

Multiple  
Sclerosis  
Trust

MS

**Defining the value of  
Allied Health Professionals**  
with **expertise in**  
**Multiple Sclerosis**

Supporting Evidence  
and Recommendations  
for Commissioners and  
Practitioners

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## Foreword

This report focusses on the range of highly skilled, knowledgeable and experienced allied health professionals who support people with MS. The voices of the patients in this report confirm the value they attach to AHPs with expertise in MS and the difference it makes to their lives. It is vital, though, that the MS AHPs are able to demonstrate their value to a wider audience. The reforms to the NHS, rising financial pressures and the need to deliver significant savings with no compromise in quality means that MS services need to make themselves visible to commissioners and show the difference they make.

The MS Trust has commissioned this work, building on the 2012 report, Defining the Value of MS Specialist Nurses, to advance our understanding about the opportunities and challenges in showing the real impact of AHPs with expertise in MS. Compared with the nurses, these challenges may be even greater, particularly given the wide variation in service configuration, the diversity of roles, types of employer, levels of expertise and in evidence of outcome.

This report makes a series of important, practical recommendations for commissioners designing and allocating resources for MS services, for MS AHPs working on the front line in a changing and challenging environment and to the national organisations with an interest in protecting and developing services for people with MS.

The MS Trust remains fully committed to the MS AHPs as well as MS specialist nurses and the other specialist services on which people with MS rely. In this report, we have heard again how important these services are to people with MS and we will continue to support, campaign for, and generate evidence about the difference they make every day.



**Pam Macfarlane, Chief Executive, MS Trust**

## 1. Introduction

This report is about the value of allied health professionals (AHP) with expertise in multiple sclerosis. It is intended for all members of the MS community, including those responsible for managing and commissioning MS services, neurologists, AHPs working with people with MS and MS patient organisations. It assesses the case for the value of AHPs with expertise in MS and outlines the work needed to strengthen this case further.

AHPs are an integral part of a comprehensive, multidisciplinary MS service. Physiotherapists, occupational therapists (OTs), speech and language therapists and dietitians all make a vital contribution to MS care. Some AHPs, however, through training and clinical experience, build up a greater depth of knowledge and skill in MS and offer a greater level of expertise in their service. This report seeks to explore the difference that an AHP with particular expertise in MS can make.

AHPs not only treat, but more importantly manage, people with MS. People with long-term conditions such as MS need help to manage their condition which affects them 24 hours a day, 7 days a week. AHPs largely work within rehabilitation services, a distinct area of practice with a distinct philosophy. They contribute to maintaining independence and the prevention of secondary complications which could otherwise greatly increase the burden of care, decrease quality of life, and accelerate disability. They aim to ensure that the people they work with achieve the highest level of function and independence. They assist people with MS to restructure their lives, learn new skills, re-learn even the simplest tasks and make significant emotional adjustments in their life.

Physiotherapists and OTs are the AHP most likely to be seen by someone with MS.

“*Physiotherapists are experts in human movement, from the way we move our backs and limbs, to the way in which we breathe. The primary aims of physiotherapy are to restore and maintain function, activity and independence and to prevent injury or illness through treatment, information and advice on healthy lifestyles.*

*Occupational therapists enable people to achieve health, well-being, independence and life satisfaction through participation in occupation. In this respect the term ‘occupation’ describes the activities that an individual undertakes and which define his or her being and their self-esteem, autonomy, and purpose for living.”*

In the preparation of this report we conducted a literature search, visited eight service providers within and outside the NHS, and interviewed people with MS being treated by AHPs. We found a picture characterised by variability:

- **of the disease itself**, which may encompass relapsing remitting MS, secondary progressive MS, primary progressive MS or each of these with a co-morbidity of another physical or mental health condition.

- **of the disease as experienced by individuals**, as each of the above types of MS can be fluctuating and variable in nature and experienced differently by individuals in different personal circumstances and at different stages of the disease trajectory.
- **of the configuration of the workforce**, which may involve different types of employer, work setting (e.g. clinic, workplace, home visits), team membership, team size, access criteria. In some places AHPs are resourced mainly by the NHS, in others by Social Services.
- **of the focus of the therapy**; for example, diagnosis, treatment of relapses, enabling people to return home from hospital, rehabilitation in the context of deterioration.
- **as a subject of research and audit**, resulting from factors such as the difficulty in obtaining big enough sample sizes, and comparable patient cohorts, environments or service settings.

Though some of the above is well known to anyone working with people with long-term conditions, we found that the above factors combine to make the working environment for MS AHPs an unusually complex one.

This variability can mean that MS AHP services are less well appreciated and understood than sometimes they ought to be, by both commissioners and other health professionals. This, in turn, may mean that MS AHPs are accessed less often than they should be by people with MS, given the benefits that they can provide. We conclude that AHPs with expertise in MS would benefit from greater emphasis on and expertise in generating evidence about their services and in communicating this evidence to users, managers, and commissioners.

## 2. Definition and scope - what is an ‘AHP with expertise in MS’?

### 2.1 Scope

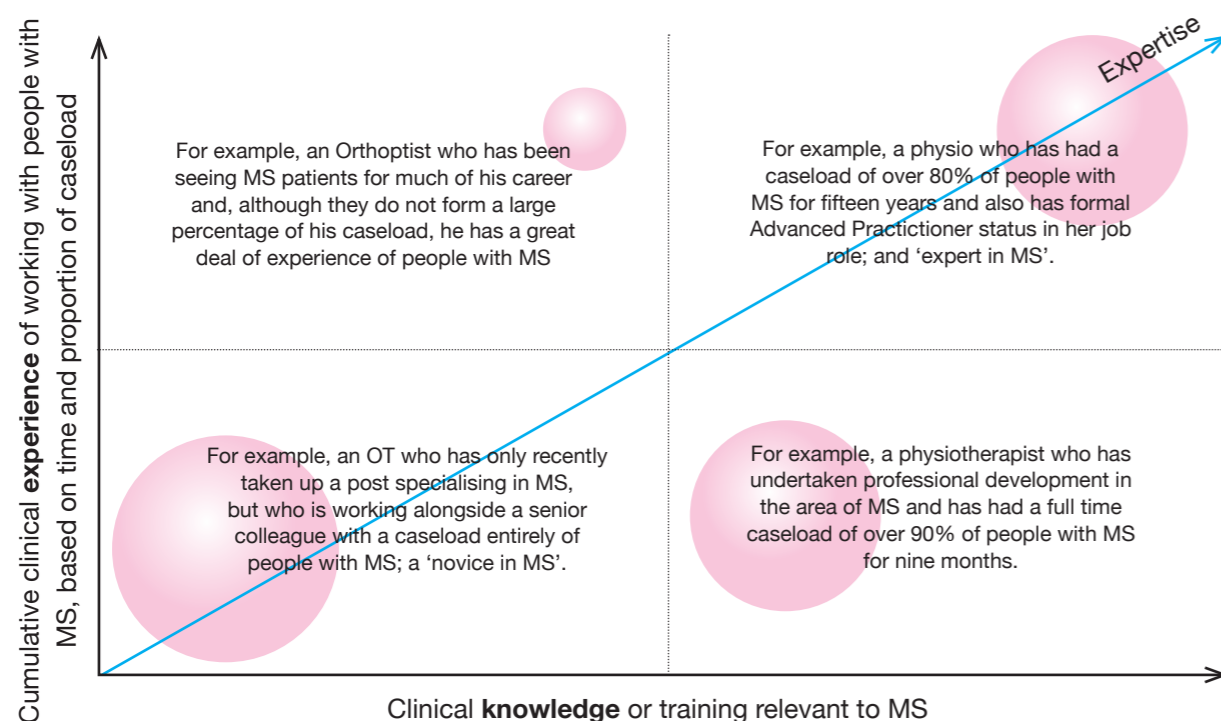
The purpose of this document is to assess the value of AHPs with an expertise in MS within the context of all the AHPs who provide services to people with MS. The scope of this document, then, is ‘all the AHPs who provide services to people with MS’. The exact breakdown of MS AHPs within the UK is hard to quantify as there is no reliable national data source. A proxy indicator, based on information gathered by the MS Trust, suggests that OTs and physiotherapists form between 80% and 90%<sup>i</sup> of those AHPs working closely with people with MS. As a result, this report largely focuses on OTs and physiotherapists.<sup>ii</sup>

### 2.2 Complexity of definition

The definition of those AHPs ‘with expertise in MS’ is not straightforward. There are no universally agreed definitions of terms. Although the term ‘specialist’ is the one that was most used in conversations with the AHPs and patients, during the course of our research we found it fraught with difficulties. This was particularly the case when trying to distinguish the ‘AHP specialist in MS’ from other types of AHP specialists. Other specialists may include those who specialise in some other aspect of a patient’s care, for example, a musculoskeletal physiotherapist in the community or a neurological OT in a hospital.

Further, the terminology of specialism means different things to different people. There is no commonly agreed definition, for example, of the terms ‘AHP expert in MS’, or ‘AHP with a special interest in MS’. The terms ‘specialist’, ‘advanced practitioner’, and ‘consultant practitioner’ have meanings within the NHS Agenda for Change<sup>2</sup> and are linked with pay bands and job titles. They therefore have potentially too precise a meaning for our purposes, because the intention of this report was not to define the value of AHPs of any particular pay band or job title. In addition, in our interviews with MS AHP teams, we found that these terms are not universally applied to the job titles of AHPs who are predominantly caring for people with MS.

Figure 1: Clinical knowledge or training relevant to MS



## 2.3 Defining the term ‘expertise’ - knowledge and experience

Figure 1 above shows how expertise is a composite of both formal clinical knowledge and cumulative clinical experience of working with MS. Although the job title, pay band, the extent of training, the proportion of people with MS in a case load (illustrated by the size of the bubbles, above) all differ for individuals and for MS teams, we found there was consensus amongst the AHPs we interviewed for two components to AHP expertise in MS: clinical knowledge of MS and clinical experience with people with MS (the x axis and the y axis in figure 1, above).

i. The following professions are identified on the MS Trust database as having a special interest and involvement in the care and management of people with MS: dietitian, neuropsychologist, occupational therapist, physiotherapist and speech and language therapist. Of these, the physiotherapists and OTs form the great majority (88%). However, this figure is no more than an indication of the actual picture on the ground.  
 ii. Despite being a recommended member of a multidisciplinary team treating MS in the NICE MS Clinical Guideline, neuropsychologists are out of the scope of this report, as they do not come under the banner of allied health professions.

## 2.4 Defining the term ‘expertise’ - novice and expert

We found that the most useful conceptual framework to draw these two components together was to use the scale from ‘novice’ to ‘expert’ (the diagonal line in figure 1 from bottom left to top right). In this diagram, a novice is embarking on developing their knowledge and clinical practice with people with MS, but does not yet know a great deal about the complexities of MS and has not yet seen many patients. At the other end of the spectrum, the expert has acquired significant clinical knowledge in providing support to people with MS and has many years of experience in seeing people with MS. This AHP can be said to have ‘expertise in MS’.

Health professionals are continually growing their expertise. Though we recognise that terminology is often inadequate to represent such complex distinctions, we have adopted the term ‘AHP with expertise in MS’ to describe the professionals on whom this report focuses. From now on, we are using the term ‘AHP with expertise in MS’ to mean AHPs who have cumulative clinical experience and clinical knowledge of MS and are providing services to people with MS on a regular basis.

## 3. The AHP in the MS workforce today

One word summarises the work of AHPs in MS services today: variability. Although AHPs share a common set of principles by which they work, we found that the service configurations are kaleidoscopic. A person with MS may see many different AHPs<sup>iii</sup>, each of whom may work for a variety of types of employer. These professionals may support people with MS in every conceivable setting, team configuration and across organisational boundaries. The depth of support available within Social Services and the way this relates to the NHS varies considerably in different areas. The referral rights and data sharing between the various configurations of MS service differ equally.

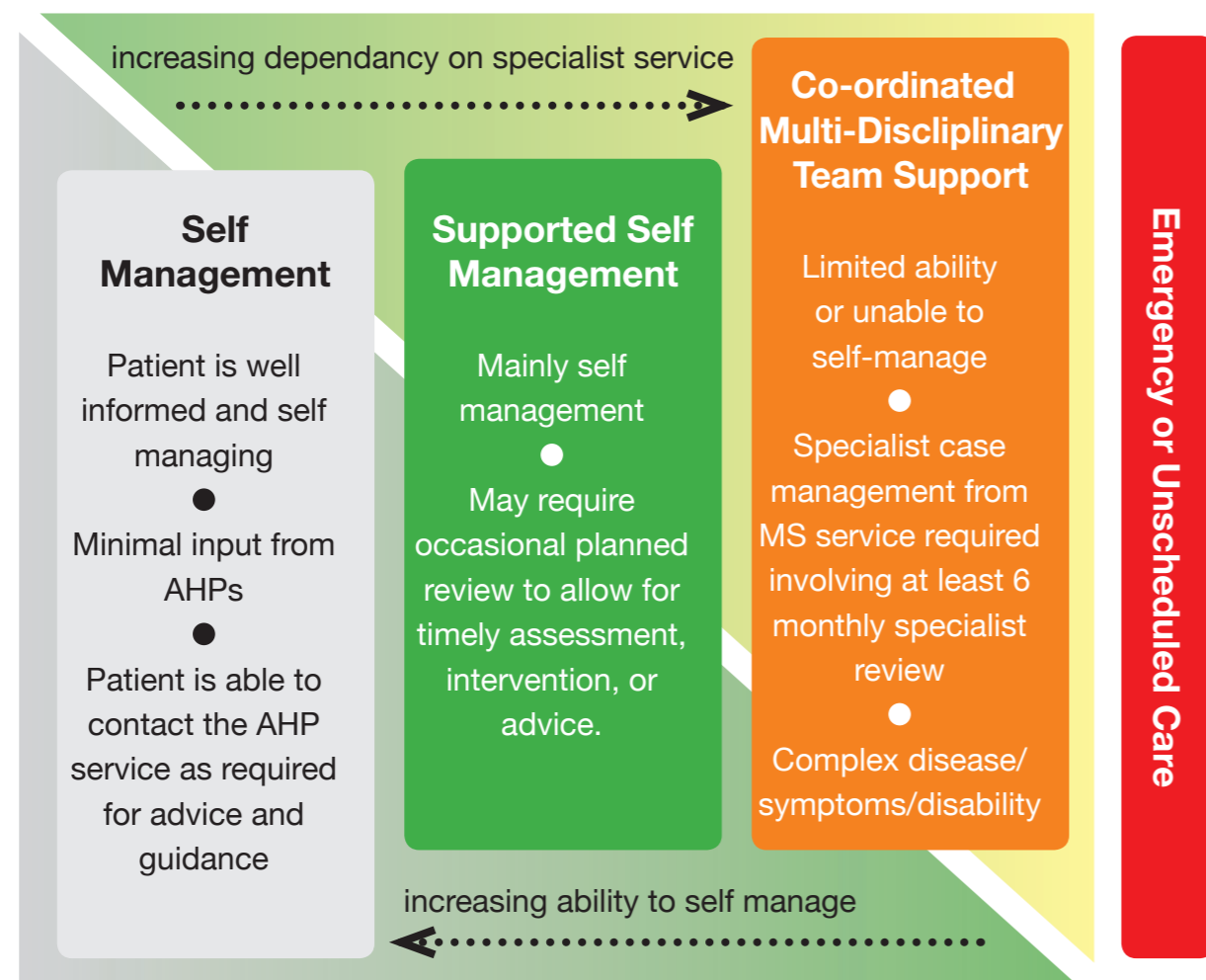
### 3.1 What AHPs do for people with MS

Despite the heterogeneous nature of the MS AHP workforce, whatever their profession, employer, work setting, case load or expertise in MS, all AHPs share the task of:

- enabling patients to be as self-reliant as possible (the leftward facing arrow at the bottom of figure 2)
- seeking to be available to the MS community with requests for support by those patients essentially managing their own condition
- aiming to provide periodic assessment and advice allowing for timely, anticipatory intervention through the whole disease trajectory (the green part of figure 2)
- helping people with MS by managing complex disease and disability (the amber part of figure 2)
- seeking to prevent a person having to have unscheduled, emergency care in hospital (the red area of figure 2).

iii. Including dietitians, occupational therapists, orthoptists, orthotists, physiotherapists, and speech and language therapists.

Figure 2<sup>3</sup>: Self Management/Specialist Service Dependency Model for People with MS



Patients are able to move fluidly in both directions between the different aspects of care illustrated, and such moves can be triggered either by the patient or their carer, or by the service professionals.

### 3.2 How AHPs provide support to people with MS

There is variation in the make-up of MS multidisciplinary teams. The NICE MS Clinical Guideline (CG8) states that: **“As a minimum, the specialist neurological rehabilitation service should have as integral members of its team, specialist:**

- doctors
- nurses
- physiotherapists
- occupational therapists
- speech and language therapists
- clinical psychologists
- social workers.”<sup>4</sup>

Having visited eight different services in England and Scotland, we find that the service a person with MS actually gets to meet their needs at different stages in their condition is variable. It depends on numerous factors, including:

- available budgets in the NHS and Social Services
- local eligibility criteria
- the blend between NHS services and the resources of a local MS Therapy Centre (charitably funded outside the NHS)
- how close they live to a neuroscience centre or indeed any MS service
- which MS AHPs are available (some may, for example, be on maternity leave or sick leave)
- the quality of communication between different local services
- other factors which could be summarised as ‘historical accident’.

AHPs may be employed by:

- a designated NHS neuroscience centre<sup>5</sup>
- an NHS Acute Trust
- an NHS Community Trust
- an NHS Mental Healthcare Trust
- a Local Authority (Social Services)
- a Third Sector organisation.

They may work in the following settings:

- predominantly in hospital
- predominantly in community clinics
- in community teams but predominantly in people’s homes or visiting employers
- in independent MS Therapy Centres.<sup>iv</sup>

Some work in multidisciplinary or inter-disciplinary teams; others work in relative isolation.

iv. There are over 50 independent therapy centres across the UK

### 3.3 Services provided to people with MS by AHPs

Below are just some examples designed to illustrate the variation of the types of service we observed:

#### The case studies

##### Pre-diagnosis rehabilitative therapy

A young person with undiagnosed MS may be treated by a physiotherapist who is a musculoskeletal 'expert', but an MS 'novice', as he or she seeks to recover lost functionality as the condition reveals itself.

This service may be delivered in a community clinic delivered by a NHS Community Trust.

##### Support with complex co-morbidity

An elderly person with advanced MS and who is recovering from a stroke may receive the support of a neurological physiotherapist attached to the neurology ward to cope with the stroke recovery. Towards the end of their stay in hospital, they may receive a highly specialised assessment from a consultant physiotherapist in MS.

This inpatient service may be delivered in the neurological ward of an NHS neuroscience centre working in a full multidisciplinary team with the capability to outreach into the person's home after discharge.

##### Provision of fatigue management

A university student may be struggling to achieve the kind of social life they aspire to and not finding generic advice about 'pacing themselves' working for them. They may receive a tailored programme from an MS OT who could educate them about how to address issues related to fatigue that are specific to MS, and those secondary to it. This may yield very different, positive results.

This service may be delivered at the university health centre by someone employed by a Community Foundation Trust.

##### Provision of equipment in the home

An older person with longstanding MS may receive the services of an OT with adaptations or equipment to help them with living at home. This person may or may not have significant MS expertise and may be, to all intents and purposes, a lone worker.

This service may be delivered in the person's home by someone employed by Social Services.

##### Support with an eye operation

A person with a squint and with concerns about the effect of the anaesthetic on their condition may receive the services of an orthoptist who, although they only see people with MS occasionally, has an interest in MS and has 25 years of experience with the condition.

This service may be delivered by an NHS Acute Trust in an ophthalmology outpatient clinic.

#### The case studies

##### Support to remain in employment

A person with MS in mid-career may receive the services of an OT who meets with her company's Chief Executive and HR director to describe how they can work round the cognitive and fatigue symptoms that are threatening the viability of her job as a result of her MS.

This service may be delivered in the person's workplace by a NHS Neuroscience centre.

##### Support during a transition

A person experiencing a significant progression of their disease, and their partner, may receive a joint assessment by an OT and a physiotherapist. They both know the person well and have prepared them for this stage and conclude that a wheelchair will now be necessary, with all the implications that brings.

This service may be started in the person's home and completed in clinic run by an NHS Community Trust.

### 3.4 Quantifying AHPs with expertise in MS

Whilst it is possible to quantify the number of MS Specialist Nurses across the UK<sup>6</sup> with a high degree of accuracy, it is difficult to do the same for AHPs with expertise in MS. As discussed in section 2.2, AHPs with expertise in MS are not limited to a particular job title or pay band that is easily identified and counted. Counting just those with the word 'specialist' in their title would necessarily exclude a number of AHPs who would fulfil the definition of having expertise in MS and so underestimate the size of the workforce.

The MS Trust maintains an extensive database of health professionals working in MS across the UK which relies principally on self-identification. There are some 2,075 AHPs on the database, with varying job titles and volume of MS caseload, but all at least have an interest in MS.

It is unclear how complete these numbers are or how many of them have expertise as defined above.<sup>v</sup> It certainly is not possible to comment on geographic spread or adequacy of provision without additional work systematically to identify all MS AHPs across the UK. A comprehensive piece of research across both the NHS and Local Authorities is therefore needed to assist AHPs and commissioners to benchmark their MS AHP provision across comparable populations.

v. 285 of them have the term 'MS specialist' in their job title which is likely to mean that they spend the majority, if not all, of their time with people with MS (202 are physiotherapists and 83 are OTs). 110 have 'neurology' in their job title (99 are physiotherapists and 11 are OTs). There are no speech and language therapists or dietitians with either 'MS specialist' or 'neurology' in their job titles. Therapists in MS (TiMS) members number about 200. These are AHPs who take a particular interest in MS.

### 3.5 Social Services

Health and Social Care policy has for decades recognised the need for a close working relationship in order to deliver the best quality outcomes. The care of people with MS, and those who support them at home, is particularly affected by the ability of the two agencies to coordinate effectively, as the social and healthcare components of MS cannot be easily separated.

Closer working<sup>7</sup> expresses itself in:

- collaborative commissioning
- joint commissioning
- formal budget sharing
- secondments between organisations
- inter-agency multidisciplinary team working
- whole-scale merging of organisations resulting in the movement of staff from NHS to local
- authority employment or vice versa.

In our visits to MS Services, we found a variety of relationships between Health and Social Services. We found some Local Authorities which employ a number of AHPs with expertise in MS in designated posts, whilst others employ none. We found one area where a whole-scale merger between Health and Social Care is taking place but where potential advantages for people with MS are not yet seen. We found other areas where no merger is planned, even in the medium term. We found some areas where the length and quality of relationship between the two separate teams was excellent, often as a result of co-location of teams. We found some areas where the relationship is less than it might be, characterised by suspicions that referral behaviours were being motivated by budgetary pressures. It is therefore clear that integrated care is currently implemented in a wide range of ways across the country.

### 3.6 Referral rights

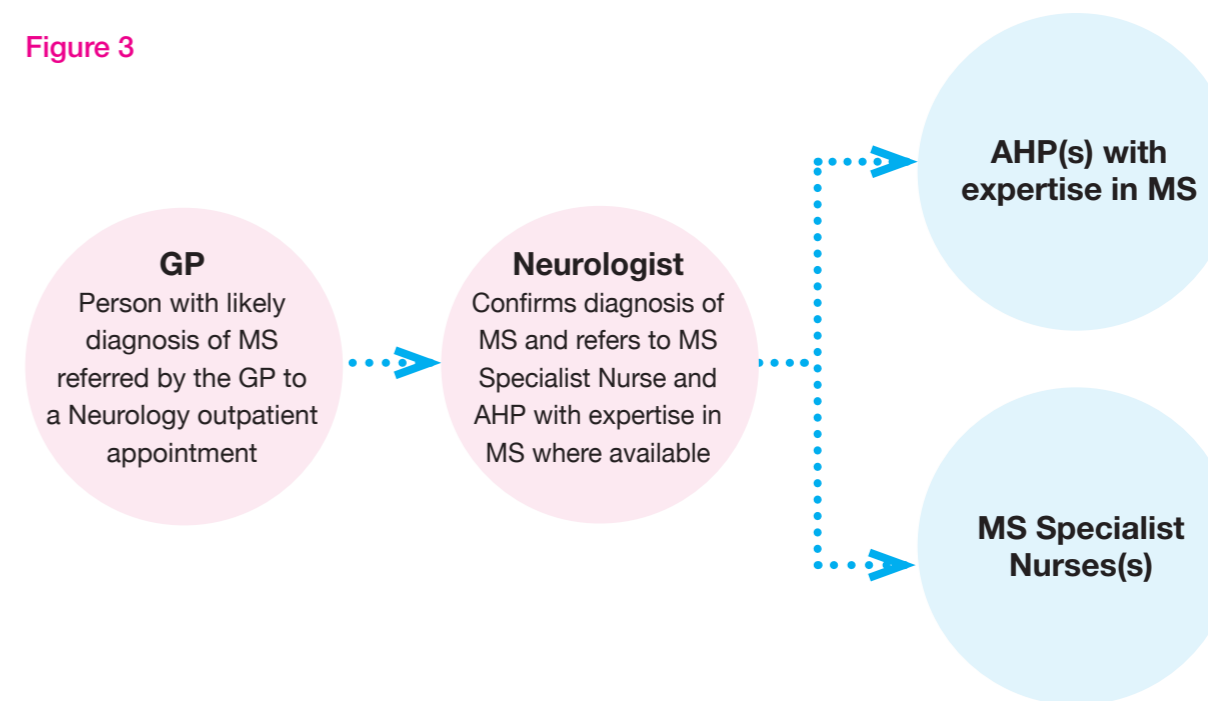
Access to services is obviously of fundamental importance to people with MS. AHPs are first contact practitioners and so have the right to take direct referrals from patients as part of their professional duty and registration. We found one referral path that applies to all the organisations we encountered. It starts from the GP who refers to the neurologist for a diagnosis, and then moves from the neurologist to the specialist MS team for people newly diagnosed with MS.

We found a perception that it is generally easier for the NHS to refer to Social Services than vice versa. A Social Services OT, for example, will usually have to go via a GP or neurologist to access an NHS physiotherapist. By contrast everyone can make a referral to Social Services and everyone is entitled to consideration for a formal assessment.

Beyond this, the picture of variability painted in this section applies equally to referral rights. We found that the referral rights between NHS organisations varied according to their configuration. Referral pathways that are open to AHPs often seem to be dependent on the strength of the relationships between the various services. Even where there are no formal referral rights, a telephone conversation between professionals ‘for advice’ about a known patient might well result in the person with MS being seen by the other professional even in the absence of a formal referral letter. The more stable the workforce in an area, the more likely this is to occur. The ability of patients to self refer (for

telephone advice or initial assessment at least) was common to all MS services to whom we spoke. In practice this was dependent on the first contact being made through a formal referral mechanism. In addition, we found that signposting and working across, or referring to other, AHP services in the rehabilitation pathway is also common.

Figure 3



### 3.7 Data

**Dataset.** In our interviews we found no common minimum dataset in use by MS AHPs. Teams reported that they collected names, contact details, basic demographics (e.g. age and gender) and use of disease modifying drugs, although not always the specific type of therapy being used. Some recorded information about type of MS, level of disability, the length of time since diagnosis, and when the next review was planned. We did not find that patient outcomes were routinely recorded.

**Integration.** Paper systems were often used by MS AHPs alongside computer based systems. Some paper systems were shared across the whole team, e.g. with MS nurses, whilst others were not as integrated, with patient records being duplicated for each discipline within the team. We were informed that, in some instances, users developed their own local databases because Trust based systems were not capable of giving them the information they needed. In some instances there were separate databases for OTs and for physiotherapists.

**Data collection.** Our analysis showed that not all AHPs were recording data systematically for all patients.

We did find, however, some examples of very thorough data collection across a number of data fields. In those cases information was being shared with other health professional in helpful graphical form.

## 3.8 Commissioning across the United Kingdom

There are significant differences in commissioning between the four countries of the UK.<sup>8</sup>

**England.** England operates a funder/provider split, with services commissioned by two types of organisations, NHS England and Clinical Commissioning Groups, and provided in a range of settings, from tertiary referral hospitals to local health centres.

Since April 2013, NHS England has been responsible for commissioning specialised MS services, and Clinical Commissioning Groups have been responsible for commissioning general neurology services, which include many services for people with MS. At the time of writing, much of the detail about what constitutes specialised and generalised services, and therefore who is responsible for funding which elements of an MS service, remains unclear.

There is contestability within English health policy where commissioners are expected to encourage a plurality of providers in an internal market and there are examples where specialist MS services are already being provided by new organisations.

Local Authorities do not have a purchaser/provider split in the same way as the NHS in England, although there are examples of them commissioning outsourced services. Resources are allocated to any MS services that are provided within the complexion of Social Services for adults or the elderly within the normal tension between service developments and budgetary constraints.

**Scotland and Wales.** Though separate, neither of these health economies have a purchaser/provider split in the same way as the NHS in England. Resources are allocated by local Health Boards to MS services within hospital and community based health services allowing for the normal tension between service developments and budgetary constraints.

There is no internal market within Scotland or Wales and we heard the case made that organisational stability was advantageous for services and therefore for the patient.

**Northern Ireland.** The Health and Social Care Board, through Local Commissioning Groups, commissions all MS services from providers, and more comprehensive progress has been made in integrating health and social care than in the other nations. The internal market has been retained.

## 4. The value of AHPs with expertise in MS

### 4.1 Review of literature

As outlined in above in sections 1 and 2, the purpose of this document is to assess the value of AHPs with an expertise in MS within the context of all the AHPs who may provide services to people with MS. To achieve this aim, we began by conducting a literature review for evidence of the value of AHPs in the treatment of MS. We looked for academic papers, relevant policy documents and any local research. This uncovered numerous articles but many had limitations. In some cases, the research was over 10 years old. In addition, none of the research spoke specifically of expertise or specialism in MS. It was therefore not clear what type of AHP the authors were referring to in their work. Of course, an assumption could be made that, in many cases, the AHPs working with people who have MS had a significant level of expertise, particularly, for example, in the work on functional electrical stimulation (FES), which is always administered by AHPs with additional training. The following therefore represents the findings about the value of AHPs in general in their treatment of people with MS.

The published evidence for physiotherapy in MS is stronger than that for occupational therapy, and the evidence for these two is stronger than that for other therapists. Many studies have shown that people with MS benefit from exercise therapy and the improvement in muscle power, function, mobility-related activities and mood that people experience as a result.<sup>9,10,11</sup> FES, as administered by a trained physiotherapist, is also acknowledged as having a positive impact on the speed of walking for a person with MS, coupled with a reduction in physiological cost of gait.<sup>12,13</sup>

The research evidence supporting occupational therapy is less conclusive. Early research indicated that it was not possible to prove that occupational therapy improved patient outcomes in MS.<sup>14</sup> However, more recently, papers have shown that occupational therapy in an inpatient setting “had a positive effect on functional performance in all categories except feeding, with significant correlations in upper-extremity dressing and memory.”<sup>15</sup> Health promotion activities such as fatigue management sessions were found to be “effective in reducing fatigue severity and increasing fatigue self-efficacy”<sup>16</sup> Helping to keep people with MS in work was recognised as being an important role for an OT, as “being employed was significantly related to good physical health”<sup>17</sup> and employment status was acknowledged to be a key determinant of mental health in younger people with MS.

Several studies discussed the benefits to be gained from AHPs working within multidisciplinary teams (MDT). Owing to the complex and variable nature of MS, MDTs were found to be effective, particularly where they took a long-term approach rather than “a fragmented series of quick fixes”.<sup>18</sup> These MDTs did not always improve the level of patient impairment, but were seen to improve the experience of a person with MS “in terms of activity and participation.”<sup>19</sup>

There was very little research into the cost effectiveness of AHPs in MS. In the past, many papers have attempted to look into this, but have failed to generate sufficient evidence.<sup>20,21</sup> Some trials currently underway are starting to include cost effectiveness as one of their research goals<sup>22</sup>, but there is an acknowledgement that future research will need to look further into this area.



There was also an acknowledgement of the difficulty of conducting gold standard research into physiotherapy and occupational therapy in the treatment of MS. As Khan points out in the Cochrane Review of Multidisciplinary Rehabilitation for Adults with MS<sup>23</sup>,

*“Rehabilitation is a complex form of treatment which is difficult to quantify, and may include multiple interventions, and depends on the interaction between the patient and the clinician. Programmes frequently involve dynamic interplay in behaviour between patient and therapist, which are dependent upon patient response and potentially confound simple division into ‘treatment’ and ‘control’ conditions.”*

Further problems emerge from<sup>24,25,26</sup>

- the heterogeneity of MS patients, meaning that it is difficult to find sufficient numbers of people who experience MS similarly
- the length of time over which interventions must be evaluated, which can lead to retention issues
- the lack of an agreed set of outcome measures
- the ethical difficulty of a randomised control trial group receiving a placebo treatment, particularly over a long period of time
- the difficulty of assessing what is an active or merely a beneficial input by a therapist
- the difficulty in assessing ‘quality of life’ benefits alongside functional improvements.

It is hoped that future research into allied health interventions in the treatment of MS can overcome these obstacles.

## 4.2 Site visits and interviews

*“I would be out to dry if I didn’t have this [specialist AHP] service; I would give up.”*

As the published evidence for the value generated by MS expertise in AHPs is limited, it is necessary to turn to the views of the AHPs who have developed expertise in MS themselves. To this end, we visited six MS AHP Services (see Appendix C for details) staffed by people who had all been novices in MS at one point and who have developed varying degrees of expertise. Amongst other things, we asked them to detail the ways in which they believed their expertise generated greater value for people with MS.

They reported that AHPs who specialise in MS have the depth of clinical knowledge to be confident in their assessment and treatment and are credible to people with MS. Interviewees stated that they knew enough about the condition to provide proactive anticipatory care, helping people through the transitions in the disease trajectory. They reported that they can get to know the patient well and so can determine the right treatment throughout the course of the condition, despite the unpredictable nature of MS. Their expertise enables them to keep up with or participate in research and education of colleagues. They also reported that they bring a different conceptual approach to treating MS, which generates better outcomes for people. Finally they believe they can generate significant financial benefits to the system, even if these cannot easily be quantified, and they bring a unique contribution to the range of expertise found in a multidisciplinary team. The following sections represent their views.

### 4.2.1 Depth of clinical knowledge about MS

As discussed in the Introduction, MS is a complex and unpredictable disease that presents in many ways.<sup>27</sup> The AHPs with expertise in MS to whom we spoke reported that this means that it can be difficult for AHPs with less knowledge and experience of MS to fully understand all the symptoms, possible medications and side effects, appropriate exercises and equipment and latest research associated with MS. As a result, AHPs with less expertise often turn to those who have specialised in MS for advice or assistance. For example, a community OT will understand about hoists and slings, but an MS OT will understand more about spasticity and the importance of postural alignment as the disease progresses. AHPs with expertise in MS will understand about the short-circuiting nature of fatigue in MS and so know how far a person can go in a given set of exercises or activities.

Specialism enables AHPs to provide specific treatments such as FES, often leading to improvements in walking speed for people with MS, thereby significantly enhancing their quality of life.<sup>28,29</sup>

*An orthoptist with expertise in MS was able to reassure someone with MS that surgery to correct their double vision is extremely unlikely to cause a relapse (as fears exist that an anaesthetic can trigger a MS relapse).*

The teams we spoke to report that the credibility that comes from this depth of clinical knowledge (sometimes coupled with the title ‘specialist’) means that often people with MS, employers, families and carers respect their opinions and ‘hear’ information more effectively from them. People with MS value the involvement of someone with sufficient expertise to help them maximise their quality of life and were sometimes blunt in describing their experience of services.

*“I think it’s a waste of time going to a GP if you have MS. They don’t know what to say. They go, ‘Mmm’.”*

*“‘There’s nothing we can do for you’. That’s all I used to hear.”*

### 4.2.2 Long-term relationship with a person with MS

Each person’s experience of MS differs so much that AHPs report that it takes time to see sufficient presentations of MS to enable them to be confident in their professional judgment. They state that seeing many people with MS enables them to more reliably recognise when a person is relapsing, judge when a person has achieved as much as they are going to achieve from a given treatment plan, to ease the process of transition from one stage of the disease to another. They know the right questions to ask (e.g. about fatigue, bladder, cognition, etc), know when to refer to another professional and know how to talk to the person so as to give them the specialist information that they require, thereby reducing their anxiety. They are able to refer to relevant case studies when explaining treatment, which is often more compelling than just reading leaflets or handouts. They are able to use MS-appropriate language, which provides reassurance.

*“Because the presentation and symptoms are so different, the non-specialists are frightened. Bless them for trying. The specialists are not frightened, though.”*

In the teams we spoke to, people with MS were able to self refer back to the MS service repeatedly and so the AHPs were able to get to know a person from the point of diagnosis through all stages of their MS. This enables them to build a long-term relationship with the person and their family and carers, which in turn helps them assess what is needed. This long-term relationship is particularly important in the treatment of MS because:

“MS symptoms can present in many different combinations, with variable severity and they can fluctuate. No two patients will experience exactly the same pattern of symptoms, so it is important to base treatment on the person involved.”<sup>30</sup>

The way a person’s MS presents on any given day may vary, so background knowledge of the person is important, as is an understanding of the person’s personality and home environment.

*A person with MS was becoming increasingly disorientated while driving. He was referred to his GP, who in turn referred him to a general psychologist who assessed the person as fit to drive based on a face-to-face meeting at which the person appeared well. In fact, the MS OT, who had known the person for some time, became aware at this time that the cognition problems had become severe enough to make driving dangerous. They consulted with the psychologist, who then revised the original assessment and came to a different conclusion.*

The long-term relationship also enables AHPs to get to know the family of a person with MS and to understand how the condition will have an impact on the wider family as a person’s impairment levels worsen. It allows AHPs to develop an understanding of how loss of function may have an impact (or not) on that person and their family and so helps them tailor treatment and care to that individual with MS. In addition, it enables the AHP to advocate for a person with MS. By understanding their values as an individual, AHPs can better support their advanced wishes regarding types of treatment, care/ treatment plans and the like.

Although self referral can also be found in general rehabilitation services, in many cases commissioners are now stipulating that patients must be seen for 6-8 sessions or for a 6-8 week period of treatment. The AHP teams that we saw did not currently face such limitations, and so were generally able to see patients according to their need. This represents the ‘best practice’ approach,

*I had four courses of physio; eight weeks at a time. But they always had an end point. All standard care has an end point, but the specialists if anything give more intervention as time goes on.”*

### 4.2.3 Proactive anticipatory care

Key to a quality service in managing people with progressive conditions is knowing how to identify those points in time when the person is getting close to entering a new phase; the ‘anticipatory moment’. The MS AHPs that we saw stated that experience and knowledge is needed to do this well and to help a person adapt to any loss of function. They reported that their detailed knowledge of MS enables them to see what is likely to be the next stage in the disease trajectory for any given person, based on past case histories and the pathway of the individual before them. This means they are able to prepare the person for these changes and minimise their impact by providing them with the relevant information and helping them, for example, retain their individual level of fitness.

AHP teams report that they can provide a person, their family and carers with the relevant information, skills and strategies to help them optimise their function within their impairment level and enable optimal self management. For example, they can teach strategies for safe swallowing or stretching/ positioning programmes to maintain muscle length. They can help a person maintain their level of fitness in order to best prepare for the next stage of the disease trajectory. In so doing the AHPs help to reduce dependency on other specialist health and social services.

For example, the MS OTs that we spoke to reported that they have sufficient MS-specific knowledge to go into workplaces or places of study to speak to employers or teachers, to help a person with MS to continue to work or study. Currently in the UK, “up to 44% of people with MS retire early due to their condition – a higher percentage than the European average (35%).”<sup>31</sup> This has a significant impact on an individual’s quality of life and removes the benefits society receives from keeping the individual as part of the workforce. MS OTs can address workplace issues before a person with MS is forced to leave work due to their employer’s lack of understanding of MS.

*One MS service is currently helping three people continue with their university studies by ensuring they are provided with longer exam time and parking spaces close to university buildings. Without these interventions, the students may be unable to complete their studies, rendering them less likely to find suitable long-term employment.*

The teams report that the ongoing relationship also enables MS AHPs to provide people with anticipatory information at a time not only when they need to hear it but, more importantly, when they are able to receive it. They can ‘drip feed’ information, which may be difficult or counter-productive to hear all at once.

*“She explains what’s happening to your body, in simple terms. You don’t retain information as easily with the MS, so she’s had to tell me more than once. She’s helped me understand why my legs are how they are, with my type of MS. You need to understand what is happening, and why it’s happening.”*

## 4.2.4 Research and education

Allied health professionals have a research component to their workload;<sup>32</sup> in particular, those in a Consultant post have a requirement to be actively involved in research. AHPs with an expertise in MS have the skills to carry out research, a role that the government deems critical to generating improvements in health outcomes,<sup>33</sup> although they are sometimes prevented from giving this sufficient priority owing to the pressures of large list sizes and the need to maximise throughput of patients to meet contract terms.

In addition, the teams report that many AHPs with expertise in MS spend time educating other health professionals in their local area, such as GPs, community OTs and physiotherapists, or fitness instructors wishing to run exercise programmes for people with MS.

Teams report that they are frequently contacted by other health professionals as a source of specific knowledge about MS. They can keep abreast of the latest research and advances in treatment, passing this knowledge on to others as needed. It would not be possible for generalist AHPs to maintain this level of detailed knowledge, given the number of areas they have to cover.

Similarly, MS AHPs are aware of the network of people with skills in the treatment of MS, so they can assist in referrals to the right person at the right time. This is particularly important with a complex disease which presents in so many different ways.

AHPs with expertise in MS report that there is a tendency for other health professionals to attribute too many symptoms to MS, even if they are not connected. This means they may refer to MS specialists, even if the person does not need specialist care which increases the burden on MS AHPs. Conversely, they may mis-diagnose an MS symptom as a non-MS problem. There is clearly a need for AHPs with expertise to be able to educate and advise the less specialised health professionals around them.

## 4.2.5 Shorter waiting lists

People with MS who have had a definite diagnosis, are generally able to see the AHPs in their MS team directly and without joining the general neurology waiting lists. This leads to shorter waiting times before treatment. This is particularly valuable in the treatment of MS, where delays in accessing services can result in a significant worsening of symptoms. A person with MS who has difficulty accessing appropriate services can end up experiencing fixed contractions in their joints or permanently entering a wheelchair when they could have remained mobile had they been seen quickly by a skilled AHP. Likewise delays in seeing a speech and language therapist may result in

the risk of aspiration when swallowing. In some cases people with MS may give up work or enter a residential home, not realising that an OT could advise them of possible adaptations which would enable them to stay in the workforce or remain living in their own home.

## 4.2.6 Financial savings

MS AHPs believe they can generate significant financial benefits to both the health system and society at large. However, as discussed in Section 4.1, it is not easy to quantify these benefits. In addition, as AHP treatment in MS is often preventative in nature, their intervention may result in a person not needing the assistance of a GP or neurologist, for example, though the financial benefits may be hard to track. AHPs are enablers of self care and self management in people with MS, which in turn reduces the need for people to seek outside assistance. In addition, the benefits they generate may fall outside the health system, as when they avoid costs within social care, or may benefit society as a whole, as when they help a person to remain in work. It is therefore difficult to generate accurate cost benefit analyses. However, the table overleaf outlines ways in which AHPs with expertise in MS report that they generate financial benefits through avoiding unnecessary health care costs.

Service/care setting	Ways AHPs can avoid unnecessary health care cost	Case example
<b>Consultant Neurologist</b>	<ul style="list-style-type: none"> <li>MS Nurses and AHPs can run follow-up appointments, removing the need for all but the most unwell to see the consultant.</li> <li>Symptom management problems can be dealt with by the MS multidisciplinary team rather than the consultant.</li> </ul>	An MS Service ensures that everyone newly diagnosed is referred to the specialist MDT. This provides early advice and information about how to access the service, so that it is not seen as a last resort. The MDT then continues to keep people with MS under review and offers direct access as symptoms change. As a result, people with MS only see the neurologists with complications or for changes in therapy.
<b>Primary Care</b>	<ul style="list-style-type: none"> <li>MS Nurses and AHPs can deal with problems instead of the person with MS seeing their GP.</li> <li>MS AHPs can advise regarding specialist equipment that means the cost of care to remain at home is minimised.</li> </ul>	An MS MDT meets local GPs for an annual case review of people with MS on their lists. This gives them an opportunity to learn clinically from the MS team, as GPs report not having seen the people under review for years, as the MDT had been dealing with all issues.
<b>Accident and Emergency (A&amp;E)</b>	<ul style="list-style-type: none"> <li>MS AHPs can help prevent presentations to A&amp;E because people with MS know they can self refer for problems they face.</li> <li>MS AHPs are aware of likely issues and can provide proactive anticipatory care.</li> </ul> <p>The tariff for typical A&amp;E attendance for MS patients ranges from £151 to £235.<sup>34</sup></p>	A person with MS was falling frequently and their family was concerned and considered calling an ambulance to take him to hospital. Instead the MS OT came to the house, assessed what equipment was needed, and ensured its provision thereby avoiding an unnecessary A&E attendance and possible admission to hospital.
<b>Hospital admissions and length of stay</b>	<ul style="list-style-type: none"> <li>MS AHPs can help to prevent unscheduled admissions to hospital by providing proactive anticipatory care, particularly with regard to relapses and falls.</li> <li>MS AHPs can help prevent or reduce hospital admissions associated with secondary complications, for example by providing physical management plans regarding posture and seating that can prevent the development of pressure areas and complications from spasticity.</li> <li>MS AHPs can facilitate discharge from hospital by enabling home modifications and providing the necessary equipment and support for a person with MS to return home quickly. They also enable the person to access continuing rehab services, thereby reducing the risk of the permanent loss of function often associated with prolonged hospital admissions.</li> </ul> <p>Admissions to Neurology with typical lengths of stay for an admission code of 'Emergency Long Stay' cost between £3,000 and £5,000 each.</p>	<p>A person was admitted to hospital with relapse of MS but was treated in general wards. After discharge, the patient suffered significant fatigue, resulting in him becoming bed-ridden and unable to walk. His family wanted the patient readmitted to hospital to rectify this situation, but an MS OT came and assessed the person's home situation and daily routine.</p> <p>They made recommendations about changes that would assist the person to leave their bed and gain a better quality of life. The person is no longer bed-ridden and the family is reassured by the availability of MS expertise whenever they need it.</p>
<b>Residential care home or care at home</b>	<ul style="list-style-type: none"> <li>AHPs can enable people with MS to remain living at home unaided by working with Social Services to ensure the necessary modifications to the house and equipment (hoists, stair lift, chairs, etc) are provided. They also work with carers to ensure that their approach is 'therapeutic', which helps the individual to remain independent.</li> </ul> <p>A nursing home place costs on average c. £550 a week. Meals on wheels typically costs c.£90 a week for three meals a day.</p>	A community OT assessed the home of a person with MS and identified a need for a stair lift but no adaptations to the kitchen. This resulted in the person becoming unable to prepare their own meals and commencing use of the 'Meals on Wheels' service. The MS OT was able to introduce a number of aids and adaptations, which allowed the person to resume their own cooking and end the 'Meals on Wheels' service.
<b>Physiotherapists with less expertise in MS</b>	<ul style="list-style-type: none"> <li>These physiotherapists are unlikely to have the detailed knowledge of MS required to know what treatment is most appropriate MS physiotherapists can support physiotherapists with less experience to provide care under supervision.</li> </ul>	A person with MS had a hip replacement and ongoing pain. The general physiotherapist continued to work with the person, hoping for an end to the hip pain. The MS physiotherapist was able to assess that the pain was complex and some of it was MS-related and therefore would be treated more effectively with medication.
<b>Workplace</b>	<ul style="list-style-type: none"> <li>MS OTs can visit a person's workplace to speak to employers about MS and make recommendations regarding adaptations to the work environment, in order to retain the person in the workforce.</li> <li>MS OTs can assist employers in job redesign to help a person with MS manage their symptoms (e.g. cognitive or memory difficulties) and remain in work.</li> </ul>	"People with MS lose an average of 18 working years, assuming a retirement age of 60. If one worker with MS draws Employment Support Allowance (ESA) for 18 years the total cost (at 2011 prices) will be £61,000. If 20,000 people are on ESA benefits for 18 years the cost to the welfare system is over £1.2 billion. This takes no account of the income tax which these workers would be paying". <sup>35</sup>

### 4.2.7 A more informed conceptual approach to MS

*"The specialist service is really important. It's very different."*

Some MS AHPs that we met believe that non-MS expert AHPs are generally trained to 'fix' problems whereas MS is a progressive condition and so cannot be 'fixed' or cured.

*"We know we don't have a magic wand." MS physiotherapist*

They stated that their MS specialism enabled them to approach treatment in a different way: for example, they recognise when a person has achieved all they are going to achieve and help them manage if their condition deteriorates. At the same time, they know that MS is not a life-limiting condition and so do everything they can to ensure the person has the best quality of life for the longest possible time.

These views may not necessarily represent current developments in allied health, however. The ageing population means that non-MS AHPs now see people with greater numbers of co-morbidities. This means that they are necessarily having to manage a person more pragmatically, based on the goals which they have agreed with the patient; goals which necessarily take account of the complexity of their multiple conditions.

### 4.3 Considerations for AHPs with expertise in MS

Whilst there are many arguments to say that AHP expertise in MS is beneficial in the treatment of people with MS, this must not eclipse the fact that AHPs who specialise in neurology also bring a valuable perspective to the treatment of people with MS. Indeed, it must be acknowledged that too great a level of MS specialism may also have shortcomings. We heard the following observations from neurological AHP teams and MS Nurses:

- Specialism can make the service too dependent on key individuals. This may mean that there is a reduced service if the key person is absent, with no one available to see people with MS.<sup>vi</sup> It may also lead to non-specialists relying heavily on MS specialists, referring to them even if this is not needed. (For example, in one centre, community physiotherapists tend to refer a person with MS to the MS physiotherapists as soon as they see a diagnosis of MS, even if the problem is not MS-related). Similarly, people with MS want only to see specialists, even if this is not necessary, leading to inappropriate use of the service.

vi. Indeed, some AHPs working across all neurological conditions can also be seen as specialists in their own right, in that over 40% of their case load may be people with MS.

- MS AHPs who solely work with MS patients can be restricted in their assessment of a person with MS by their knowledge only of MS. There is a concern that MS AHPs may miss out on the helpful perspectives of patients with other progressive neurological conditions (e.g. Parkinson's or motor neurone disease). This is particularly valuable if it enables an AHP to treat people who have another condition as well as MS, e.g. a person with MS who has a stroke.
- Management of an individual's needs may not necessarily require specific MS expertise but can be effectively undertaken by other AHPs, such as those working in rehabilitation services in the community – which can often be much closer to home than the nearest neuroscience centre. Alternatively if they have, for instance, complex spasticity issues, they may require advice or care from an AHP or nurse with expertise in spasticity management. In addition, there will be times when a non-MS AHP would be able to treat someone in place of an expert, as long as they were acting within their competencies and were able to access an expert for guidance and advice. AHPs with limited knowledge of MS do not always know to whom they can turn for this assistance or indeed there may not be an AHP with expertise in MS in their area or region.

An MS AHP service therefore needs to take these considerations into account. Regardless of the level of MS expertise, the key is access to the appropriate level of provision for the patient, depending on his or her needs.

## 5. Challenges facing AHPs services in their drive to achieving better outcomes for people with MS

A major challenge facing MS AHPs services in their drive to achieving best outcomes for people with MS is how to ensure their 'visibility': to commissioners, senior managers, other professionals and even users. Few are fully aware of the value resulting from an MS AHP service and it is difficult for AHPs to provide cogent evidence for it. First, the inherent difficulty of measuring outcomes for patients with a degenerative and particularly complex condition makes it hard to make the case to commissioners and sometimes senior managers. Secondly, difficulty measuring patient outcomes is directly linked to problems in demonstrating cost effectiveness outside the conventional productivity-type measures. The third challenge is the organisational change both at commissioner and provider level associated with the NHS reforms and the relationship between Health and Social Services. These make it even harder to be visible on the radar of priorities. With case loads increasing and patient expectations rising, this relative invisibility to commissioners means that outcomes for patients may suffer.

## 5.1 The challenge of defining and measuring outcomes for people with MS

As the NHS develops, commissioners are increasingly commissioning for patient outcomes rather than outputs or activities, and AHPs with an expertise in MS need to define and measure the outcomes they are seeking to achieve and report these clearly.

Defining and measuring outcomes in a degenerative condition is not easy. As identified earlier in section 3, MS AHPs focus on minimising disability and helping people through transitional phases in their MS. For example, an MS AHP may assist someone through the transition to being a wheelchair user without a psychological denial and the consequent pressure on themselves and their carers. They will also help them achieve this without a fall which could result in hospital treatment. Therefore MS AHPs are aiming for patient outcomes which represent a relative improvement on where the person would have been without the intervention, but often not an absolute improvement in their condition. Measuring and demonstrating these outcomes is a real challenge.

In addition, as well as being a degenerative condition, MS is also fluctuating and variable in the way it affects individuals. Two people with MS put it well when being interviewed for this report:

*"I've got primary progressive which is a very different type of MS from other types."*

*"But I've got primary progressive as well, and yours is completely different from mine."*

AHPs described the disease trajectory of people with motor neurone disease, for example, as much more predictable than MS and the epidemiological incidence of Parkinson's Disease in older age, for example, as much more uniform. Measuring outcomes in long-term conditions is always a challenge, but is even more so in a condition which presents differently in each person and at different times in their lives. However, progress can and should be made.

In England, the NHS Outcomes Framework<sup>36</sup> defines the outcomes that will be used to hold NHS England to account from 2012/13 onwards. It consists of five domains (see figure 4 below) all of which are relevant to people with MS. Within each domain is a series of indicators, the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS)<sup>vii</sup>, which can be used to assess the effectiveness of service commissioning. These are split into overarching indicators (1-3 per domain) which are applicable across populations and conditions (e.g. the 'Friends and Family' test for hospital services), together with improvement indicators (6-9 per domain) which target areas where there is greatest national potential gain from improving service outcomes (e.g. targeting stroke outcomes).

vii. Formerly known as the Commissioning Outcomes Framework or COF.

There has been concern amongst neurology organisations that the first set of indicators contains nothing that is specific to long-term neurological conditions, despite their obvious impact across the population. A Neurological Alliance report published in 2012<sup>37</sup> recommends the definition of neurology specific indicators tied to the outcomes framework. For professionals working in MS, there is a need to go a step further than this and to define measurable outcomes which are specifically relevant to the unique needs of people with MS. During the MS Trust Generating Evidence in MS Services (GEMSS) project<sup>viii</sup>, the MS nurse teams involved, working in collaboration with the MS Trust, drafted a set of outcomes under each of the domain headings (see figure 4) relevant to MS specialist nurse services. Most of these outcomes are highly relevant to AHP services, and through a second phase of the GEMSS project, beginning in early 2014, this will be tested with multidisciplinary teams of AHPs and nurses working together.

Figure 4 MS-specific outcomes targeted by MS Specialist Nurses, developed through the GEMSS project

NHS Outcomes Framework Domain	Suggested outcomes for people with MS
<b>Domain 1 – preventing people from dying prematurely</b>	<ul style="list-style-type: none"> <li>Prevent secondary complications (e.g. unusual infections, pressure sores, aspiration pneumonia) some of which can be life threatening.</li> </ul>
<b>Domain 2 – enhancing quality of life for people with long-term conditions</b>	<ul style="list-style-type: none"> <li>Reduce the impact of symptoms, e.g. pain, spasticity, cognitive problems, incontinence, swallowing problems, depression and anxiety</li> <li>Promote adherence to disease-modifying drugs to maximise their effectiveness</li> <li>Increase the ability of people with MS to live well and lead a full life</li> <li>Reduce unemployment and work absence</li> <li>Enable people to stay in their own home for longer</li> <li>Reduce the physical and emotional impact of MS on family and carers</li> <li>Enable family and carers to be confident and capable</li> </ul>
<b>Domain 3 – helping people to recover from episodes of ill health or following injury</b>	<ul style="list-style-type: none"> <li>Shorten the recovery time from relapses and other episodes of ill health such as infections.</li> </ul>
<b>Domain 4 – ensuring that people have a positive experience of care</b>	<ul style="list-style-type: none"> <li>Provide an equitable service for different types of patients and stages of MS</li> <li>Provide a responsive and timely service</li> <li>Provide joined up / seamless care by brokering and coordinating treatment</li> <li>Recognise and enhance the dignity and autonomy of people with MS</li> <li>Maximise independence and self management</li> <li>Offer care where patients need it (close to or at home if necessary)</li> </ul>
<b>Domain 5 - treating and caring for people in a safe environment; and protecting them from avoidable harm</b>	<ul style="list-style-type: none"> <li>Avert crises (rescue work)</li> <li>Identify risks and prevent avoidable harms (e.g. falls, injuries to carers)</li> <li>Avoid adverse events with disease modifying drugs through vigilance.</li> </ul>

viii. See www.mstrust.org.uk/gemss

## 5.2 Inflexibilities within the tariff system

Where managers require services to generate income in excess of cost, the current tariff system operating in England is not necessarily well suited to the type of services that AHPs provide and tends to reward episodic care rather than the preventative and long-term work that AHPs do. For example, we found examples of health promotion activities like ‘Back to Work’, or fatigue management clinics, or visits to employers to help people with MS stay in work being cancelled. This was because they do not generate sufficient income, despite their benefit to society as a whole, as evidenced by one person with MS who spoke passionately about how his MS OT had enabled both him and his carer to remain in work:

*“Before I got to the specialists, I was being advised that my partner might have to give up work to look after me. She’s a bit forthright. She wasn’t going to give up work. And when I found [specialist MS support] I began to think, ‘I’m not going to give up work either’. I’m working full time now.”*

In addition, the application of the current tariff rules is inconsistent and can lead to anomalies, which make it hard for the MS AHP service to demonstrate income in excess of cost. For example:

- AHP clinics can be linked to the consultant spell and so do not appear to generate independent income for the hospital
- an FES clinic may be tariffed as an outpatient physiotherapist appointment, but this does not pay for the costs of equipment needed or provide amortisation for its replacement
- in many cases a spell is expected to have a set number of contacts which may be less suitable for a person with MS than with, for example, a more conventional course of therapy for a musculoskeletal problem
- clinic tariffs are paid regardless of length of consultation, which means MS treatment can seem non cost-effective when AHPs may need more time to see patients at a point of transition or with cognition impairment

## 5.3 Complex service models during organisational change

MS AHPs would not be alone in noticing some of the unintended consequences of the reorganisations associated with the NHS reforms in England. However, these have a greater effect when a service is struggling to demonstrate conventional quality and productivity outcomes. In site visits with six varied AHP teams, only one knew who the commissioner for their services was. There were hopes, however, that new commissioning relationships would become increasingly ‘clinical’ and not so managerial and opaque.

In addition to the introduction of Clinical Commissioning Groups in England, some MS AHPs are facing uncertainties around mergers of community and acute NHS Trusts, and also transitions (or failure to transition) to Foundation Trust status.

Not only this, but NHS England is committed to integrating health and social care,<sup>8</sup> although, as they acknowledge:

*“these services can be fragmented, and those who need to rely on them often find that they are hard to access and that there are inadequate links between them.”*

Different MS teams in the country are at very different stages: some are already notionally integrated, while others are not at all joined. In addition, an AHP team may cover a number of different local authorities<sup>ix</sup> and so has to deal with multiple people and systems, making it hard to build up strong working relationships in the interest of the people to whom they are providing care.

OTs from Social Services and Health were reported to approach people with MS in different ways, leading to different attitudes and aims. The emphasis of OTs in the NHS is to improve the quality of life for people with MS by providing fatigue management skills, support to continue study or to stay in work and the like. Social Services OTs tend to focus on assisting the people with MS to live as independently as possible in their own home environment. This, combined with different budgetary incentives, has sometimes led to difficult working relationships between the two teams.

Until full budgetary integration is achieved, AHPs may experience attempts to shift cost from social care to their area. For example, a Social Services carer may refer a person with MS to the NHS asking AHPs to ‘increase the person’s independence’ so that they can reduce the care budget for that person. This is not always possible and in some cases what a person needs is an increase to the care budget instead.

All this organisational change may result in some loss of organisational memory which makes a service that is already struggling to make itself ‘visible’ in conventional ways, all the more vulnerable. People can lose track of the new names of services or organisations. People who knew what was available may leave or move areas and replacements may take a long time to learn. Understanding a complex service takes time and local experience; two things that are scarce during reorganisations.

There are examples where this is not just indirectly prejudicial to the services people with MS receive in their area; we also found cases where it affects patient outcomes directly - because they do not know of the existence of services available to them. Two people with MS explained, when being interviewed for this document:

*“It was an absolute coincidence that I discovered the specialist service. I left hospital after four months as an inpatient, and no one ever told me about it. Communication is astonishingly poor.”*

*“Yes, my friend had seen it in the paper and she told me about the specialist service”.*

As a result of the upheaval associated with organisational change, AHP services for people with MS need to publicise their services to senior management and other services supporting people with MS, in order that existing services are preserved and used.

ix. The Ayrshire and Arran Multiple Sclerosis Service covers 3 local authority areas, for example.

## 5.4 Inequality of service provision, increases in case loads and a shift from anticipatory care to reactive care

As with MS services in general, access to AHP-specific treatment across the UK is uneven. For example, we have been able to identify FES as being available in 24 centres in the UK<sup>38</sup> with some geographic areas having no service within 50 – 100 miles of their location. Likewise, botulinum toxin clinics to manage spasticity are often only available in major cities so patients have to travel long distances from rural areas. As fatigue is such a major symptom of MS, this means that the treatment is often less effective, as patients arrive at the clinic already tired and less able to benefit from the treatment. Finally, access to psychology services is inconsistent, with all six sites visited reporting that they faced long waits if they needed to refer their patients to a psychologist. (This experience is confirmed by the audits of MS services against the National Service Framework carried out by the MS Trust and the Royal College of Physicians.<sup>39</sup>) We found all MS AHP services would welcome better access to psychological therapies, because cognitive issues often impact on the effectiveness of rehabilitation and it is the AHP who often picks up on such problems. In the absence of psychology services, these problems can go unresolved and patient outcomes may suffer.

AHP teams reported an inequality of service provision across disease trajectory. There are fewer therapy services for those who are no longer walking and, in particular, those who are confined to bed or are only able to sit in a wheelchair for up to 1-2 hours. In these cases, people with MS can struggle to access consultant clinics, MDT clinics, or therapy outpatient appointments. This means that a person may be unable to access any MS therapy services (other than generalist community therapy) unless home visits are available.

In part, due to the inability to persuade managers to value their service as highly as their other priorities, we have found an increase in workload for MS AHPs across the country. One centre, for example, has increased the number of consultant neurologists within their service from one to five in 12 years, with no concomitant increase in AHPs. Another has seen an increase in number of patients from 320 to 850 in five years, but is working with the same number of AHPs. In addition, where funding is made available, often it is only for part-time positions, which can lead to lack of service stability, as AHPs move to find full time roles and take their expert knowledge with them.

MS services are quite rightly identifying patients earlier and facing increased expectations about the quality of service, but the level of investment in them is not rising proportionately, which can force care away from the anticipatory end of the spectrum to the reactive.

Thus, as workloads increase and priority is given to the more severe cases, we found evidence of MS services which are solely based in a hospital and can no longer visit patients in their homes, despite the absence of a community-based service and the policy aspiration to move care closer to home. We found evidence of services no longer visiting the workplace to assist employers keeping people with MS in work. We found evidence that people with MS were having to attend a clinic to learn how to get into and out of a wheelchair because it reduced travel time for AHPs, despite the fact that the home can provide a much more clinically effective environment to provide this support. Despite covering a wide rural area, one team stressed the need to continue seeing people at home if at all possible. For example, when conducting a full swallowing assessment it is critical to monitor: where does a person sit?, what are the distractions?, who else is involved at meal times? These changes are not uniform across the country, so the service a person with MS receives can vary greatly depending on where he or she lives.

## 6. Conclusion and recommendations for commissioners and health professionals

*“It’s an expertise. A whole different way of working. I have worked with ordinary physios and the expertise here [in a specialist service], it just shines. It’s like a GP; the generalists know a little bit about everything. With [the MS specialist], it’s like going to a consultant. It’s like that.”*  
Support worker who works with AHPs with different degrees of expertise in MS

In summary, we conclude that the complexity and variability of MS means that clinical expertise in MS is particularly important. The availability or absence of services with expertise in MS has a significant impact on the 100,000 people estimated to have MS in the UK<sup>40</sup> and their carers and those who are close to them. Whilst we gained anecdotal evidence from our site visits that there is considerable variation in the level of, and indeed the presence or absence of, MS AHP services in different parts of the country, we have not been able to quantify this. However, AHPs with expertise in MS are universally highly valued by people with MS and are definitely needed, albeit not all the time.

The UK therefore needs a blend of different types of expertise suitable to the varying needs of people with MS. It is crucial that professionals of all sorts have access to AHPs with significant knowledge and experience to support them in their clinical practice. There should be recognition by all health professionals of the strengths and limits of their competencies and what expertise they can call on when caring for people with MS. For this to work, there must be good communication across services, awareness by all professionals of what expertise is available and the ability to signpost to others appropriately.

Finally there needs to be more research into the role of AHPs in supporting people with MS, most particularly into their cost effectiveness.

### 6.1 Recommendations for commissioners

Commissioners should ensure that:

- **Any MS service that they commission includes MS expertise in occupational therapy and physiotherapy** as indicated in the NICE MS Clinical Guideline.<sup>4</sup> People with MS need to see specialists at key stages of their disease, for example when they are newly diagnosed or experience a relapse, but can be seen by less specialised professionals at other times (e.g. for exercise classes or for related conditions), confident in the knowledge that they have access to the MS expertise if required.
- **There are sufficient AHPs with expertise in MS** both to enable people diagnosed with MS to have direct access as well as adequate telephone access for other clinicians to obtain MS-specific information and advice about when and where to refer on. Understanding how case loads have increased in recent years will assist in making decisions about appropriate levels of investment.

- **They commission explicitly for high standards of inter-agency communication from MS services:** outbound (e.g. an annual communication plan to inform other professionals supporting people with MS) and inbound (e.g. response time standards to other professionals seeking advice).
- **All MS service teams have access to neuropsychologist support** for people with MS, wherever they are based, again as indicated in the NICE MS Clinical Guideline.<sup>4</sup>
- **MS services are commissioned according to the widest definition of value for money,** recognising the long-term financial value to the NHS of maximising people’s day-to-day living functions. Commissioners should consider adopting the model for long-term conditions within the Year of Care,<sup>41</sup> which contains a practical guide to commissioning and delivery of non traditional services to support self management.
- **Whilst challenging MS services to demonstrate service outcomes, effects, and outputs, ensure that MS services are not disadvantaged** by the fact that supporting people through a long-term degenerative condition means they may not be able to quantify the benefits as easily as other types of service.

### 6.2 Recommendations for Allied Health Professionals

AHPs with expertise in MS should:

- **Further raise awareness of their services amongst GPs and other professionals,** for example by providing leaflets, posters and professional development training sessions, and (in England) being listed separately on their unit’s Choose and Book directory of services.
- **Formally provide open access to advice for professionals providing services to people with MS,** to promote optimal management and recognise when a referral to MS specific services is needed. This advice service should meet published standards of accessibility that meet other professionals’ needs.
- **Choose at least a few measures from the National Outcomes Framework<sup>36</sup> and adopt or adapt them to measure their service against.** In the short term, AHPs working in MS could identify a manageable number of important outcomes that their service is targeting (drawing on the list in figure 4), and think about ways in which they could measure and report on them.
- **Survey service users and carers systematically** to learn about their health-related quality of life and how their service can be improved, act on the results and use the material to demonstrate the value of their service. User uptake and endorsement is going to have increasing influence on commissioners so AHPs may consider using the MS Trust’s GEMSS patient survey service (which has been piloted by AHPs) which would facilitate the comparison of their findings with other NHS MS services.
- **Keep a portfolio of case studies in preparation for questions** from senior managers and commissioners as to the effects of their service.



- **Audit their services to identify strengths and weaknesses and plan and act on the results.** This will require comprehensive collection of data for all patients within a common minimum dataset. They may consider undertaking the Therapists in MS (TiMS) Clinical Audit<sup>42</sup> which links to the quality requirement for services as laid out in the National Service Framework for Long-term Conditions.
- **Participate in research** to strengthen the evidence base and publish results in the public domain. Because this can be hard for a service to do on its own, it might be beneficial to do so in collaboration with others as, for example, through the TiMS network.

### 6.3 Recommendations for MS services nationally

These recommendations are for those who have an interest in the quality of MS services in the UK, which would include national commissioning bodies, MS charities, umbrella organisations for neurological conditions, professional bodies, and patient organisations.

- **Commissioning guidance.** One method of assisting in providing evidence for the value of the AHPs with expertise in MS would be to develop a commissioning guideline document articulating how AHPs involved in treating MS bring benefits at every stage of the disease trajectory. This could be based on the Allied Health Professional Stroke Toolkit.<sup>43</sup> This toolkit provides information on the following:
  - which interventions most positively benefit patient care
  - what range of interventions over time will reap the most benefits during illness and lead to independence
  - how interventions map to the Outcomes Framework
  - which interventions are able to save money to the system
  - how functional ability of people is enabled by using AHPs.

A similar document could help AHPs in MS articulate and explain their interventions to a wider audience, particularly commissioners.

- **Service outcomes.** The work to define outcomes for people with MS, and particularly to develop the measurement tools to evidence them, should continue. We recommend that, in future iterations of the CCG OIS, the outcomes which are important to people with long-term neurological conditions, including MS, are more explicitly taken into account.
- **Specialist and local commissioning.** There should be close scrutiny of the effect of the changes in commissioning in England to ensure that MS services do not suffer by falling into a potential gap between the commissioning of specialised services (NHS England) and local services (Clinical Commissioning Groups).
- **An MS Best Practice Tariff (BPT).** As Payment by Results evolves in England, attention should be paid to the difficult and sometimes perverse incentives that can be created in conditions such as MS, and work continued on flexible tariffs that reward the kinds of service models which serve people best. A BPT is a standardised, national cost that a commissioner pays a healthcare provider for a particular service. For example, there is a Parkinson's BPT. It aims to ensure all providers are paid the same amount for that service. The introduction of an MS BPT could assist commissioners and providers to offer healthcare services that are consistent, high quality and in line with the NICE MS Clinical Guideline.

- **An AHP MS Competency Framework and agreement about terminology.** There should be greater clarity about competency levels expected for different roles, and consistency of terminology in describing those roles. The current MS Specialist Services Competency Framework is strong on competencies for MS Specialist Nurses.<sup>44</sup> We found evidence of MS AHPs using it for their purposes, but believe that it would be beneficial to review it and revise it from the AHP perspective so that it could better assist in reducing variation between MS AHP services and articulating workforce requirements.
- **Audit development.** Audit tools should be reviewed and revised in the light of the anticipated revision to the NICE MS Clinical Guideline (expected in the second half of 2014) and the Standards (expected within six months of the Clinical Guideline). Audit services should be made available to NHS MS services to enable at least annual benchmarking against other services carrying out the same audit.
- **The distribution of AHPs with expertise in MS.** A comprehensive exercise should be carried out to determine the amount of MS OT and MS physiotherapy available to people with MS at the level of commissioning units (clinical commissioning groups, health boards, local commissioning groups, and local authorities) to determine the degree to which postcode provision is present.

## Glossary

A&E	Accident and Emergency
AHP	Allied Health Professional
BPT	Best Practice Tariff
CCG OIS	Clinical Commissioning Group Outcomes Indicator Set
ESA	Employment Support Allowance
FES	Functional Electrical Stimulation
GEMSS	Generating Evidence in Multiple Sclerosis Services
MDT	Multidisciplinary Team
MS	Multiple Sclerosis
NICE	National Institute of Health and Care Excellence
OT	Occupational Therapist
TiMS	Therapists in MS

## Appendix A: The commissioning and authorship of the report

This report was commissioned as part of the MS Trust's Generating Evidence in MS Service (GEMSS) Programme.<sup>45</sup> GEMSS was launched in March 2012 as a one year project, following the publication of the MS Trust commissioned report Defining the Value of MS Specialist Nurses. The success of the project has resulted in the extension of the programme both to more MS specialist nursing teams and also to Allied Health Professionals working with people with MS.

The programme's aim is to demonstrate the quality, value and impact of MS specialist services. Its objectives are:

- To improve the breadth and quality of the evidence base for MS specialist services
- To develop MS specific service outcome measures and quality indicators which are aligned with current NHS policy
- To support evidence-driven service improvement
- To build capacity amongst MS specialists in gathering, analysing and presenting evidence about their services
- To build a repository of evidence of patient experience of MS specialist services.

The programme has two projects: one for MS Specialist Nurses and one for AHPs. The AHPs with Expertise in MS project has two components: the inclusion of integrated teams in Phase 2 of the nurses' project and the production of this report, a successor to the report which spawned GEMSS initially.

Katy Dix initially worked for Andersen Consulting in their strategy consulting group before specialising in healthcare projects at Deloitte Consulting. She holds a Masters in Health Administration (MHA) and has worked in healthcare for over 13 years in both Australia and the UK. Her clients have included large private hospitals, pharmaceutical companies and health authorities, with an emphasis on leading focus groups, conducting literature reviews and developing structured arguments.

Howard Green spent 16 years in the NHS culminating in executive leadership in a Primary Care Group and a Shared Support Services organisation. With 13 years of board level experience in both the NHS and private health sector, he is currently an independent healthcare management consultant and has worked for a number of organisations including Bupa, UnitedHealth UK, McKesson and Tribal Consulting. He holds a Masters in Business Administration (MBA).

## Appendix B: Methodology

### 1. Setting the scope

A Study Proposal was drawn up within the MS Trust with the help of Geraldine Mynors and tested with the Therapists in MS (TiMS) Network Working Group.

Five months later the authors met the TiMS Network Working Group to share their approach to the Study Proposal and receive their guidance and direction.

### 2. Desk-based research

Building on the bibliography of Therapists in MS: Delivering the Long-term Solutions<sup>1</sup> and with the support of the MS Trust's Information Department, a computer based literature search was conducted within Medline. The search terms were refined in the light of initial results. Linda Renfrew, consultant physiotherapist in MS in NHS Ayrshire & Arran and researcher at the School of Health and Life Sciences, Glasgow Caledonian University validated the scope of the search and gave advice about the literature in related areas.

### 3. Refining the structured interview questions

The authors were able to have preliminary one-to-one discussions with key members of the TiMS Network Working Group who not only informed and advised them, but also kindly contributed their perspective to the structured interview questions necessary for the case study visits.

### 4. Case study visits

Seven different NHS MS teams around England and Scotland made themselves available to the authors. The sites were chosen to get a spread of size, geographical location, urban and rural, and employer type (e.g. specialist neuro-science centre, NHS Acute Trust, and integrated acute, community and Social Services NHS Trust). The case study interviewees are listed at Appendix C. The authors benefited from 84 'man hours' of structured interviews. The results were compiled under the common headings and cross-referenced between both authors and visit sites.

In addition to these visits, many professionals with long experience of working with people with MS gave their time and answered questions that arose during the course of writing.

### 5. Patients

The Norwich Branch MS Centre allowed one of the authors access on two occasions. Wendy Hendrie, PhD provided assistance with the key themes early on in the study and introduced a number of patients.

Later, seven patients of different ages, length of time since being diagnosed with MS, and with different

experiences of MS and health care in Norfolk and beyond kindly agreed to be interviewed in a group, providing between them over 12 hours of interview content. Their voices are heard in this document.

## 6. Editorial Group

An editorial group consisting of Amy Bowen, Director of Service Development at the MS Trust, Geraldine Mynors, partner in Mynors Suppiah, and Jane Nicklin, Independent Healthcare Advisor, and co-chair of TiMS met with the authors as 'critical friends' and examined the text as it was produced, crucially clarifying terms and honing down the questions the report set out to answer.

A number of team members from the case study visits, members of TiMS, and staff from the MS Trust commented on and contributed to late drafts.

## Appendix C: Interviewees and acknowledgements

The authors very gratefully acknowledge the help of so many people who gave generously and freely of their time and understanding to support the writing of this report, as evidenced below.

People with MS from Norfolk

Ros Edwards, West Berkshire Council

Wendy Hendrie, Norwich Branch MS Centre

### Members of MS AHP teams

#### **Bradford Teaching Hospitals NHS Foundation Trust**

Emma Manchester, Emma Matthews

#### **Douglas Grant Rehabilitation Centre, Ayrshire General Hospital**

Lynn Lamont, Joanna Plaine, Linda Renfrew, Gael Riddle

#### **Poole Hospital NHS Foundation Trust**

Heather Beatty, Helen Cole, Sarah Collyer, Helen Conyers, Alison Nock, Brefini Perkins, Vicky Slingsby

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#### **The Walton Centre NHS Foundation Trust, Liverpool**

Helen Curran, Alison Johnson, Sarah Savage, Jenny Thain, Val Trimble

#### **Wye Valley NHS Foundation Trust**

Gillian Burdon, Natalie Butler, Marcus Cottrell, Julie Gwyne, Olga Steward, Kate Stock

#### **Cambridge University Hospitals NHS Foundation Trust**

Mary Fraser, Chrissy George

## Appendix D: Bibliography of key policy and research papers on AHPs in MS

Bevan S, Zheltoukova K, McGee R, Blazey L 'Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis.' The Work Foundation, June 2011

College of Occupational Therapists, 'The importance of occupational therapy to people with long-term conditions'

The Council for Work & Health, 'Training and Development for Advanced Practitioner Health Professionals in Occupational Health and Wellbeing', September 2011

Department of Health, The National Service Framework for long-term conditions, 2005

Department of Health, 'National Outcomes Framework 2013 to 2014', November 2012

Department of Health, 'Integrated Care: Our Shared Commitment', 13 May 2013

Department of Health, 'Report to the National Allied Health Professional Advisory Board on the outcomes of the Modernising Allied Health Professional Careers Programme', February 2011

MS Society, 'MS 2015 Vision: A report by the MS Forum', June 2011

MS Society, 'A lottery of treatment and care: MS services across the UK,' April 2013

MS Trust, 'Key Steps to delivery of a person centred relapse service', May 2010

MS Trust, 'Therapists in MS: Delivering the Long-term Solutions', March 2006

MS Trust, 'MS information for health and social care professionals', Fourth Edition, November 2011

Mynors et al., 'Defining the Value of MS Specialist Nurses', MS Trust, March 2012

National Institute of Health and Care Excellence (NICE) clinical guidelines, 'CG8 - Multiple sclerosis: Management of multiple sclerosis in primary and secondary care', November 2003

The Neurological Alliance, 'Thinking ahead: The case for a Strategic Clinical Network for Neurology', June 2012

NHS England, 'Prescribed specialised services: commissioning intentions for 2013/14', November 2012

NHS England, '2013/14 NHS Standard Contract for Neurosciences: Specialised Neurology (Adult)', 2013

NHS National Workforce Projects, 'Long-term Neurological Conditions: A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse', January 2009

Scottish Government, 'Consultant Nurses, Midwives & Allied Health Professionals (NMAHPs) Guidance for NHS Boards,' March 2010

Skills for Health: Workforce Project Team, 'Long-term Neurological Conditions: A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse', January 2009

### References

1. Therapists in MS, delivering the long-term solutions, MS Trust 2006.
2. NHS terms and conditions of service handbook, NHS Staff Council.
3. Derived from an on-going project by Disability Action, Dorset HealthCare University NHS Foundation Trust and the Dorset Multiple Sclerosis Service, Poole Hospital NHS Foundation Trust and with their permission.
4. Multiple sclerosis, Management of multiple sclerosis in primary and secondary care, National Institute for Health and Care Excellence (NICE) Clinical Guideline 8, November 2003.
5. NHS England have identified 25 neuroscience centres in their service specification for Neurosciences: Specialised Neurology (Adult), 2013/14.
6. Mynors et al., 'Defining the Value of MS Specialist Nurses', MS Trust, March 2012.
7. Integrated Care: Our Shared Commitment, Department of Health, 13 May 2013.
8. Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland, Report by the Comptroller and Auditor General, HC 192 Session 2012–13, National Audit Office, 29th June 2012.
9. Rietberg MB et al., 'Exercise therapy for multiple sclerosis (review).' Cochrane Database Syst Rev, 2005 Jan 25.
10. Petajan JH et al., 'Impact of aerobic training on fitness and quality of life in multiple sclerosis.' Annals of Neurology 1996;39:432-441.
11. Miller L et al., 'Evaluation of a home based physiotherapy programme for those with moderate to severe Multiple Sclerosis: a randomized controlled pilot study.' Clinical Rehabilitation. 2011; 25(8): 720-730.
12. Rafferty P et al., 'The effect of functional electrical stimulation on the physiological cost of gait in people with multiple sclerosis'. Multiple Sclerosis, 2008, 14: 954-96.
13. Scott SM et al., 'Quantification of gait kinematics and walking ability of people with multiple sclerosis who are new users of functional electrical stimulation.' J Rehabil Med. 2013 Apr;45(4).
14. Steultjens EM et al., 'Occupational Therapy for Multiple Sclerosis', Cochrane Database Syst Rev 2003; (3): CD003608.
15. Maitra K et al., 'Five-year retrospective study of inpatient occupational therapy outcomes for patients with multiple sclerosis.' Am J Occup Ther 2010.
16. Thomas SM et al., 'A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis.' J Neurol Neurosurg Psychiatry, 2013 Jul 10.
17. Krokavcova M et al., 'Employment status and perceived health status in younger and older people with multiple sclerosis', International Journal of Rehabilitation Research: March 2012 - Volume 35 - Issue 1 - p 40-47.
18. Freeman J, 'Improving mobility and functional independence in persons with multiple sclerosis', Journal of Neurology, April 2001, Volume 248, Issue 4, pp 255-259.
19. Khan F et al., 'Multidisciplinary rehabilitation for adults with multiple sclerosis', Cochrane Database Syst Rev. 2007 Apr 18;(2).
20. Scott SM et al 'A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis.' J Neurol Neurosurg Psychiatry, 2013 Jul 10.
21. Khan F et al., 'Multidisciplinary rehabilitation for adults with multiple sclerosis', Cochrane Database Syst Rev. 2007 Apr 18;(2).
22. Saxton JM et al., 'Pragmatic exercise intervention for people with multiple sclerosis (ExIMS Trial): Study protocol for a randomised controlled trial', Contemporary Clinical Trials, Volume 34, Issue 2, March 2013, Pages 205–211.
23. Khan F et al., 'Multidisciplinary rehabilitation for adults with multiple sclerosis', Cochrane Database Syst Rev. 2007 Apr 18;(2).
24. Khan F et al., 'Multidisciplinary rehabilitation for adults with multiple sclerosis', Cochrane Database Syst Rev. 2007 Apr 18;(2).
25. Wiles CM, 'Physiotherapy and related activities in Multiple Sclerosis', Mult Scler. 2008 Aug;14(7):863-71.
26. Rietberg MB et al., 'Exercise therapy for multiple sclerosis (review)', Cochrane Database Syst Rev, 2005 Jan 25.
27. Disanto G et al., 'Heterogeneity in Multiple Sclerosis: Scratching the Surface of a Complex Disease.' Autoimmune Diseases Volume 2011 (2011), Article ID 932351.
28. Rafferty PL et al., 'The effect of functional electrical stimulation on the physiological cost of gait in people with multiple sclerosis.' Mult Scler. 2008 Aug;14(7):954-61. doi: 10.1177/1352458508090667. Epub 2008 Jun 23.
29. Scott SM et al., 'Quantification of gait kinematics and walking ability of people with multiple sclerosis who are new users of functional electrical stimulation.' J Rehabil Med. 2013 Apr;45(4):364-9. doi: 10.2340/16501977-1109.
30. MS Trust, Therapists in MS (TiMS), 'Therapists in MS: delivering the long-term solutions', March 2006.
31. Bevan S, Zheltoukova K, McGee R, Blazey L Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis. The Work Foundation, 2011 June.
32. NHS National Job Profiles, Occupational Therapy and Physiotherapy, Agenda for Change.
33. "The Government is committed to the promotion and conduct of research as a core NHS role. Research is vital in providing the new knowledge needed to improve health outcomes and reduce inequalities. Research is even more important when resources are under pressure – it identifies new ways of preventing, diagnosing and treating disease." Department of Health, 'Equity and Excellence: Liberating the NHS', July 2010.
34. NHS Tariff, 2013-14, category 3 investigation with category 1-3 treatment or category 3 investigation with category 4 treatment.
35. Bevan S, Zheltoukova K, McGee R, Blazey L 'Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis.' The Work Foundation, 2011 June.
36. National Outcomes Framework 2013 to 2014, Department of Health, November 2012.
37. Intelligent Outcomes: applying the health and social care reforms to improve outcomes for people with neurological conditions, Neurological Alliance 2012 (<http://www.neural.org.uk/store/assets/files/275/original/Intelligent-Outcomes-Neurological-Alliance-MHP-Health-Mandate-report.pdf>)
38. Based on MS Trust Map of Services.
39. Second national survey of MS services, MS Trust and the Royal College of Physicians, 2008.
40. <http://www.nhs.uk/Conditions/Multiple-sclerosis/Pages/Introduction.aspx>
41. Year of Care, Report of findings from the pilot programme, Diabetes UK, Department of Health, the Health Foundation, and NHS Diabetes, 2011.
42. [www.therapistsinms.org.uk/audit/audit/](http://www.therapistsinms.org.uk/audit/audit/)
43. How AHPs improve patient care and save the NHS money, produced by NHS London on behalf of the Strategic AHP Leads Group (SAHPLE). [www.networks.nhs.uk/nhs-networks/ahp-networks/ahp-qipp-toolkits/AHP\\_Stroke\\_Pathway\\_final%20-2.pdf](http://www.networks.nhs.uk/nhs-networks/ahp-networks/ahp-qipp-toolkits/AHP_Stroke_Pathway_final%20-2.pdf).
44. A Competency Framework for MS Specialist Services, MS Trust with the UK Multiple Sclerosis Specialist Nurse Association (UK MSSNA), the Royal College of Nursing, and Therapists in MS (TiMS)
45. [www.mstrust.org.uk/professionals/gemss/](http://www.mstrust.org.uk/professionals/gemss/)

*“The Chartered Society of Physiotherapy welcomes this report from the MS Trust, and its recognition of the vital contribution that specialist physiotherapists have in supporting people living with multiple sclerosis. This report will be a useful resource for commissioners and NHS managers in designing and planning effective MS services.”*

Natalie Beswetherick, CSP Director of Physiotherapy Practice

*“Securing the correct level of skill and expertise within any service is particularly difficult, though essential. This document provides some very helpful definitions which would be of particular value to service managers and commissioners alike. It is great to see the specific contributions of occupational therapists recognised by such a range of professionals and people with MS.”*

Julia Skelton, Director of Professional Operations, College of Occupational Therapists



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