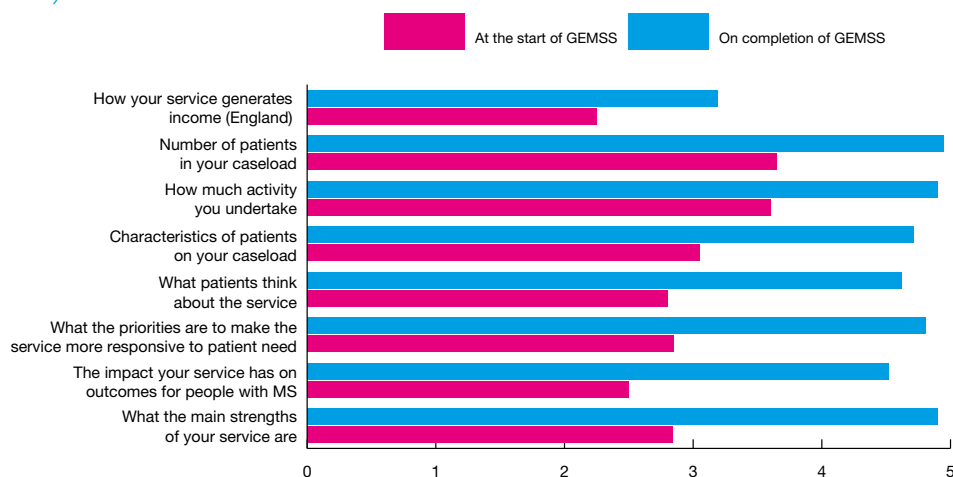
"Collecting data in a systematic way as resulted in a major shift in how one particular colleague views data collection and measuring outcomes. She had perceived this as time consuming and taking away her time with patients but now completely sees the value of such work as it helps her to articulate what she does."

5.1.2 Participants' knowledge of their services

It was essential in GEMSS that the time and effort invested in collecting data resulted meaningful information on important aspects of MS services and that this enhanced GEMSS leads knowledge of their services. To establish whether this had been achieved we asked GEMSS II teams how much knowledge they had at the start of the project and asked them the same question again on completion of their final reports. They were asked to give their answers on a five-point scale where '1' indicated that they had no information and had not given the issue much thought, and '5' meant that they had comprehensive information that they knew how to use. The results are shown in figure 4.

Figure 4: GEMSS II leads' views on the information known about key elements of their services before and after their participation in GEMSS (average response on a 5-point scale)

Legend: ■ At the start of GEMSS ■ On completion of GEMSS

Categories (top to bottom):
- How your service generates income (England)
- Number of patients in your caseload
- How much activity you undertake
- Characteristics of patients on your caseload
- What patients think about the service
- What the priorities are to make the service more responsive to patient need
- The impact your service has on outcomes for people with MS
- What the main strengths of your service are

Prior to GEMSS, most leads said of most issues that they had given it some thought but they didn't have much information, or that the information they had was incomplete or unreliable (2 or 3 on the five point scale). Following the project most GEMSS leads said that they had comprehensive information that they knew what to do with (a score of 5), with a small number stating that they had comprehensive information but not put together in a way that could be used (score of 4).

Examples of what they have learnt about their services through GEMSS, in the words of GEMSS II leads

"That we have a larger caseload than we thought! Our activity is a lot higher than we thought. Our service is effective but capacity is poor."

"It identified that we were not reaching a fair proportion of our caseload as often as we should be; it proved what a diverse service we offer, we are reaching those quickly with acute deteriorating symptoms better than what we thought."

"It clarified several issues which we had an idea about but needed evidence for e.g. our DNA rate, not carrying out enough home visits, and our need for an extra nurse."

"Actual details of service have been useful and especially as we were audited by the hospital and found to be underusing our service but the data that had been collected about us was wrong and incomplete. Having up to date information about our service from GEMSS was extremely important in this case."
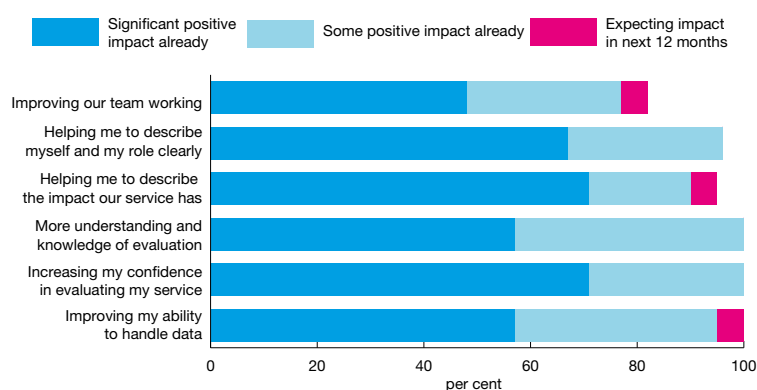
"We know our service is extremely stretched but GEMSS has helped us to evidence this and hopefully will improve as a result."

GEMSS II teams completed their reports over the summer months of 2015 and are now in the early stages of disseminating their findings, but many have already experienced a positive impact as a direct result of their involvement in GEMSS, as shown in figure 5.

Figure 5: Benefits of GEMSS reported by GEMSS II leads on the completion of their final reports

Listed below are some of the ways in which taking part in GEMSS may have benefited you already or may benefit you in the future. To what extent has this happened or do you expect it to happen?

Examples of benefits of participation in GEMSS, in the words of the GEMSS II leads

"Although at times we find it difficult to get together as a Team, through the process of working towards completing GEMSS, I feel we enhanced our communication and interaction as a Team. So, all in all, I suppose this has been a "discovery" in regards to identifying that although I thought we worked well together, we actually worked very well together and appreciate each other's individual efforts and roles within the Team. We do this in a much more meaningful way than we did prior to GEMSS."

"I thought I wasn't a data person, but really I only needed the appropriate systems in place to encourage me."

"I would admit to having being reasonably proud of my nursing service prior to GEMSS, now I feel even more proud of the service that we provide and we have the evidence to prove it. However, I will admit it is an ongoing, yet worthwhile effort to know that we do aim to get it right most of the time. Nevertheless, after 15 years as an MSSN, complacency should never set in."

"The enormity of our service when all the numbers are combined. The existence of business analysts within the hospital!"

"It has given me greater confidence in talking about the service to Consultant colleagues and managers, with the supporting evidence."

"Being part of GEMSS has helped me to focus on more than the clinical aspect of my role and the importance of evidencing what we do. It's been a tough year and I hope that if we can secure more funding, we can continue to build on this."

Usefulness of the GEMSS tools

During the GEMSS year, teams were expected to collect data on activity and KPIs on a regular basis as well as implementing one-off surveys and compiling an accurate database of their caseload if this was not already available. Minimising the burden of data collection was a significant factor in the design of GEMSS, but even so for some teams the effort required was significant. This was particularly the case in large teams where GEMSS leads needed to motivate other team members, in services with very high caseloads per MSSN, and for teams with little or no administrative support.
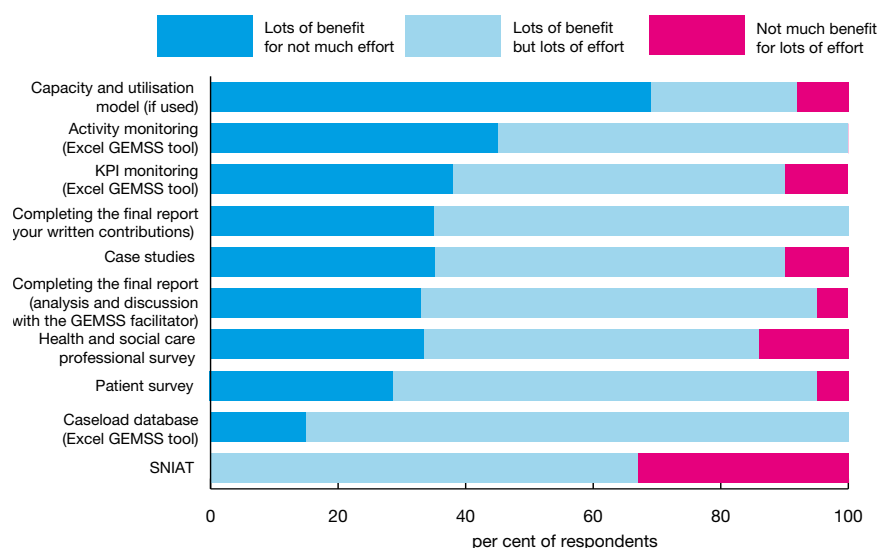
GEMSS I teams were asked about the value of GEMSS tools and their intentions to collect data moving forward on the completion of their GEMSS project. All the GEMSS tools were deemed worth the effort with the exception of the Cassandra™ tool, an audit of the range of activities carried out by MSSNs. The evidence generated by Cassandra™ was helpful in explaining the complexity of the MSSN role and led to a publication[4] but it was not repeated in GEMSS II. Instead teams were offered the option of piloting the Dorset Specialist Neurological Intervention Audit Tool (SNIAT), an audit of all face to face consultations which was carried out over a three week period. This tool proved useful in demonstrating the range of topics being covered within consultations and the level of urgency (from routine preventative and monitoring work, to urgent and unscheduled care). In the overall analysis of GEMSS which combines the data from six teams that implemented the tool, the data showed how the complexity of issues dealt with increased amongst people with progressive MS and that overall the majority of interventions were focused on preventing problems down the line.

Figure 6 presents the views of GEMSS II leads on the value of GEMSS tools, having completed their final reports. It shows that GEMSS tools were on the whole considered to deliver benefit for the effort involved. Three elements of GEMSS, developing a caseload database, activity monitoring and completing the final report were universally thought to have delivered benefits, but with significant workload involved for a proportion of teams. The GEMSS tool delivering the 'quickest win' in terms of lots of benefit for not too much effort is the capacity and utilisation model developed within the programme, which has since been made available to other teams outside of GEMSS. The SNIAT tool was felt to have delivered the least benefit to teams, but this does not factor in the wider benefit to services of the ability to publish the meta analysis of the SNIAT data.

Figure 6: Views of GEMSS II leads on the benefits vs. effort involved in GEMSS tools

What would you say about the benefit vs effort involved in each of these GEMSS tools?
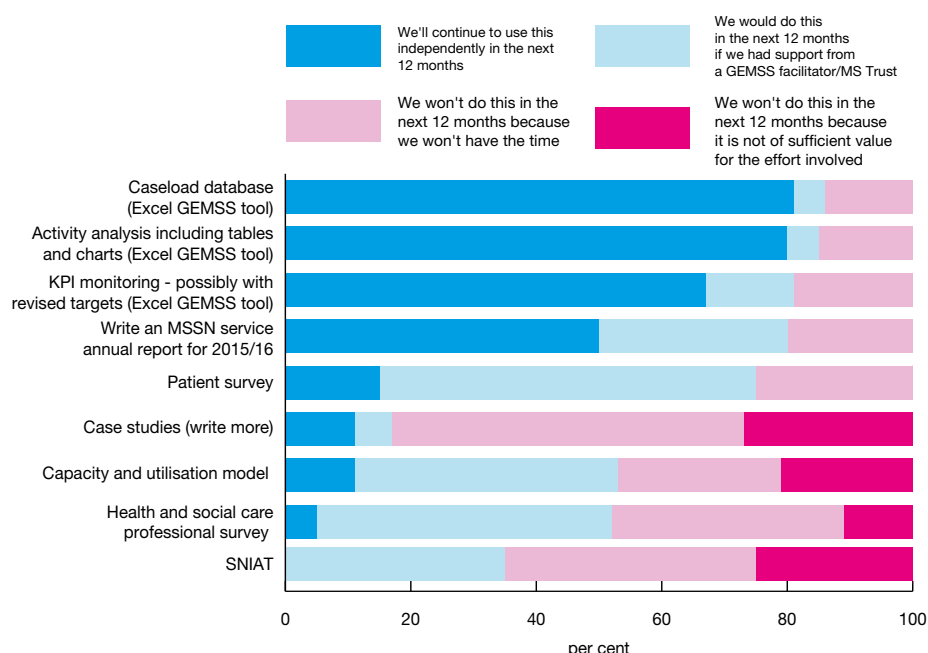

	Lots of benefit for not much effort	Lots of benefit but lots of effort	Not much benefit for lots of effort

Capacity and utilisation model (if used)
Activity monitoring (Excel GEMSS tool)
KPI monitoring (Excel GEMSS tool)
Completing the final report your written contributions)
Case studies
Completing the final report (analysis and discussion with the GEMSS facilitator)
Health and social care professional survey
Patient survey
Caseload database (Excel GEMSS tool)
SNIAT

per cent of respondents

"I have really valued being given the opportunity to be part of the GEMSS project…

Feedback was very valuable in assessing and planning the ongoing development of the service. GEMSS has equipped me with a comprehensive tool to manage and capture data. This empowered me to build evaluation skills and the mindset required for service judgment and improvement into the MS specialist nursing service in [place]. I am continuing to use these tools and will continue to collect data to allow me to continue to evaluate and improve the MSSN service beyond GEMSS."

GEMSS II lead

Figure 7: Views of GEMSS II leads on which GEMSS tool that they plan to continue using

Which of the GEMSS tools are you planning to use again or keep up-to-date going forward?

5.2   Integrating data collection into routine work

The aspiration in GEMSS was that teams would integrate at least the core elements of GEMSS data collection (monthly activity monitoring and maintaining a caseload database) into their services on completion of the project.

GEMSS I leads were asked about which GEMSS tools they planned to continue using. They all expressed an intention to continue with the GEMSS caseload and activity monitoring and KPIs. From the impact assessment report on the GEMSS I project and teams' continuing involvement in the work of the MS Trust we know that four out of five GEMSS I teams have maintained their caseload databases and continued to collect data on their activity and elements of KPIs that are of most relevance to their service. Some teams have integrated GEMSS data into hospital systems or local databases and one team has expanded data collection across its entire caseload of neurology patients. Four of the five GEMSS I teams have repeated the GEMSS patient survey and two have used the capacity modelling tool used by GEMSS II teams. Only one team to date has subsequently written another service evaluation report. .

GEMSS II leads were also asked about their plans for using tools going forward and their response to this is shown in figure 7. The majority of GEMSS leads expressed their intention to continue to maintain a caseload database and monitor activity independently of MS Trust involvement. Some GEMSS leads also indicated that they would continue to collect data on KPIs, possibly with revised targets, write an annual report for 2015/16 and repeat the patient survey, although it was clear from some that these activities would be contingent on ongoing support from the MS Trust.

The main reason for not continuing with other GEMSS tools was insufficient time. There was one GEMSS II team that at the point this survey took place had chosen to not continue with updating their caseload and activity figures. However the team has since secured some temporary administrative support to enable this and is in the process of drawing up a business case for additional resources, which if successful will allow MSSNs to embed data collecting more thoroughly into their work.

Overall, GEMSS has been relatively successful in embedding core elements of data collection into the routine work of MSSNs and convincing them that this is well worth the time involved. It remains the case, however, that a lack of administrative support hampers the ability of some teams to do this. It is regrettable that NHS patient record systems in many cases do not support the kinds of data collection which MSSNs would find most useful, such as a register of pwMS on the caseload which could be used to stratify pwMS and plan care proactively. Data collection remains an add-on activity in most cases, to be done in addition to the day job rather than as part of routine care.
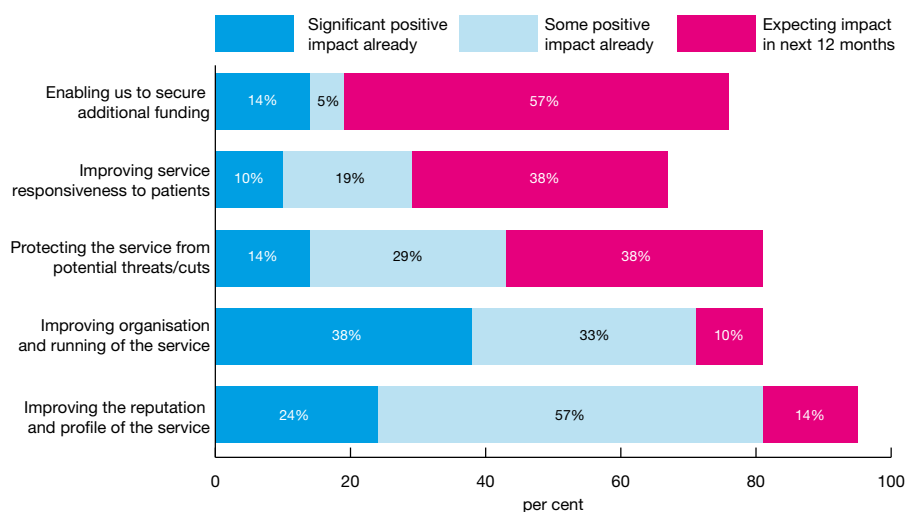
5.3   Impact on improving MS services

Although service improvement was not an explicit objective of GEMSS, reflecting on the evidence generated by GEMSS inevitably lead to recommendations on how services could be improved. In GEMSS II, the growing body of knowledge within the MS Trust/GEMSS facilitator team meant that the facilitators were able to introduce service improvement principles at an early point. The introduction of the capacity modeling tool, for example, allowed GEMSS teams that opted in to critically review their productivity against the benchmarks established by the sustainable caseload model. All teams had the opportunity to consider the findings of their patient survey against the range and average of scores achieved by the GEMSS cohort, giving GEMSS leads important feedback on their performance against measures of patient satisfaction and the responsiveness of their service. It therefore felt appropriate to ask GEMSS II leads whether in the year of intensive activity on data collection there had been any impact in the service as a result of GEMSS. Responses to this question are set out in Figure 8.

Figure 8: Impact of GEMSS on MS services reported by GEMSS II leads on the completion of their final reports

Listed below are some ways in which taking part in GEMSS may have benefited your service already or may do so in the future. To what extent has this happened or do you expect it to happen?

	Significant positive impact already	Some positive impact already	Expecting impact in next 12 months

The area of most impact to date has been the improving the reputation and profile of the service, with 81% of respondents saying that they had already seen impact in this area. This compares to 44% of GEMSS I leads who said at the end of the year that participating in GEMSS had already improved the way managers or other clinicians viewed their service. In GEMSS II there was a stronger emphasis on connecting with senior managers, such as Directors of Nursing, with the project and updating them on progress at key points via email bulletins. Presentations by GEMSS leads and facilitators at the start of the project introduced a wide group of stakeholders to the project: one GEMSS team presentation was attended by the Trust's Chairman and most GEMSS II leads have followed up and sought to maintain this level of engagement. Three quarters of GEMSS leads stated in the survey following the completion of their final report that they already have firm plans to present the findings of their GEMSS report to professional colleagues, managers, directors and in one case the Trust's Board. Other GEMSS leads were yet to decide, but no one said they would not be presenting their work.

> *"It has taken a while to set up but now have a date where the chief nurse, assistant divisional director, assistant business director and neurologists can attend...will now think of others to invite. A copy of the report has already emailed to most of them."*
>
> **GEMSS II lead**

Over two-thirds of GEMSS II leads reported some positive or significant impact in the organisation and running of their service as a result of GEMSS. A wide range of examples have been given by GEMSS II teams and among these are:

• Increasing the number of clinic appointments and varying appointment length in

response to data on caseload numbers and the frequency with which people on the caseload have been reviewed.

• Changing answerphone messages to enable more effective triage of callers and earlier responses to urgent calls.

• Integrating GEMSS data into a hospital information system or local database that has, in the case of two services, made paper caseload records redundant.

• Pro-actively contacting pwMS that GEMSS data showed had not been reviewed in the previous 12 months.

• Development of a hand-held 'MS passport' in the case of one GEMSS team, with details of a persons' MS history to aid communication with different members of the MDT.

> *"For the MS nursing team taking part, GEMSS has enabled us not only to have the "numbers" about caseload, activity and patient demographics on a scale that we have never had before, but it has enabled us to look at the whole process of data collection and turn it into meaningful, quantitative data to help shape the future of the service. The GEMSS principle is now embedded in our daily practice and is helping us move to a fully integrated service where all patient contact is recorded in a meaningful way and in turn helping us to work more efficiently upholding the "better care at lower cost" philosophy."*
>
> **GEMSS II lead**

Just under a third of GEMSS II leads reported that GEMSS had so far made an impact on the responsiveness to people with MS on the caseload. Examples of changes made included the recording of telephone activity on an electronic clinic management system enabling MSSNs to instantly review all previous patient contact by phone and an improved system for storing and retrieving messages without relying on mobile phone reception in a rural area. Several GEMSS leads pointed out that the process of creating an accurate caseload database had led them to contact patients not seen by an MSSN in the last twelve months.

Finally, GEMSS II leads gave views on the impact of GEMSS on securing existing posts and additional funding for services. These are undoubtedly complex issues as decisions are not solely made on robust evidence of a service's value but influenced heavily by Trust and Clinical Commissioners' priorities and finance arrangements. Protecting services was, however, ranked first out of a list of eleven possible factors motivating engagement in GEMSS by GEMSS II leads before they started the project. Across GEMSS I and GEMSS II teams, no services have been reduced since the start of their involvement in the project, and three teams have said that GEMSS data has been instrumental in specialist nursing reviews of their MS nurse services in the past six months. Two of the most stretched GEMSS II teams have taken significant steps towards developing a business plans to gain additional resources.

GEMSS I teams have, in the two years since the completion of the project, successfully secured posts and used evidence generated by GEMSS to argue the case for additional resources or a change in how resources are used. These examples are set out in the box below that draws on the findings from the impact assessment of GEMSS I teams.

"We have used the 2012/13 evaluation report in business planning to justify what we do and carried out an exercise on caseload and our capacity to manage the caseload. This led to changing the skill mix within the staff time when a vacancy arose and even though this did not help us to get additional staff, the change in skill mix has enabled us to see new patients sooner."

"The first patient survey helped to reduce DNAs as it had identified that data about the patients needed to be collected more accurately. I have just completed a second patient survey that is positive but will also help me in my business case for having a permanent office as patients stated that it was not always possible to contact me. I do not have a desk so need to pick up messages from an answerphone and am hoping that I can demonstrate the importance of having a desk with a phone so that I can be more responsive to patients."

"The programme is an excellent way to give confidence to the team and promote the service as well as make an assessment of staff capacity and skills and produce evidence for the need to change the service, new equipment and increased staffing. We have been able to secure a support worker and two more specialist nursing staff."

"We have carried out two patient surveys and based on the findings have changed the way the service is delivered by running more clinics and reduced home visits. The team is more pro-active about contacting patients and has secured the service of one of the secretaries who calls patients a few days before appointments as a reminder. This has significantly reduced the number of DNAs. We also identified that a significant number of MS patients are not in touch with our service and are carrying out a survey to identify the cause of this. When our Trust was being inspected by the Care Quality Commission (CQC) … the team was very quickly able to produce reports on how the service met the CQC standards as all the evidence had been systematically gathered."

"Following on from the 2012-13 evaluation report, the team implemented a number of recommendations in the report. One was to set up a telephone triage service every afternoon for patients run by support workers. This has meant that patients are getting a response from the team on the same day and if urgent passed onto relevant professionals. It has also led to 85% of the telephone calls being dealt with by the support workers which has led to specialist staff being able to use their time more effectively dealing with complex cases. Using the GEMSS programme has made the team more aware of how to use their time more effectively. GEMSS tools have enabled the team to assess the staff capacity to effectively manage the team's caseload and re-model the team when a vacancy occurred. It has also enabled the team to make a business case for more staffing which has not brought in more resources but helped to bring in a better skills mix into the team."

"Yesterday I was informed that I have a substantive post after three and a half years of three months, six months and 12 months extensions of contract on a fixed term. The evidence I have collected as a result of the support I have had and the opportunity to be part of GEMSS has played a major part in supporting business cases, job plans and future forecast."

6. Conclusion: lessons from GEMSS for evaluating specialist services

The experience of running the GEMSS evaluation project has been an enormously rewarding one for the MS Trust and has resulted in three areas of benefit:

- For the participating teams, the evidence in this report shows that participation in GEMSS has been beneficial both for their own skills and confidence in evaluation, and in improving the services they are able to provide for pwMS. The host NHS organisations in which GEMSS participants work universally welcomed the input by the MS Trust in delivering GEMSS.

- For the wider MS community, the data and knowledge generated through GEMSS has enabled the MS Trust to produce a whole range of outputs from the project, including the GEMSS final report in November 2015 which represents a unique compendium of information and recommendations about MS services in the UK.

- For the MS Trust as an organisation, working so intensively with the 16 teams in GEMSS has enabled the organisation to develop an in-depth understanding of how MS specialist services are working in today's NHS. This understanding is invaluable in informing the work of the MS Trust going forward, including the training and development which the Trust provides to MS specialists.

Reflecting on the process, there are a number of conclusions which can be drawn about this type of work.

The environment in which the GEMSS evaluation project place presented a number of challenges, including the following.

- **The transition from evaluating a patient to evaluating a service is a long journey.** The language and logic of evaluation was new to most MS specialists that took part in GEMSS and many were inexperienced at collecting data systematically on a regular basis. GEMSS leads' confidence and skills to analyze quantitative data was low at the outset.

- **NHS systems are not always supportive.** GEMSS participants work in large, highly complex organisations where management changes are frequent and the commissioning environment (in England) is marked by complexity.

- **There is an inherent tension between presenting the evidence that services are improving outcomes and identifying areas for improvement.** GEMSS provided the opportunity for teams to document and describe their work but this sat alongside the assessment and judgment derived from such tools as the patient survey, capacity and utilisation model, and KPIs. In most part, teams were judging performance against targets they had set themselves, but the patient survey presented the added opportunity (and challenge) of benchmarking individual teams against the average and range across the GEMSS teams. The data presented harsh or constructive criticism, depending on its reading.

- **Data collection is a burden.** NHS information systems do not always support the collection of the type of data which MS specialists need to evaluate their services, and in many cases new relationships needed to be forged between GEMSS participants and information departments in order to understand what is

available and how systems work. GEMSS leads rated data collection as the single biggest challenge and it is understandable why, when for some teams constructing a caseload database meant manually extracting data from thousands of individual paper records and inputting this into an Excel spreadsheet. The GEMSS project provided tools for data collection in the absence of local alternatives, but recognised that this is far from ideal: ultimately data collection should be integrated into routine systems used for patient care.

> *"Being part of GEMSS has enabled me to talk confidently about the service and what we have achieved. Also feeling part of the wider community in terms of MS. Have previously felt very much on the outside at meetings etc."*
>
> **GEMSS II lead**

> *"Whilst some of the results from the questionnaire and KPIs are not as good as we would have liked, we feel that it gives a true reflection of where the services is at currently and has helped identify areas where we need to improve. However, we feel overall that the service upholds a safe and personal approach that meets our patients needs which we will continue to strive to improve."*
>
> **GEMSS II team, concluding comments in their evaluation report**

Given these challenges, some of the success factors in GEMSS were as follows:

- **Training, ongoing facilitation and peer support.** The experience of GEMSS has confirmed that providing a 'toolkit' would not have enabled participants to achieve what they have; ongoing tailored support throughout the project was necessary. The MS Trust made a significant investment in hand-on support from facilitators knowledgeable and experienced in service level evaluation. The strength of relationship between facilitators and their teams contributed to their continued engagement. GEMSS developed in to a community of interest with individuals sharing motivation for involvement and providing each other with encouragement and support.

- **Tight focus on what data was collected.** Given the burden of data collection, it was essential to have a clear evaluation framework at the start of the project and focus attention only on the collecting the most valuable and important data. Trade-offs and flexibility were required to keep this manageable.

- **The competitive selection process for choosing teams.** The strongest teams in terms of existing evaluation data, weren't automatically chosen in GEMSS, but those that demonstrated greatest willingness to commit time and energy on top of existing commitments and a receptiveness to change were chosen.

- **Balancing co-production with ensuring evidence-based tools.** The GEMSS team worked with the participants to develop the evaluation framework and tools, but also made constant reference to the research literature and experts to ensure that the process remained evidence-based. The MS Trust were able to bring their expertise to bear within the process.

- **Minimising the burden of report writing and data analysis.** Whilst in principle it might have been ideal to use GEMSS as a vehicle for developing specialist nurses' report writing and data analysis skills, a pragmatic decision was taken to provide support for these activities, allowing GEMSS leads to concentrate on drawing out conclusions and recommendations from the data. This support was reported by the vast majority of GEMSS II leads as essential to the project.

- **Engaging wider stakeholders within host organisations.** Through the initial introductory meeting at which GEMSS was presented, and through regular updates and e-bulletins, stakeholders including line managers, neurology consultants and Directors of Nursing were engaged with the project. This undoubtedly helped teams to negotiate barriers faced along the way, and gain greater impact with their final project reports.

Overall, the GEMSS evaluation was a highly innovative project whereby a third sector organisation has brought its expertise and resources to bear in working collaboratively with NHS services, for the benefit of people with the condition. We would recommend it as a way of working, but commend others thinking of following not to underestimate the resource and time commitment involved.

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Appendix 1 Overview of Project Stages

Stage one - launch	
GEMSS I March 2012	The project was launched with a presentation at the MS Trust MSSN meeting in Crewe and facilitators were available during the conference to talk to interested teams about what was involved in taking part.
GEMSS II Sept – Nov 13	GEMSS II was launched in September 2013 and facilitators held an application 'surgery' at the MS Trust Conference in November 2013.

Stage two - team recruitment and project scoping	
GEMSS I March – May 2012	The MS Trust selected five teams (26 MSSN teams expressed interest and nine applications were received). The original intention had been to include four teams, but two teams working together in Dorset submitted a very strong joint application and were both accepted into the project. Facilitators visited teams on site to meet them and their line managers and colleagues, understand more about the context in which they are working and answer questions about the programme The GEMSS Advisory Group was formed, held its first meeting and agreed the GEMSS I rationale and principles which should underpin the GEMSS evaluation framework Facilitators and the MS Trust core team (Director of Service Development and Nurse Advisor) produced a draft evaluation framework through a collaborative working session.
GEMSS II	The MS Trust selected 11 teams from 22 applications. Facilitators and the MS Trust core team reviewed the evaluation framework, KPIs and tools collaboratively. Successful teams were asked to nominate GEMSS leads to drive their teams' engagement in GEMSS. Teams put forward between one and three individuals. Training pre-work included the preparation of case studies by each GEMSS lead.

Stage three - initial training	
GEMSS I May 2012	A two day residential training workshop was held for the GEMSS leads from each team - eight in total. The workshop was led by the GEMSS facilitators and an external trainer lead on some of the personal effectiveness elements of the training. Taught sessions introduced participants to evaluation logic and collaborative working was used to populate the draft evaluation framework and establish Key Performance Indicators (KPIs) Following training, Excel data collection tools were developed with the support of a data analyst.
GEMSS II Feb – Mar 2014	22 GEMSS leads attended a two day workshop led by a GEMSS's facilitator and the MS Trust's Director of Service Development with some external training input to build group dynamics. Stronger emphasis placed on applying the theory of evaluation to the GEMSS evaluation framework and supporting nurses to understand how GEMSS data will enable them to assess and judge their services. The evaluation framework was introduced to participants and KPIs were jointly reviewed.

Stage four - data collection and further training	
GEMSS I June 2012 – March 2013	Individual two hour working sessions were held by phone with each team to enable them to set up and understand the use of the Excel activity, KPI and caseload tools Six-weekly Webexes were held with all teams (seven in total), together with ad hoc individual telephone support over the course of the 10 month period. Teams collected activity and caseload data using the GEMSS excel tools. Teams implemented a patient survey, health and social care professionals survey and used an audit tool ' Cassandra' to capture data on their activity. The final report template was developed and modified based on the feedback from GEMSS teams and the MS Trust. The GEMSS teams came together at a workshop at the MS Trust nurses meeting in March 2013 to work on their data and develop elements of the final report.
GEMSS II April 2014 – March 2015	Facilitators visited GEMSS teams on site to agree local KPIs and ensure that the GEMSS activity and caseload excel tools were correctly set up. The GEMSS team and facilitator jointly presented the project to neurologist, managers, patient representatives, commissioners and other stakeholders to locally launch GEMSS. Teams collected activity and caseload data using the GEMSS excel tools. Teams implemented a patient survey, health and social care professionals survey. Teams also had the option of undertaking a capacity modeling exercise and using an audit tool (SNIAT) to capture data on their activity. Three Webexes provided additional training input on implementing the patient survey, conducting the SNAIT and writing case studies. GEMSS leads came together at workshops at the MS Trust Conference (November 2014) and Nurses Meeting (March 2015) to review their data as a group and plan their final reports.

Stage five - reporting	
GEMSS I April – Sept 2013 GEMSS II April – July 2015	GEMSS teams sent the GEMSS facilitators their anonymised data and themselves wrote case studies and service descriptions for their final reports. The GEMSS facilitators undertook analysis of each teams data to create charts, and collated each teams' local report using a standard template developed within the project. GEMSS facilitators discussed the draft reports with GEMSS leads and jointly developed conclusions and recommendations before reports were finalised. In GEMSS II, a meta analysis of all the teams' data was undertaken for publication.

Appendix 2 The GEMSS Teams

The GEMSS programme would not have been possible without the commitment and enthusiasm of the GEMSS leads in each of the participating teams, together with all the other team members who collected data. A brief summary of the teams who took part in GEMSS is given below. For further information, see the GEMSS findings report[1].

Organisation	Team composition[1]	GEMSS leads
Calderdale & Huddersfield NHS FT	2 MSSNs	Audrey Owen, Denise Winterbottom
Leeds Teaching Hospitals NHS Trust	2 MSSNs	Gale Metcalfe, Julie Taylor
Mid Essex Hospital Services NHS Trust	2 MSSNs	Helen Willis, Julie Webster
Northern Devon Healthcare NHS Trust	1 MSSN	Carol Turner
Royal Devon and Exeter NHS FT	1 MSSN	Louise Jarrett
Salford Royal NHS FT	6 MSSNs, 1 MSSN Consultant, 1 MS Support Nurse	Karen Vernon, Will Lusher, Alison Bradford
The Shrewsbury and Telford Hospital NHS Trust	2 MSSNs	Kate Womersley, Denise Cooper
Tayside and North Fife Regional MS Service	Multidisciplinary team including 3 MSSNs, MS physiotherapist and MS social worker based in Dundee City Council	Shona Flucker, Pam Walker
The Walton Centre NHS FT	Multidisciplinary team including 3 MSSNs, 2 physiotherapists, 2 occupational therapists and MS orthoptist	Carolyn Cairns, Helen Curran
University Hospitals of Leicester NHS Trust	3 MSSNs	Deborah Wilkinson, Fiona Cray, Allison Smith
NHS Western Isles	1 MSSN	Rachel Morrison
Poole Hospital NHS FT	3 MSSNs	Caroline Chandler, Cheryl King
Northumbria Healthcare NHS Trust	2 MSSNs	Jane Metcalfe, Miriam Forster

The Dudley Group NHS FT	1 hospital based MSSN (community based MSSN alongside not part of GEMSS)	Tracy Dean
Dorset Healthcare University NHS FT	Multidisciplinary team including 1 MSSN, 1 Neurology Nurse, 2 physiotherapist , 1 OT and 2 healthcare support workers.	Michelle Davies, Tracy Evans
Sheffield Teaching Hospitals NHS FT[2]	6 MSSNs	Daisy Cam, Helen Parry

1 Team members are not all full time. See the GEMSS Findings report for further information.

2 GEMSS I only

Appendix 3 – The GEMSS Advisory Group

We are grateful to the members of the GEMSS Advisory Group who have guided and advised the programme.

Amy Bowen (Chair)		Director of Service Development	MS Trust
Juliet Ashton	From Dec 14	Sapphire Nursing Consultant – Epilepsy Commissioning	Epilepsy Society
Pam Bostock	From Dec 14	Consultant Neuro-Occupational Therapist	Staffordshire and Stoke on Trent Partnership NHS Trust
Dr Peter Brex		Consultant Neurologist	Kings College Hospital
Amanda Cheesley		Long Term Conditions Advisor	RCN
Michelle Davies	From Mar 13	Clinical Specialist Neuro-Physiotherapist	Dorset Neurology Service
David Foster		Deputy Director of Nursing	Department of Health
Rosie Grove		Policy Advisor	UKMSSNA
Karen Harrison Dening		Director of Admiral Nursing	Dementia UK
Sally Hughes		Programme Director – Policy and Influencing	MS Society
Prof Alison Leary		Professor of Workforce Modelling	South Bank University
Vicki Matthews	To Nov 13		'MS Pro', and RIMS
Jane Nicklin		Independent Health Consultant / Physiotherapist	
Debbie Quinn		MS Specialist Nurse / MS Trust Nurse Advisor (until summer 2014)	Northamptonshire
Julie Rigby	To Jul 13	Quality Improvement Programme Lead	NHS England
Helen Sandell	To Dec 14	Co-Chair	Therapists in MS Group
Delyth Thomas		Co-Chair	UK MS Specialist Nurses Association