## **Preventing Job Loss for People with Multiple Sclerosis**

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### Abstract

Multiple Sclerosis (MS) is the most common chronic neurological condition affecting young adults. Many people are diagnosed with MS while they are of working age, and many leave the workplace prematurely. Vocational Rehabilitation (VR) aims to support those with illness or disability to find new employment, remain in or return to work (RTW). The effectiveness of VR for people with MS is inconclusive. This thesis aimed to develop, implement, and evaluate a job retention VR intervention for employed people with MS.

The VR intervention was developed following the Medical Research Council Framework for developing and evaluating complex interventions and the personbased approach (PBA). The first study was a systematic review to identify VR interventions implemented to support people with MS to find new employment, remain in or RTW. Fourteen studies met the inclusion criteria describing thirteen interventions. There was considerable variability across the interventions and no clear conclusion about the most effective intervention characteristics or components was reached due to the poor reporting of the interventions.

The second study was a qualitative study to explore the experiences of people with MS who work, their needs for VR, and perceived barriers and facilitators to implementing the intervention. I conducted 20 semi-structured interviews with people with MS, healthcare professionals, and employers. Analysis was informed by the framework method and interviews were underpinned by theoretical frameworks. I identified nine themes reflecting the main MS symptoms (e.g., cognition, fatigue), difficulties at work, and support received (e.g., change of working hours). Providing tailored support and early intervention were seen as important attributes for the intervention. The main barrier identified to delivering VR support referred to lack of resources. Having flexibility in the intervention delivery was seen as a facilitator to receiving VR.

The findings were combined following the PBA to develop the intervention's guiding principles, logic model, and a job retention intervention.

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The feasibility and acceptability of the intervention were tested using a mixedmethods single case study design. Secondary objectives included determining whether receiving this intervention was associated with changes in quality of life, fatigue, functional outcomes, and goal attainment. The intervention was tested between June 2020 and January 2021. I recruited 15 participants with MS, 3 employers and 4 healthcare professionals. On average the participants with MS received 8.36 (SD=4.48) hours of intervention and the employers received 1.94 (SD=0.38) hours. The most common topics addressed were managing cognitive problems, fatigue management, and reasonable accommodations. The intervention was only delivered remotely due to the Covid-19 pandemic.

It was feasible to deliver the intervention, but it had no impact on quality of life, fatigue, and functional outcomes. However, it had a positive impact on goal attainment. Compared to baseline, the paired t-test showed a significant difference on goal attainment at the post-intervention assessment (t(14)=7.44, p=.0001, d=1.9), three (t(13)=4.81, p=.0001, d=1.28), and six (t(11)=4.45, p=.001, d=1.28) months follow-up. Participants reported that the intervention was acceptable in the post-intervention interviews. Four themes were derived from the post-intervention interviews regarding the (1) context, (2) the employer, (3) empowerment, and (4) intervention components and attributes.

Future research should focus on understanding how VR interventions can be embedded within existing healthcare services.

### **PhD** Publications and Dissemination

#### **Publication:**

De Dios Perez B., Radford D.K., & das Nair R. (2021). Experiences of people with Multiple Sclerosis at work: Towards the understanding of the needs for a job retention vocational rehabilitation intervention. Work (accepted for publication).

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MS Frontiers Conference (July 2019), poster presentation: De Dios Perez B., Radford D.K., Evangelou D.N. & das Nair R. (2019). A Systematic Review of Vocational Rehabilitation for People with Multiple Sclerosis.

British Society of Rehabilitation Medicine (BSRM) and Society for Research in Rehabilitation (SRR) joint meeting (November 2019). A Systematic Review of Vocational Rehabilitation for People with Multiple Sclerosis.

De Dios Perez B., Radford D.K., Evangelou D.N. & das Nair R. (2020). Experiences of people with Multiple Sclerosis at work: Towards the development of a vocational rehabilitation job retention intervention. Multiple Sclerosis Journal, 26, 31-32. <u>https://doi.org/10.1177/1352458520969077</u>

#### **Oral:**

Vocational Rehabilitation Association (November 2020)- Vocational rehabilitation for people with multiple sclerosis.

Rehabilitation in Multiple Sclerosis (RIMS) Conference (December 2020)-Experiences of people with multiple sclerosis at work: Towards the development of a vocational rehabilitation job retention intervention.

Sue Watson Postgraduate presentation event, School of Medicine (March 2021)

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#### Other:

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## Declaration

I, Blanca De Dios Perez, certify that this is my own work, except where indicated by referencing. No part of this thesis has been submitted elsewhere for any other degree or qualification.

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# Abbreviations

BCW	Behaviour Change Wheel
BSRM	British Society for Rehabilitation Medicine
CNS	Central Nervous System
DLA	Disability Living Allowance
DMT	Disease Modifying Treatment
DWP	Department for Work and Pension
EQ5D	Euroqol
GAS	Goal Attainment Scaling
GBP	Great Britain Pound
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HR	Human Resources
ICF	International Classification of Functioning Disability and Health
IOSH	Institution of Occupational Safety and Health
LTNC	Long-term Neurological Conditions
MRC	Medical Research Council
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSF	National Service Framework
NUH	Nottingham University Hospital
ОН	Occupational Health
ON	Optic Neuritis
ΟΤ	Occupational Therapist
PBA	Person-Based Approach

PDQ	Perceived Difficulties Questionnaire		
PIP	Personal Independence Payment		
PIS	Participant Information Sheet		
PPI	Patient and Public Involvement		
PPMS	Primary Progressive Multiple Sclerosis		
PRISMA Analyses	Preferred Reporting Items for Systematic Reviews and Meta-		
PRMS	Progressive Relapsing Multiple Sclerosis		
RRMS	Relapsing-Remitting Multiple Sclerosis		
RTW	Return-to-Work		
SCI	Spinal Cord Injury		
SOC	Standard Occupational Classification		
SPMS	Secondary Progressive Multiple Sclerosis		
TBI	Traumatic Brain Injury		
TIDieR	Template for intervention description and replication		
UK	United Kingdom		
VR	Vocational Rehabilitation		
WHO	World Health Organisation		
WIS	Work Instability Scale		

### **Chapter 1: Introduction**

#### **1.1. Multiple Sclerosis**

Multiple Sclerosis (MS) is the most common chronic neurological condition affecting young adults and the most common non-traumatic disability in adults (1,2). MS is characterised by progressive damage to the Central Nervous System (CNS), producing plaques in the brain and spinal cord (3). These lesions are caused by the loss of myelin sheaths that lead to inflammation and axonal damage (or loss) (1).

#### 1.1.1. Epidemiology

MS currently affects 700,000 people in Europe, and over 130,000 people in the United Kingdom (UK) (4,5). People are usually diagnosed with MS when they are between 20 to 40 years of age (6). The prevalence of MS by gender shows that women are two times more likely to present MS than men (7).

Researchers are yet to understand what causes MS, although there is evidence to believe that it is caused due to a combination of genetic and environmental factors (8). There is a large geographical variability in the prevalence of MS (2,9). In general, countries at higher latitudes presenting more cases of MS, with North America and Europe having most cases (2,8). Other factors considered to have an impact on the development of MS are Vitamin D deficiency, exposure to ultraviolet light, and smoking (10).

#### 1.1.2. Clinical Course

MS can present as four different clinical courses (Figure 1) (7).



Figure 1 Clinical courses of MS (Pugliatti et al., 2006).

The clinical courses are characterised by both the relapses and the progression of the condition (11,12). The relapses or exacerbations are the expression of MS caused by inflammation in the CNS (13). The inflammation usually leads to either a new lesion or damage of a previous lesion, which leads to worsening of the MS symptoms (12). Understanding the prognosis of MS is important to make decisions about medical treatment and support that best matches the needs of the person with MS (12). The main clinical courses are:

- Relapsing-Remitting MS (RRMS) is characterised by relapses followed by full recovery of the symptoms. There is usually no disease progression between the relapses (14). This is the most common clinical course, especially at the early stages after diagnosis (15).
- Secondary Progressive MS (SPMS) initially follows the disease progression of RRMS, but with time there is not a complete recovery of the symptoms. The transition between clinical courses is gradual and it can be challenging to identify when a person with MS progresses from RRMS to SPMS (16).

- Primary Progressive MS (PPMS) is characterised by a constant progression of the disease from the onset (16).
- Progressive Relapsing MS (PRMS) is the least common clinical course and is characterised by a constant progression of the disease from the onset with clear relapses without recovery (14,16).

As the disease progresses, new damage appears leading to different cognitive or physical problems (17).

#### 1.1.3. Symptoms

Due to the damage to the brain, people with MS can present with a range of physical, cognitive, and psychological problems. The most common physical problems are gait difficulties that can lead to people needing a wheelchair, and balance disorders which lead to an increased risk of falls (18). In fact, after 15 years with the condition, approximately 50% of people with MS need support walking (19). Other common physical symptoms are muscle spasms, stiffness, and feelings of numbness or tingling (20).

People with MS can also experience visual impairments, almost a quarter of people with MS presents with optic neuritis (ON) at the time of diagnosis (21). ON can cause loss of vision, visual fatigue, and blurred vision among other difficulties (21).

Some people with MS can also present with bladder and bowel issues (22,23), and pain, which can be caused by the damage of the CSN (neuropathic pain) or pain caused directly by MS (musculoskeletal pain) (24).

Regarding the neuropsychology of MS, approximately 65% of people with MS present some level of cognitive impairment (25,26). The most common cognitive problems are:

• Memory: Approximately 60% of people with MS present with some degree of memory impairment (25,27). Memory problems are the most common cognitive impairment which people with MS present (26). The memory system is complex, and it encompasses different types of memory (e.g., short- and long-term memory, recognition memory, etc.) and not all types of memory are affected in people with MS (26). Problems with working

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memory (e.g., processing information stored temporarily) and long-term memory have been commonly reported (28).

- Attention: Problems with sustained attention have been identified in people with MS, common problems involve difficulties performing tasks simultaneously as this requires a larger attentional load (29).
- Processing Speed: People with MS can present with slower processing speed and reaction time, which might be caused by the demyelination of the CNS hampering the progression of the information (30).
- Language: Language is typically preserved in people with MS; early research on MS did not identify language deficits in people with MS (30). However, the presence of mild word-finding difficulties have been described as a common event for people with MS (31,32).
- Executive functions, a term used to refer to the complex cognitive abilities to direct behaviour towards a goal and overcome demanding problems or changes, can also be impaired because of MS (33,34).

This variability of cognitive deficits that people with MS can present reflects the heterogeneity of the condition, which affects each person in a different way (26). These impairments can be present even at early stages of the disease, and due to the progressive nature of the condition, they also progress over time (33). Previous studies into MS and cognitive impairment have not found a relationship between years with the condition and degree of cognitive impairment; however, the severity and intensity of these deficits vary according to the type of MS (29,35). The progressive forms of MS lead to greater cognitive impairment (35).

Psychological factors can also influence the presence or intensity of cognitive impairment in people with MS. In particular, the presence of depression and fatigue can affect cognitive impairment, although this association is complex and not very clear (34,36).

Fatigue is one of the most common symptoms reported by over 80% of people with MS (37,38). Fatigue caused by MS is not the same as the normal levels of fatigue

that a "healthy" person presents. MS professionals have defined MS fatigue as "a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities" (39). Fatigue is considered an invisible symptom; interestingly, its impact on the wellbeing of people with MS is equal to the impact of physical and cognitive deficits (40). In fact, fatigue is a major factor leading to work-related difficulties and change in work status (such as reducing working hours) (41).

Another major symptom is depression. Approximately 50% of people with MS present with some degree of depressive symptoms (2,42). Understanding depression in MS is complex, as it can appear because of the impact of MS in different aspects of the life of an individual, rather than a symptom by itself (43). The presence of depression is one of the main factors leading to reduced quality of life in people with MS (44).

#### **1.1.4.** Treatment Available

#### 1.1.4.1. Disease Modifying Treatments

Currently, there is no cure for MS, however over the last two decades, several disease-modifying treatments (DMTs) have been developed (45,46). These DMTs have shown a positive impact on the number of relapses and disability progression in RRMS (46). The DMTs can reduce the signs of MS progression (47). However, finding the right treatment can be complicated as it depends on factors such as disease severity and the presence of other health conditions (45,48)

The treatments in MS are usually divided into three categories known as first, second or third line of treatment. The medications that may lead to higher risk of severe adverse events are included in the second or third line of treatment (45,46).

Since DMTs aid to stop the progression of MS, they are also very important in delaying the progression of cognitive impairment (33).

#### 1.1.4.2. Symptomatic Treatment

The array of physical and cognitive symptoms that MS can cause can be addressed with symptomatic treatments that target the symptom rather than the disease itself (49). These treatments are quite common and focus on addressing issues that appear as the disease progresses, such as fatigue management, bladder urgency, emotional lability, pain, and cognitive problems (49). It is important to address these issues as they can reduce quality of life of the person with MS (50).

#### 1.1.5. The Cost of MS

The presence of cognitive and physical disability in people with MS is usually associated with reduced quality of life and higher levels of disability, which by extension lead to a great cost associated to MS (51). MS is the costliest neurological condition for several reasons (52). First of all, people with MS are diagnosed at an early age (between 20-40 years), and the life expectancy is relatively high, but with life-long disability; the second factor refers to the provision of medical and social services to address the impact of the condition (51,52). The most common services that people with MS use for MS reasons are neurology and other MS specialists (i.e., physiotherapy) (51).

Unemployment in people with MS also increases the cost associated with the condition. People with MS tend to become unemployed a few years after being diagnosed, which means they retire prematurely (51,53,54). There is also a cost associated with productivity loss as people with MS need to take days off work or reduce their working hours to cope with job demands and MS symptoms (51). A study evaluating the cost associated with the care and resource utilisation of people with MS in the UK (n=779), identified that although over 72% of the participants included were of working age, only 36% of the total were employed (55). Additionally, of those working, 92% were working part-time, largely because of the impact of MS at work (55).

Table 1 presents a comparison of the increase in the cost associated with healthcare cost vs. employment cost according to the level of disability of the person with MS (55).

	Mild Disability	Moderate	Severe	
	(EDSS=0-3)	(EDSS=4-6.5)	(EDSS=7-9)	
	Mean (SD),	Mean (SD),	Mean (SD),	
	GBP	GBP	GBP	
Total medical cost				
(e.g., DMTs,	5903 (8599)	5511 (7547)	5039 (9941)	
consultations)				
Total non-medical cost				
(e.g., community	1050 (4601)	6924 (10,132)	19,624 (19,257)	
services, informal care)				
Total productivity loss	4480 (9989)	10,166 (12,937)	11,875 (13,831)	
Short-term absence	191 (1117)	118 (843)	0 (0)	
Long-term absence,				
invalidity, early	4289 (10,009)	10,166 (12,937)	11,875 (13,831)	
retirement				
DMTs= Disease modifying treatments; GBP= British Pound; SD= Standard deviation; EDSS=				
Expanded Disability Status Scale				

Table 1 Mean cost of MS per year (Thompson et al., 2017)

The burden of disability caused by MS is usually presented using the Kurtzke's Expanded Disability Status Score (EDSS) (56). This scale is distributed in 20 categories ranging from 0 to 10, with levels increasing by 0.5 as the level of disability increases. In general, these scores are grouped between 0-3.5 (moderate disability), 4.0-6.5 (severe disability), and 7-9.5 (severe disability/ dependency); a score of 10 indicates death caused by MS (7). People with higher values on the EDSS present higher levels of disability, and lower quality of life (51).

The estimated annual cost associated with productivity loss for people with lower disability level (as measured by EDSS) was approximately 4,480 GBP per person, increasing up to 11,875 GBP for those with higher levels of disability (55). However, the cost associated with medical care (such as DMTs, consultations, and day admissions, etc.) barely fluctuates with increased disability levels, ranging from 5,903 GBP per year for those with lower disability levels to 5,039 GBP for those with higher disability levels (55). These figures represent the impact that productivity loss has on the economy of the UK.

#### 1.2. International Classification of Functioning Disability and Health

To date, there is not a clear understanding of the factors that cause unemployment in people with MS. Although several disease-related and environmental factors have been described, these do not fully account for the extent of their unemployment levels. Therefore, to get a better understanding of these factors and develop support that meets the needs of people with MS, we need to understand their employment situation from a biopsychosocial perspective.

The biopsychosocial model emerged in the 1970s and helps us understand the impact of an illness taking into consideration the biological, psychological, social factors (57). This model evolved from a previous biomedical model of illness that did not take into consideration other aspects of the condition, such as the social environment and the person's psychological response to the disease/ illness (58).

Thus, I selected the International Classification of Functioning Disability and Health (ICF) from the World Health Organisation (WHO) (59), to underpin the studies of this thesis that aim to understand and explain the work situation of people with MS. This framework has also been recommended to map the vocational needs of people with MS by the BSRM (60).

The ICF framework provides a standard language to describe health and healthrelated factors and can be used as a coding scheme for health conditions and help researchers understand the environmental factors that act as a barrier or enabler for a person with a health problem (59).

The ICF allows understanding the functional capacity and difficulties presented by a person while working (activity/participation) with MS (health problem) (59). The relationship between employment and MS is multifaceted; moreover, there are health and environmental factors that lead to employment issues (61).

This framework can be used to describe health and health-related domains from the viewpoint of the body, individual, and society (59). The ICF is divided into two parts with two components each (Figure 2):

• Part 1 (Functioning and Disability) is divided into two components *body functions and structures*, and *activities and participation*.

• Part 2 (Contextual Factors) is divided into two components *environmental factors* and *personal factors*.



Figure 2 ICF Components

Because of the comprehensiveness of this theoretical framework, the ICF has been commonly used to describe the research available on employment and MS and the perspective of stakeholders in topics such as vocational rehabilitation (VR) and patient's needs (61–66).

#### 1.3. Impact of MS on Employment

People with MS experience significantly more unemployment and underemployment than the general population (67). Furthermore, unemployment in people with MS is at a higher rate than people with other chronic disabilities, and at a higher rate than expected given the nature and severity of symptoms (61,68,69). It is estimated that the unemployment rate for people with MS is around 80% (41).

Apart from the number of people who become unemployed after a diagnosis of MS, there is also a large proportion of people that need to reduce their working hours because of MS (53).

When understanding the impact of MS on work, two terms need to be studied: these are "presenteeism" and "absenteeism". Presenteeism refers to someone attending work but not being able to work for example because of illness, leading to an

employee becoming less productive (70). This term emerged because the cost associated with productivity loss is only partly associated with absenteeism (time missed from work) (70). People with disabilities tend to go to work feeling unwell, leading to a loss of productivity (presenteeism) (70).

People with MS can also be out of work (absenteeism) because of MS symptoms or a relapse of the condition, and usually, companies offer a limited number of sick days per year. This may lead to people with MS going to work even though they are feeling poorly. Research has shown that loss of productivity due to presenteeism in people with MS, is approximately three times larger than the impact of absenteeism (71).

The availability of DMTs has improved the diagnosis and treatment of MS, potentially because the diagnosis can be made at an earlier stage (72). Those treatments that reduce the progression of the condition can be beneficial to reduce some of the problems the person with MS presents at work (73). A study about the impact of different DMTs on the employment situation of people with MS showed that those DMTs that prove to have higher efficacy in clinical trials (e.g., Natalizumab), also lead to greater reported work attendance and productivity than those having DMTs with lower efficacy (74).

#### **1.3.1.** Common problems at work

People with MS can experience a range of problems at work. These usually arise from an interaction between MS-related and environmental variables.

People with MS experience fatigue, which causes problems keeping consistent energy levels throughout the day (37,41). It is also common for people with MS to experience memory problems such as remembering meetings (75), and problems concentrating at work (54). Difficulties concentrating at work usually worsen when the person works in an open-plan office or noisy environment.

People with MS can also present with speech difficulties which are characterised by either difficulties finding works (i.e., anomic deficits) or difficulties articulating works (i.e., dysarthria) (31,76). These language problems can cause difficulties using

the telephone, speaking in meetings, or giving presentations at work (77).

Mobility issues are also commonly reported in MS. These have a negative impact at work by causing difficulties walking in the workplace, balance problems, and difficulties with handwriting (78,79). Pain can also have a negative impact at work, as people experience difficulties getting work done while experiencing pain (80,81).

Other common MS symptoms that cause difficulties at work are problems regulating temperature, bowel and bladder problems, and spasticity (82). Psychological factors affecting employment have also been identified in the literature such as the presence of depressive symptoms (83,84) and mood disorders (85).

As discussed when introducing the ICF, the MS symptoms alone do not account for the range of problems that people with MS experience at work. In fact, environmental variables and MS symptoms interact with each other creating further barriers at work (6). A common problem that people with MS experience at work refers to difficulties travelling to and from work (54). This problem is usually caused because of difficulties using public transport, or challenges walking from the parking to the office. Another barrier refers to difficulties accessing the workplace, such as problems accessing the desk, or meeting rooms (54).

People with MS can also face discrimination at work due to social attitudes, which is mainly associated with employers failing to provide reasonable accommodations, lack of support, and hostility towards them (82,86–88). This discrimination can originate because the employer does not understand the condition or because they believe that working might harm their employee's health (6,89).

As can be seen, these MS-related and environmental variables interact with each other leading to wide variability in terms of needs and problems at work. Generally, working in the public sector, sedentary jobs, and workplaces where it is easy to adapt the environment to the needs of the person help individuals with MS to remain in work for longer (90).

A study by Smith and Arnett, (2005) found that people with MS with more years of education and stature in the workplace have better opportunities to either reduce their working hours or modify their role (41). It also suggested that those with higher

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levels of education usually have a sedentary job, which can mitigate the impact of physical problems in the workplace (91). Furthermore, a stronger economic position can make a person reduce their working hours instead of retiring due to disability to rely on disability benefits (41).

#### **1.3.2.** Predictors of unemployment.

Several predictors of unemployment for people with MS have been identified in the literature. The predictors identified largely refer to MS symptoms and sociodemographic characteristics. Although recently more attention is paid to the impact of environmental factors on job retention.

The main sociodemographic factors that have been identified as predictors of job loss are age (older people are more likely to be or become unemployed) (68,75,92– 95), lower levels of education (68,75,92,93,95,96), and female gender (68,84).

The main MS characteristics identified as common predictors of unemployment are higher levels of physical disability (i.e., higher EDSS) (68,83,84,92,93,97), progressive disease course (84,92,95–97), and longer disease duration (84,92,97). Unfortunately for people with MS, there is a direct relationship between years with MS and unemployment (54). Usually, fewer than 50% of people with MS remain at work after 10 years, decreasing to 20-40% after 15 years (53).

The presence of depressive symptoms (83,84), fatigue (93,97), and cognitive problems (83,93,96,97) have also been recognised as predictors of unemployment. The evidence regarding cognitive impairment is less consistent because its impact can vary according to job type and strategies that people adopt to manage their cognitive deficits in the workplace (41,75).

Another common predictor of unemployment for people with MS is having a physical job (95). People with MS who have a physically demanding job usually experience difficulties at work (98). In fact, unemployed people with MS tend to have higher levels of physical disability (41,54,68,75).

#### 1.3.3. NICE Guidelines for MS

The National Institute of Clinical Excellence (NICE) has developed evidence-based guidelines for managing MS in adults in the UK. The guidelines recommend that people with MS should receive information about what is MS, treatments available, support with symptom management, advice about local support services, and legal rights at the point of diagnosis (99). The guidelines advocate for a multidisciplinary team supporting the person with MS including neurologists, MS nurses, OTs, and psychologists. However, there is no direct guidance to provide support with employment. This is a clear gap as most people are diagnosed with MS when they are of working age.

NICE has also developed guidelines for best practice for managing long-term sickness absence and capability to work (100). These guidelines are not MS-specific and can be applied to any person that has been out of work for a long time. The guidelines provide advice for employers' representatives, GPs, or commissioners (among others) to support people on long-term sickness absence to RTW, preventing them from moving to long-term sickness absence (100).

The guidelines recommend that when a person is likely to be out of work for more than four weeks, they should be referred to rehabilitation services (e.g., Occupational Therapy) or other sources of support relevant to their condition (100). Taking into consideration the unpredictability of MS due to the presence of relapses of the condition, this recommendation can apply directly to people with MS as it will help them at a time when they are vulnerable to job loss.

They also provide advice about the best plan to support the person to RTW, which includes steps such as seeking information about how the condition affects the work ability of the employee, understand the support they might need in the workplace, and identify adjustments for the workplace if the person is likely to have ongoing needs when returning to work (100).

These adjustments at work are known as "reasonable adjustments" or "reasonable accommodations". The WHO defines reasonable accommodations as "necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities

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enjoy or exercise, on an equal bases with others, all human rights and fundamental freedoms" (87 p.308). These sometimes include providing auxiliary aids (e.g., ergonomic chair) or changes such as providing a parking space close to the entrance of the workplace or allowing the person to have a flexible schedule (102,103).

To ensure these reasonable accommodations match the needs of people with disabilities; the guidelines provide advice as to how reasonable accommodations should be implemented and recognise the need to keep a record and timeframe for implementing the support, as well as monitoring the need for certain accommodations and provide information about other interventions that might be beneficial (100).

Unfortunately, these guidelines have been developed to support those in long-term sickness absence, and they do not provide information about how to best support a person with illness or disability that has not been out of work.

#### **1.4. Rehabilitation as a process**

Rehabilitation is considered an essential process in the provision of health services (104). The WHO defines rehabilitation as "a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment" (104). Rehabilitation has the potential to reduce the impact of a health condition, which enables the individual to remain independent (104).

Rehabilitation should be understood as a problem-solving process, with a biopsychosocial approach that understands the needs of a person (e.g., personal and environmental), and collaborates through a multidisciplinary team to plan the rehabilitation process, and review it over time to track progress (105).

Rehabilitation interventions include processes such as setting goals tailored to the aims and needs of the patient, these are reviewed over time (105,106). It also includes coordinated effort, good communication, education, and training to both patient, healthcare team, and other relevant individuals such as family, and the process is usually refined with feedback from the patient (105,106).

Rehabilitation interventions can be considered complex interventions according to their characteristics. The complexity increases according to the number of intervention components, people involved in the intervention, skills required to deliver the content, and ability to define and measure outcomes among other characteristics (105).

#### 1.4.1. Vocational Rehabilitation

Those rehabilitation interventions with a work-related interest are classified as VR. The British Society of Rehabilitation Medicine (BSRM) defines VR as "a process whereby those disadvantaged by illness or disability can be enabled to access, maintain or return to employment or other useful occupation" (p.5) (107). Its purpose is to enable those who can work, to do so. There are several definitions of VR according to the context where the term is used (108).

At this point, it is important to define two key terms: "work" and "employment". Work can be considered an umbrella term as it can include family responsibilities, self-employment, and working for a company (101). Employment refers to regulated work in either public or private sectors where the person receives a salary and other benefits such as health insurance (101).

For people with MS who are generally diagnosed when they are of working age, VR can be crucial to extend their professional lives and improve their quality of life (109). It aims to improve the capability of work, leading to a reduced number of people claiming benefits and increases the employment rates of a country (108). Furthermore, VR improves work outcomes and leads to better health for people with illness or disabilities (110).

There are different approaches to VR according to the intensity and specialization of the service (108). Those with complex needs might need the support of a multidisciplinary team; however, other common health problems might be addressed through generic services that address a specific problem (108).

There are four distinct areas in VR (108):

• Job Preparation: Supporting an individual to enter the workforce.

- Job Retention: Supporting people who are currently working to remain at work.
- Work Return: Supporting an individual to return to their previous role or find a new job for unemployed people.
- Planned withdrawal from work: Supporting an individual who no longer wants to work, to leave the workforce.

The different aims of VR are necessary to address the needs of each individual at the right time. For example, RTW interventions should aim to support an individual who is unemployed because of sickness or disability within 12 weeks, as remaining unemployed for longer can be detrimental to the physical and mental health of the individual (107). Employment is important from the financial perspective, but also, there is increasing evidence that being unemployed for a long time can be detrimental to people's mental and physical health (91,110).

#### 1.4.2. VR in the UK

Historically, rehabilitation was considered as the support provided after a person receives medical treatment (111). Then, healthcare professionals saw VR as a priority to support people with illness or disabilities to return to work (RTW) (112). However, this trend shifted towards supporting healthy individuals back to work; and move out of the workforce those with illness or disability, so that they could receive incapacity benefits (112).

Unfortunately, this approach led to a split between the National Health Service<sup>1</sup> (NHS) and the Department of Employment (112). Thus, over the last two decades, the healthcare and employment services have been separated such that the NHS is not responsible to support a person with illness or disability to RTW, and they lack knowledge about how this should be done (107). Therefore, people with illness or disabilities are not supported adequately to remain or RTW in the UK.

Because of the lack of VR services in the NHS, private organisations started developing VR services in the UK that were usually paid for by the insurance sector

<sup>&</sup>lt;sup>1</sup> Publicly funded healthcare system of the UK.

(112). However, it is typically only people with accidental injuries who receive this support.

Recently there has been an interest from both the UK Government and the NHS to support people with illness or disability to remain or RTW. In fact, supporting people to remain at work is considered a relevant clinical outcome by the NHS (53,113). However, the support currently provided is patchy, and there are common barriers to receiving these services in the NHS such as long waiting lists, lack of flexibility in the services, poor links with external organisations (e.g., Jobcentre Plus<sup>2</sup>), and lack of expertise about preventing job loss (107).

An avenue of support that employers in the UK can access is Occupational Health (OH) services provided by employers. OH aims to reduce the impact of illness or disability on work and reduce the adverse effects that work can have on health (114). Unfortunately, only half of UK employees can access an OH department through their employer, and the support provided varies considerably according to the organisation type and size (115).

General practitioners (GPs) also play a key role in supporting people to RTW in the UK. When an employee has been off sick for more than seven days, employers request a "Fitness for Work" statement from a GP or hospital doctor (116). GPs can assess whether a person is fit for work or provide advice regarding the impact of a health condition at work to improve the likelihood of supporting the person in work (116). Unfortunately, GP services lack resources such as funding that limit the number of referrals to specialised services to address further needs (107).

Finally, another venue of support in the UK is provided by local Jobcentre Plus; a government-funded agency of the DWP that aims to support people to find employment and financial support for job seekers (117). This service also has Disability Employment Advisors (DEAs) that support people with illness or disabilities to RTW (117). However, these services tend to lack links with healthcare services, and specialist training to address the complex needs of the population receiving the services (107).

<sup>&</sup>lt;sup>2</sup> Government-funded employment agengy and social security office.
Other countries have successfully integrated healthcare and employment services, leading to adequate VR support (107). These countries provide incentives at both organisational and individual levels to support the person to RTW (118). For example, at an individual level in the UK statutory sick pay is low (£96.35 per week as of August 2021); therefore it is difficult for people to remain on sick leave (117,118). On the contrary, in the Netherlands employees receive their full salary during the first year of sickness absence; but they must be actively involved in rehabilitation to RTW, or the employer is allowed to terminate their employment (117,118).

At an organisational level, countries such as Germany prioritise supporting the employee to RTW by providing rehabilitation, rather than promoting disability pension (118). For other countries such as Finland and the Netherlands, having an OH department is mandatory, and they provide recommendations to support the employee to RTW (118).

These approaches towards VR fluctuate between countries, and those countries with better policies become more successful at reducing claims for disability pension and sickness absence (118).

#### 1.4.2.1. Equality Act 2010

Apart from the services available to support people with illness or disabilities at work, the UK Government has implemented new regulations to reduce the inequalities that people with disabilities experience at work.

The Equality Act 2010, implemented in October 2010, presents a series of antidiscrimination legislation to reduce inequalities in society (119). The Equality Act now replaces the Disability Discrimination Act (DDA) from 1995 (120). Under the Equality Act, a person is considered disabled if (a) the person has a physical or mental impairment and (b) the impairment has a substantial and long-term adverse effect on the ability to conduct everyday activities (119). For this reason, people with MS are considered disabled and protected by the Equality Act (119).

This Act requires employers to implement reasonable accommodations to support the person at work, to overcome the negative impact that the disability has on the work performance (119). Unfortunately, a report from the UK Trade Union UNISON about disability equality in the workplace found that 34% of disabled workers who disclosed the condition to their employer felt that their employer was not supportive (121). The results of this report reflect the situation that people with disabilities face at work and how employers might not implement the support that could facilitate the work of their employees. In fact, 50% of respondents recognised that the barriers they faced at work could be removed by implementing reasonable accommodations; and for all the respondents who had requested reasonable accommodations, 67% had all or some of those accommodations refused (121).

These figures show that in general people with disabilities are not being accommodated as they should resulting in them leaving the workforce prematurely. People with disabilities present higher rates of unemployment than people without disabilities (101). For example, UK data from April 2021 regarding the employment rate of people with disabilities and the general population showed that 52.3% of people with disabilities were employed compared to 81.1% of the general population (122).

These figures represent the striking difference between the general population and those with disabilities. People with disabilities are capable of performing almost every job with the right support and environmental changes implemented (122). However, people with disabilities are less likely to be economically active than those without disabilities, and as of December 2020, there were 400,000 unemployed people with disabilities and looking for work (122).

#### 1.4.3. VR for people with long-term neurological conditions

The National Service Framework (NSF) developed a best practice guidance for people with long-term neurological conditions (LTNC) (123). The guidelines set eleven quality requirements to improve the care of this population, and VR is the 6<sup>th</sup> quality requirement, highlighting the relevance of supporting this population to remain or RTW or education (123). This quality requirement was included because being involved in work or an alternative occupation can improve quality of life and independence, especially for a population that experiences difficulties at work (123).

The current models of VR for people with MS have built on the experience from other conditions. The BSRM pathway for best practice recommends five steps for providing VR for people with MS (60):

- 1. Understand what the person wants from their employment situation.
- 2. Multidisciplinary approach referring to relevant professionals to address issues.
- 3. In-depth assessment of vocational needs following a biopsychosocial model.
- 4. Prioritising key issues identified in the assessment.
- 5. Open access intervention that people can access as their situation changes.

Ideally, the person should receive VR support throughout their working lives as their needs change.

#### 1.4.3.1. Brief history of VR for people with MS

When VR was developed to meet the needs of people with disabilities, people with MS did not always meet the criteria to receive these services, as their impairments were not as severe as in other conditions (89).

One of the first VR programmes for people with MS was developed in 1980 in the USA, known as "MS back-to-work", and renamed later as "Operation Job Match" (89). A characteristic of the initial VR interventions for people with MS is that the focus was on supporting individuals to RTW due to the large unemployment figures (89,124,125). Unfortunately, the longer a person has been out of work (unemployed), the more challenging it is to support them to go back to the workforce (107). Therefore, with the progress and understanding of their vocational needs, the focus of these interventions changed to supporting individuals to remain in work by providing support before the person becomes unemployed (early intervention) (85). Furthermore, the projects that aimed to support people who are unemployed to go back to work found that this was particularly challenging for those people claiming unemployment benefits (in the USA), because they lost the benefits when they went back to work, and if they became unemployed, the process to claim back the benefits was significantly complicated (85). The impact of benefits on RTW is applicable to the USA, but there are differences between countries according to their social support services and policies (118).

The later projects aimed to empower the person with MS in the workplace (68). They also acknowledged the relevance of including the employer in discussions around employment issues, conducting job site analysis, providing recommendations about reasonable accommodations and follow-up on the employment situation (85).

#### 1.4.3.2. Evidence of VR for people with MS

Previous attempts to develop interventions to support people with MS have not shown enough evidence of the effectiveness of VR for people with MS. To date, there have been three randomised controlled trials (RCTs) (77,126,127), one clinically controlled trial (CCT) (128), and two pilot RCTs (129,130). Most of the studies have been conducted in the USA and include a low number of participants.

Unfortunately, because of the differences in outcome measures used, aim of the interventions (e.g., job retention, RTW), and intervention characteristics, it is not possible to synthesise the evidence to understand what VR support is most beneficial for people with MS. Further information about these interventions is presented in Chapter 2.

The evidence suggests that people with MS do benefit from receiving information about MS and employment; however, this is not enough to meet their needs, and the support should be provided for a prolonged time due to the changing needs of this population (129).

One of the most recent VR interventions to support people with MS in the workplace was developed in the UK (131). This intervention ('Working yet Worried') was developed following the previous guidelines of the Medical Research Council (MRC) Framework (132) and provided new insight into VR for people with MS. This intervention was also developed following previous anti-discrimination legislation such as the DDA (120); which has been subsequently substituted by the Equality Act 2010 (119).

The results from the exploratory trial presented an improvement in wellbeing, however, the impact of the intervention on employment was difficult to capture because of the lack of an adequate outcome measure (131). Therefore, the researchers used a qualitative approach to understand the impact of the intervention.

The participants who completed the intervention reported a positive impact on their work as a result of the intervention (131).

The researchers conducted a final RCT, but this was methodologically flawed and the preliminary results were underpowered (131). Therefore, the authors concluded that there was no evidence about the effectiveness of the intervention, and the final results were not published (131).

#### **1.5. Frameworks for Intervention Development**

Taking into consideration the lack of evidence about the effectiveness of VR for people with MS, further research is warranted to understand what support works for whom (108). To develop a job retention VR intervention for people with MS, it is important to follow theoretical frameworks to guide the development and evaluation of a complex intervention. Selecting the adequate framework for the development of the intervention is necessary to improve the quality of the research and link adequately the knowledge currently available with the standard practice (133).

#### 1.5.1. MRC Framework

The MRC Framework was selected because it provides guidance to develop, evaluate and implement complex interventions (133). This framework is particularly relevant when developing new interventions, as it encourages evaluation of the evidence available and building interventions based on what is already known (133).

By definition, VR is a complex intervention, it requires tailoring to the individual, is sensitive to the behaviours of different stakeholders, requires behavioural change on the part of the patient and employer and can produce a variety of different outcomes (134). It also crosses boundaries between health, social care, welfare and employment contexts, and requires behavioural change by the patient, family and employer (135). These interventions are also characterised by the presence of methodological difficulties to link the activities or components of the intervention with the desired outcomes (133).

As can be seen in Figure 3, the MRC framework has four stages. The stages presented in the figure are linked with two-directional arrows because the process of developing a complex intervention is cyclical (133). This cyclical process is an

update from previous versions of the MRC framework that saw the intervention development as a linear process (136).



Figure 3 MRC Framework for intervention development and evaluation

For this thesis, the focus of attention is on the stage of *intervention development*. The first step involves *identifying evidence base* (133). The MRC recommends conducting a systematic review to identify previous work and to understand the quality of the information available. It also helps researchers understand how recent the evidence is. According to the quality and quantity of data identified, researchers should conduct further research to update the knowledge available.

The second step involves *identifying/ developing appropriate theory* (133). When developing an intervention, researchers should have a clear idea of the theory or theories that underpin the development of the intervention. This could be done either by drawing from existing theories or complementing this with primary research such as qualitative methods with relevant stakeholders. This step applies even to those planning on evaluating an intervention that has been implemented before, as differences in context and/or users can lead to different needs and results.

The third and final step involves *modelling processes and outcomes* (133). Before the intervention is ready to be implemented at a large scale, it is important to evaluate it at a smaller level to identify weaknesses that can be refined before implementing the intervention in a larger trial. This stage is key to managing time and resources (e.g., funding) wisely (137). As the framework recommends, it is crucial to understand the needs and views of potential users, as well as the context that surrounds them (133). In fact, previous interventions to support people with MS at work have developed interventions with input from end-users (127,129,131,138).

#### **1.6. The Person-Based Approach**

The MRC framework provides guidance and further resources to support the development and evaluation of complex interventions (133). However, it does not provide sufficient detail to guide step-by-step the iterative process for intervention development.

To develop the VR intervention presented in this thesis, I complemented the MRC framework with a methodology for intervention development based on stakeholder input. I selected the Person-Based Approach (PBA), which emphasizes the relevance of understanding the needs of the potential users when developing interventions that meet the changing needs of the target population (139).

This approach allows us to gain an in-depth understanding of an issue through an iterative process using qualitative methods (140,141). Furthermore, it allows us to integrate evidence- and theory-based approaches to enhance the acceptability and feasibility of the intervention (141).

The PBA can lead to developing interventions that are more acceptable for service users and service providers because it allows researchers to identify the key features that will make the intervention more relevant for the potential users (139).

By following the PBA, we can understand not only the needs of potential service users, but also include their views about the delivery mode, intensity of intervention, location, and even the materials that the intervention should include. The potential users are also involved in selecting the content (e.g., activities) and help identify potentials barriers and facilitators of the future implementation of the intervention (139). To achieve this, stakeholders are involved in all stages of the intervention development (139).

There are two systematic steps to develop an intervention according to the PBA (139). Step one involves conducting qualitative research with relevant stakeholders.

The aim is to develop an intervention that meets the needs of potential users. Previous literature available can inform the content of the interventions; however, the feedback from further qualitative research can inform how best to provide this support (139). For example, it can lead to the identification of attributes, and barriers and enablers for implementing the intervention.

The content of the qualitative research leads to the development of a "prototype intervention" that should be presented to relevant stakeholders to obtain a greater understanding of the characteristics of the context and potential users (139). This phase is key to refine the intervention, as well as understand how the intervention brings about the desired change (140).

The second step of the PBA involves identifying "guiding principles" to inform the development of the intervention addressing the issues highlighted through the qualitative research (139). These guiding principles are made of two elements, the *intervention design objectives* and *features* to achieve the objectives (139). The *objectives* are selected according to the needs identified by the stakeholders; the *features* are the characteristics that the intervention should have to achieve the objectives (140).

Overall, the PBA focuses on developing interventions aimed at changing behaviour; therefore, the feedback from stakeholders is included to understand their views about the intervention (and its content), as well as barriers to use the intervention (139). The in-depth understanding of the problem that the intervention is addressing and the context of the intervention and those receiving the intervention make the PBA a comprehensive approach to developing an intervention with improved acceptability (139).

#### **1.7. Intervention Description**

Once the intervention has been developed, it is important to report the content and structure accurately so that other researchers can understand how the intervention works. Because VR is a complex intervention with multiple components interacting with each other, it can be challenging to describe the intervention (133). In fact, complex interventions are usually poorly reported, which leads to gaps in the

understanding of how the intervention works in practice (133,142). For this reason, I have selected a template to guide the description of the intervention.

#### 1.7.1. TIDieR Checklist

The TIDieR checklist (Template for Intervention Description and Replication) is a guide to report and explain how an intervention works and what it entails (142). It is particularly useful because it provides a guide to report an intervention and future researchers will have the necessary information to build or refine interventions based on what has been done before (142). Similar guidance exists to report trials (CONSORT; Schulz et al., 2010), observational studies (STROBE: Knottnerus & Tugwell, 2008), and health research (EQUATOR; Simera et al., 2010) among other tools. Since this study involves reporting an intervention, the TIDieR checklist is the most appropriate tool. This checklist includes twelve items that should be mentioned when describing an intervention.

This checklist can be useful for researchers to understand the content they should report and it can be a practical tool not only for other researchers not involved in the intervention developed to understand what the intervention included, but is also useful as it provides a structure to guide the description of what researchers/clinicians did during the intervention (142).

#### **1.8. Summary of chapter**

This chapter presented an overview of the literature available about MS and VR. It also covered the array of cognitive, psychological, and physical symptoms that people with MS present and their interaction with the social and environmental variables that complicate the employment situation of this population.

For a population with an average age of diagnosis between 20-40 years of age, it is important to provide them with the right support soon after diagnosis ("early intervention") to help them remain at work for as long as they wish (5).

Unfortunately, there is a lack of specialised support to help people with MS to remain in work in the UK. This gap in the service has been attributed to two main issues. The first one is the lack of confidence and/or experience addressing certain MS problems, leading to clinicians providing only generic information about work (54,91,107). The second issue is the lack of time in the clinics, as clinicians have

limited time to understand the needs of the person with MS, thus, those interventions (such as VR) that require longer time are not provided (91).

Further research is necessary to understand the type of support that people with MS need to remain at work according to the characteristics of their MS and work environment. This support needs to be highly individualised and monitored over time (105).

#### 1.9. Thesis aims and objectives

The overarching aim of this thesis was to develop, implement, and evaluate a VR intervention to help people with MS to remain employed for as long as they wish. This work also focused on understanding the barriers and enablers to deliver this support.

To achieve this aim, I systematically reviewed the literature available to identify VR interventions that have been implemented with people with MS and understand the characteristics of those interventions.

To complement the knowledge gap from the literature, I conducted a second study using qualitative methods with relevant stakeholders to understand further key intervention characteristics and outcomes to improve the acceptability of the intervention.

I developed a job retention VR intervention following the MRC framework and PBA. The intervention was evaluated in a mixed-methods case study design with an embedded qualitative study to assess the feasibility and acceptability of delivering the intervention and determine whether the intervention was associated with changes in functional outcomes and job retention.

Table 2 presents an overview of the thesis structure, methods used, and research studies.

Aim	Methods/ Approach	Study	Thesis Chapter
Explore literature available about VR for people with MS.	Systematic Review	One	Two
Explore experiences of working with MS and need for VR support	Qualitative methods	Two	Three
Intervention development	Person-Based Approach		Four
Feasibility and acceptability of delivering the intervention Final intervention description	Mixed methods single case study design	Three	Five Six

#### Table 2 Thesis structure overview.

# Chapter 2: Vocational rehabilitation for people with multiple sclerosis, a systematic review

The previous chapter presented an overview of MS and evidence regarding VR for people with MS. Common problems at work and symptoms affecting work performance have been identified; however, the literature did not reveal sufficient evidence about VR for people with MS.

This chapter presents a systematic review about VR for people with MS to identify the main approaches, intervention components, outcomes, and underlying mechanisms of these interventions. The findings of the review will inform the design of the subsequent studies and development of a job retention VR intervention for employed people with MS.

#### 2.1. Rationale

Considering the average age of diagnosis and chronic character of MS, it is important to understand what can be done to help people with MS to remain employed. Before engaging in the development of an intervention to support people with MS at work, I reviewed the literature available on VR and MS to understand the VR interventions that have been implemented to support people with MS to either remain, return, or find new employment.

There have been two previous reviews focusing on VR for people with MS. The first was a Cochrane review conducted by Khan, Ng, & Turner-Stokes (146), which evaluated the effectiveness and cost-effectiveness of VR for people with MS.

Only one RCT and a CCT met the inclusion criteria for the review. The interventions included were a RTW intervention "Career Possibilities Project" (128) and a job retention intervention "Job Retention Intervention" (77). The review found insufficient evidence for the effectiveness of VR for people with MS (146). In fact, comprehensive quantitative analyses were not possible because of methodological heterogeneity and differences in outcomes measured (146).

The second was a systematic review conducted by Sweetland et al. (2012). This review aimed to identify the research undertaken into MS and employment. The review reports on factors leading to unemployment using the ICF (13) and factors

that help people with MS to remain at work (59,61). The authors concluded that although factors that lead to unemployment for people with MS are complex, it is the combination of MS symptoms, work environment and demands of the job that can make people with MS leave employment earlier (61).

The aforementioned reviews differ from this review, in that in addition to providing a more recent review of the evidence of VR, ours<sup>3</sup> provides an overview of the key characteristics that should be considered when designing a VR intervention for people with MS. This information can help researchers develop or refine interventions to add to the body of knowledge about VR and MS.

Since the Cochrane Review conducted by Khan, Ng, & Turner-Stokes (146) only found one RCT and one CCT on VR and MS, for this review we included all studies that described a VR intervention or its components regardless of the methodology used for the study.

The primary objective of this systematic review was to identify the VR interventions that have been implemented with people with MS. Once we identified the interventions, we aimed to extract information regarding the participants, approaches to VR, treatment components, outcomes, and underlying mechanisms of action.

## 2.2. Methods

The protocol for this systematic review was registered on PROSPERO (https://www.crd.york.ac.uk/prospero/) (CRD42019118526).

#### 2.2.1. Eligibility criteria

Research articles were included if the: (*i*) study described a VR intervention or its components; (*ii*) participants included were adults (+18) with MS; (*iii*) intervention aimed to facilitate RTW, remain at work or find a new job; (*iv*) primary goal of the intervention was improving work capability or occupational outcomes such as sickness absence. We excluded articles if (*i*) fewer than 50% of the participants had MS and no separate data for the participants with MS was available; (*ii*) the study focused solely on barriers or enablers to work with MS; (*iii*) the intervention was not

<sup>&</sup>lt;sup>3</sup> I use the words 'our', 'ours', and 'we', because in the spirit of Team Science, although I led this work, I had the support of my supervisors and other colleagues in completing this review.

focused on improving work capability or occupational outcomes; (iv) not research, (v) research abstracts or conference proceedings, and (vi) not human studies. Nonresearch articles describing an intervention evaluated in research were included if the original report of the intervention was not available. The intervention could have been implemented either remotely or face-to-face. No date restriction was applied.

#### 2.2.2. Data sources and study selection

A comprehensive search was developed by tailoring the PubMed search strategy from the aforementioned Cochrane review (10), and included the following terms: Multiple Sclerosis, VR, work, employment, work capability evaluation, supported employment, vocational education, vocational assessment, vocational guidance, sheltered workshops, career mobility, work retention and job retention.

We ran the search on the following electronic databases: PubMed (1950- 12<sup>th</sup> August 2021), MEDLINE (1946- 12<sup>th</sup> August 2021), EMBASE (1980- 12<sup>th</sup> August 2021), PsycINFO (1806- 12<sup>th</sup> August 2021), Web of Science (1990- 12<sup>th</sup> August 2021) and CINAHL (1953- 12<sup>th</sup> August 2021). The search strategy for all databases is presented in Appendix A.

The reference list of eligible papers was reviewed to identify studies not found in the searches. We contacted the authors and/or the organisation that funded the research to obtain further information about the interventions or to find the original research report and one author responded via email providing further information about Neurological Vocational State Unit (3).

We contacted national and local government organisations, and charities, as well as conducted web-searches of organisations that fund research in MS to obtain research reports not published on academic databases. The organisations contacted were the MS Society, MS Trust, National Multiple Sclerosis Society, BSRM, College of Occupational Therapists (COT), Department for Work and Pension (DWP) and Institution of Occupational Safety and Health (IOSH).

One researcher (BDP) searched all the electronic databases and contacted the aforementioned organisations. Two reviewers (BDP; KP) independently screened the titles and abstracts of the studies identified. Studies were selected for inclusion

according to the criteria described above. Any disagreement was resolved through discussion with a third reviewer (RdN or KR). Full texts of all potentially relevant studies were consulted.

#### 2.2.3. Data extraction and synthesis

Two reviewers (BDP; KP) conducted the data extraction process independently. We developed a screening template to aid the selection of studies and a data extraction template. We extracted the following information from the studies: author, country, type of intervention, inclusion criteria, components of the intervention, outcomes, length of intervention, professional delivering the intervention, implementation mode, and type of study. The TIDieR checklist was completed for all the interventions to understand the content of the interventions (142).

#### 2.2.4. Data Items

The data extracted from each manuscript referred to the intervention characteristics and participants. Clinical and demographic characteristics of the participants included in the interventions were extracted using a data extraction form. We selected the BSRM definition of VR to define the interventions. For this review, we have drawn the main approaches to VR for people with MS from the ones identified in the Cochrane review by Khan, Ng, & Turner-Stokes (146):

- General rehabilitation programs: Generic programs that offer rehabilitation and may include a component about VR.
- Specialist MS VR services: Programs designed specifically to support people with MS to return or remain at work.
- Statutory pan-disability VR services: Characterised for supporting disabled people to return or remain at work.

The *treatment components* refer to the components provided in the intervention. For example, a VR intervention focused on RTW might include two treatment components such as vocational assessment and support with job seeking. The nomenclature and definitions of the components were extracted from the services provided by state VR agencies (67). This list was constructed and adapted from a list of intervention components of VR for people with Traumatic Brain Injury (TBI)

(149). A list of the intervention components and definitions is available in Appendix B.

The *mechanisms of action* refer to processes by which an intervention brings about its change (150). The likely mechanisms of action of the interventions were extracted from the characteristics highlighted by the authors of the identified interventions. Following the previous example, one of the mechanisms of action could be that the intervention was individually tailored to the needs of the client.

Finally, we included a description of the intervention *outcomes* reported for the interventions.

# 2.2.5. Methodological quality assessment

Two reviewers (BDP; KP) critically appraised all studies included using the typology of the NSF-LTNC (123). The NSF typology was selected because preliminary searches identified wide variation in study designs and reporting of information (123). For this study, the NSF typology allowed us to systematically assess the evidence available about VR for people with MS including both research as well as expert evidence (123).

Within the NSF typology expert evidence is only classified into two levels E1 (user expert opinion) or E2 (professional expert opinion). Research-based studies are rated in three domains: design, quality, and applicability. The design domain evaluates the research design used in the study (Table 3)

<b>Research-based evidence</b>	Typology
Primary research-based evidence	
Primary research using quantitative approaches	P1
Primary research using qualitative approaches	P2
Primary research using mixed methods	Р3
Secondary research-based evidence	
Meta-analysis of existing data analysis	<b>S</b> 1

Table 3 Categories of research design within the NSF typology

Secondary analysis of existing data	S2
Review-based evidence	
Systematic reviews of existing research	R1
Descriptive or summary reviews of existing research	R2

The quality of the study was scored using five items (Table 4). The applicability was classified as direct (direct information from the same condition) or indirect (evidence extrapolated from other conditions) (123). In case of disagreement between raters, consensus was achieved through discussion with a third reviewer (RdN or KR).

Table 4 Quality assessment rating within the NSF typology

Each quality item is scored as follows:	Score
1 Are the research question/aims and design clearly stated?	
<b>2</b> Is the research design appropriate for the aims and objectives of the research?	
<b>3</b> Are the methods clearly described?	
<b>4</b> Is the data adequate to support the authors' interpretation/conclusions?	
<b>5</b> Are the results generalizable?	
Total	/10

Low quality= 0-3; Medium quality= 4-6; High quality= 7-10

Due to the heterogeneity of study design and aims of VR interventions for people with MS, we decided to report the findings of the systematic review as a narrative.

#### 2.3. Results

#### 2.3.1. Study selection

We identified 3,354 studies after excluding duplicates from the searches and reviewing the reference lists of possible studies. Fourteen studies were included in this review. Data regarding the number of patients receiving the intervention were only available for eight of the thirteen interventions (67,77,127–131,147,148,151–154). Based on the studies which provided information on the number of participants

who received the intervention, approximately 9053 participants were included in the review.

The inclusion and exclusion process depicted in Figure 4 exemplifies the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) (155).



Figure 4 PRISMA 2020 flowchart of study selection

#### 2.3.2. Characteristics of included studies

From the fourteen studies identified reporting interventions, twelve were research studies (67,77,127–131,147,148,152,153,156), and two were expert opinion articles (as classified by the NSF typology) (6,89). The research articles were three RCTs, two pilot RCTs, one CCT, five quantitative studies, and a mixed-methods study.

Information about five interventions was extracted from the expert opinion articles. Each expert opinion article reported information regarding more than one intervention. The original reports of those interventions were not available even after contacting the primary author and organisation that funded the study.

Appendix C provides an overview of the VR interventions identified in this review. Because the original reports for several interventions were not available, we could not complete the TIDieR checklist for the interventions fully (Appendix D).

#### 2.3.3. Methodological quality

Full consensus was reached between the two independent reviewers (BDP and KP) on the NSF-LTNC typology. The typology for each study on the NSF typology can be found in Table 5.

Study	National Service Framework Typology
LaRocca et al. (77)	R P1 Medium Direct
Rumrill et al. (128)	R P2 High Direct
Sweetland (131)	R P3 High Direct
Dorstyn et al. (127)	R P1 High Direct
Dorstyn et al. (129)	R P1 High Direct
Rumrill et al. (89)	E2 Direct
Rumrill et al. (6)	E2 Direct
Rumrill et al. (156)	R P3 High Direct
Tansey et al. (152)	R S2 High Direct
Chiu et al. (67)	R S2 High Direct
Chiu et al. (153)	R S2 High Direct

Table 5 National Service Framework Typology

Study	National Service Framework Typology	
Fraser et al. (148)	R P1 High Direct	
Fraser et al. (147)	R P1 High Direct	
Stimmel et al. (130)	R P3 High Direct	
R= Research; P1= Primary research using quantitative approach; P2= Primary research using qualitative approach; $P2=$ Primary research		
using mixed-methods; S2= Secondary analysis of existing data.		

Twelve studies (85.7%) reported research-based evidence (6,67,77,127– 131,147,148,152,153). Two (14.3%) were expert-based evidence describing VR interventions implemented in research (6,89). Following the classification of the NSF typology, the research-based studies were categorised according to type of research. Nine studies reported primary research (77,127–131,147,148,156), and three secondary research (67,152,153).

Overall, there were eleven research studies rated as "high methodological quality" (67,127–131,147,148,152,153,156) and one as "medium methodological quality" (77). No study was classified as "low methodological quality". For this systematic review, we only included studies describing interventions for people with MS; hence, all studies were classified as having direct applicability.

#### 2.3.4. VR for people with MS

Thirteen VR interventions for people with MS were identified; of which, five aimed at RTW (89,127–129), six at job retention (6,89,130,131), and two general VR programmes supporting people with MS to either RTW, remain at work or find a new job (67,147,148,152,153). Table 6 provides the name and aim of the interventions.

Name of the intervention	Approach Return	Aim of the intervention		
		Return to	Job	Find
		work	retention	new job
Career Possibilities	Specialist MS VR services	x		
Work and MS	Specialist MS VR services	x		x
MS Back to Work (Operation Job Match)	Specialist MS VR services	x		
Return to Work	Statutory pan-disability VR services	x		
Job Raising Program	Specialist MS VR services	x		
MS Employment Assistance Service	Specialist MS VR services		Х	
Job Retention Intervention	Statutory pan-disability VR services		x	
Working yet Worried	Specialist MS VR services		x	
Project Alliance	Statutory pan-disability VR services		x	
Career Crossroads	Specialist MS VR services		x	
State VR Program	Statutory pan-disability VR services	x	x	x
Neurological Vocational Service Unit	Statutory pan-disability VR services	x	x	x
Neuropsychologically- based vocational intervention	Specialist MS VR services		x	

Table 6 VR interventions grouped according to aim.

Only two interventions were implemented outside the USA; these were "Work and MS" in Australia (127,129) and "Working yet Worried" in the UK (131).

There were considerable differences in the characteristics of the interventions. The maximum length of the interventions was twelve months, for "Working yet Worried" and "Job Retention Intervention" (77,131). However, most interventions lasted a few weeks ranging between 4 and 16 weeks (6,89,127–129). One intervention provided no clear information about the intervention length but reported that participants received follow-up feedback at one and six months post-intervention (130). There was no information about the length of "MS Back to Work" or "Project Alliance" (6,89).

The services provided in the State VR program (67,152,153), MS Employment assistance services (6,156) and Neurological Vocational Service Unit (147,148)

varied in length according to the characteristics of the client.

Regarding the delivery of the intervention, a variety of professionals were involved: Psychologists and employment specialists (77,130), VR counsellor (128), rehabilitation counsellor (6,147,148,156), rehabilitation professionals (6,89) and occupational therapists (OT) (131). Self-help interventions were also implemented to support people with MS (Work and MS), these interventions are characterised by not having direct contact with the professionals delivering the intervention (127,129). In Work and MS, participants received support via email. Information concerning the professional(s) delivering the intervention was not available for "MS back to work: Operation Job Match" and "Career Crossroads" (6,89).

The most common delivery modes were face-to-face *and* telephone contact for five interventions (77,128,130,131,147,148) and group interventions for five (6,89). Two interventions were delivered remotely via email, telephone or a combination of the two (6,127,129,156). This information was not available for the state VR program; possibly not reported due to the variability of services offered (67,152,153).

#### 2.3.5. Characteristics of the participants

Consistent with the prevalence of MS, most participants included in the interventions were women (n=6169). Participants ages ranged between 24 and 65 years. We only found information regarding participants' years with MS for six interventions, and this varied between 4 months and 24 years (77,127–131,147,148). Only six interventions provided years of education. Most participants included had achieved high levels of education with an average of approximately 14 years of education (67,77,127–129,131,148). Data about ethnicity was only available for two interventions (130,157). These interventions only reported the number of participants from a white ethnic background and classed the rest of participants as "other ethnic background" (130,157).

Concerning the employment status of the participants, the majority were unemployed (n=6371). From the studies that reported type of MS (127,129,131), most participants presented with RRMS (81.90%), followed by SPMS (11.05%), PPMS (5.52%), and RPMS (1.50%).

No study reported information regarding the work context such as the size of the company or type of employer. Only one study provided an occupational profile of the participants included in the intervention (148). This profile included characteristics of the current or last job held by the participants in the study according to the *Dictionary of Occupational Titles* (158).

#### 2.3.6. Approaches to VR

The interventions identified represented the three approaches reported on the Cochrane review by Khan, Ng, & Turner-Stokes (146). Appendix C presents the approaches under which each intervention falls.

The most common approach was specialist MS VR services, used by eight interventions. These interventions had a unique focus on either job retention or RTW. The statutory pan-disability VR services approach was present in five interventions; and they focused on supporting people with disabilities to remain, RTW or find employment according to the needs of the person.

VR for people with MS initially focused on supporting individuals to RTW due to the large unemployment figures (89,124). Unfortunately, the longer a person has been out of work (unemployed), the more challenging is to support them to go back to the workforce (107). Therefore, with the progress and understanding of MS and their vocational needs, the focus of these interventions changed to supporting individuals to remain at work by providing support before the person becomes unemployed (early intervention) (159).

The specialist MS interventions were developed specifically for people with MS. According to the aim, the interventions supported individuals to prepare to re-enter the workforce or support managing workload and relationships at work (89,128,130,131). These interventions focused on empowering the person with MS and support them in identifying jobs or workplace accommodations that met the needs of the person with MS (77,89,130,157).

The statutory pan-disability VR services were interventions developed for people with disabilities or other neurological conditions. These interventions offered support focused on understanding the impact of the disability in the workplace,

engaging the employer (or prospective employer) to reduce the stigma associated with disability, and provided support towards empowering the person to disclose the disability (89).

#### **2.3.7.** Intervention components

An overview of the intervention components used in each intervention is provided in Appendix C.

The most common intervention components were vocational assessment and vocational counselling. The vocational assessment component focused on understanding the skills and preferences of the person with MS. Through vocational counselling, the participants with MS received education about the impact of the MS on their work ability, how to request reasonable accommodations, information about disability discrimination, how to manage social and personal expectations, and support with disclosure (128,131).

Job retention interventions were more likely to provide support focused on improving and maintaining MS at work (126,157). These interventions included assessment of work ability, employer engagement, and assessment of work requirements. Furthermore, these interventions were characterised by providing case management and ongoing support to address new problems as they arise.

The RTW interventions supported individuals in the path to find employment, therefore the support provided focused on job-seeking skills, finding work placements, and further training (77,89). These interventions also included support during the job search process such as approaching the employer, drafting a resume, and other relevant activities. The emphasis was on understanding the skills, experience, and preferences of the clients, rather than the disabilities they present (89). The RTW interventions also empowered the person with MS at managing conversations such as disclosure of disability with prospective employers (67,152,153).

Two interventions ("Job Retention Intervention" and "Neuropsychologically-based vocational intervention") provided adjunctive rehabilitation components (e.g., cognitive remediation) to those participants who needed it (77,130). Adjunctive

rehabilitation components are those that are not specific to VR but can be delivered as part of a VR programme to provide a more comprehensive intervention (149). For example, where a particular problem such as cognitive impairment is seen as detrimental to employment, cognitive rehabilitation targeted at addressing these problems might be included.

#### **2.3.8.** Underlying mechanisms of the interventions

To develop and optimise VR interventions, it is important to understand the underlying mechanisms by which these interventions lead to positive outcomes such as job retention.

It is important to note that sometimes there is a fine line between approaches, treatment components and underlying mechanisms. For example, the act of educating a person can be a component of an intervention. However, the change in attitudes and behaviour produced by education can be considered an underlying mechanism.

Another mechanism refers to *early intervention* which has been largely recommended in the VR literature for people with chronic disabilities and by extension people with MS (6,77,126,148,160). Early intervention could be an approach to VR; however, it could also be considered as an underlying mechanism, as the act of providing timely support, in areas that are relevant for the person could lead to better work outcomes. Early intervention is of major importance, as the person may have experienced difficulties at work even before they were diagnosed with MS.

Although no consensus exists in the MS literature about what is considered "early intervention" in MS, it can be understood as providing support soon after diagnosis or before a crisis developed (131). Early intervention might also target familiarising people with MS with the types of problems they might encounter at work, rather than abrupt implementation of employment modifications (77).

Providing *individually tailored* support was the most frequent underlying mechanism identified in the interventions. This underlying mechanism involves understanding the needs of the person with MS at work and providing support that matches their

needs from a biopsychosocial perspective. Because of the heterogeneity of MS symptoms and employment characteristics, the support recommended in VR interventions must match the needs of the person receiving the support. This maximises the impact of the intervention, as opposed to providing generic support that the person cannot generalise to their workplace. Individually tailored support was achieved through a detailed assessment of the impact of MS at work.

The interventions were also characterised by providing *realistic advice about work* according to the abilities of the person and the demands of the role. For the unemployed participants, this underlying mechanism focused on identifying jobs that matched the person's abilities. The participants who were employed were provided with support to manage their difficulties at work or modify their role to reduce or prevent work disability (131). This knowledge *empowers* the individual to regain control of their working lives and learn to manage their condition/disability in the workplace (131). Empowerment was one of the main underlying mechanisms identified, as the knowledge and skills gained through the VR interventions made the person with MS more willing to address the issues they experienced at work and gained confidence to address worries with their employers.

These interventions were also characterised by *co-operating* with other agencies. VR understands the person in their given context; therefore, to support the person at work it is important to also take into consideration their medical or educational needs. Interventions that included different healthcare and employment professionals in the intervention were capable of providing a holistic approach that improved the support that the person with MS was receiving at work. Following similar lines, *employer engagement* has also been recommended, as they provide reasonable accommodations and it can help improve workplace relationships (6,131). When employers are keen on supporting the person with MS at work, both employer and employee can work towards identifying targets to reduce work instability.

Finally, providing long-term support or *re-accessible services* is highly relevant for people with MS, as their needs change over time as a result of the progression of the condition or environmental changes (e.g., new manager) (131). This is particularly important for a condition such as MS, as new symptoms may appear leading to different needs in the workplace. Providing services that are re-accessible or that

monitor their progress through time can provide a sense of stability and security at employment; they are also beneficial to identify difficulties implementing the support provided during the intervention (130,131).

#### 2.3.9. Outcomes

Outcomes were available for five interventions (77,126–130). The outcomes included are presented in Appendix C. There was considerable variability in the outcomes measured, with only one outcome collected across two interventions (Patient health questionnaire; PHQ-9). Overall, the interventions included measures to assess employment status, the impact of MS at work, and job-seeking activities. Other outcomes referred to measures of self-efficacy, quality of life, fatigue, and mood amongst others.

#### 2.4. Discussion

To our knowledge, this is the first systematic review to identify VR interventions for people with MS and extract the main approaches, treatment components, and underlying mechanisms of the interventions.

In this review, we identified thirteen VR interventions for people with MS. There was considerable variability among the interventions in terms of content and attributes.

There were similarities across the interventions in terms of the support provided. Overall, the interventions adopted a holistic approach targeting both diseases-related, and environmental barriers such as co-workers attitudes or physical barriers (69,107,148). This approach is common in VR interventions for people with LTNC, as these conditions can progress and change over time; therefore, the workplace and their responsibilities have to be adapted to the abilities and needs of the person (60).

The interventions included a vocational assessment to understand the preferences and expectations of the person with MS. Employer engagement was also identified as a key intervention component to educate them about MS and negotiate accommodations. Employer engagement is recommended as it can help employers to be more willing to make reasonable adjustments in the workplace and improve workplace relationships (124,131). Detailed assessment of work ability was also recognised as a relevant intervention component, as this allows therapists to provide support tailored to the needs of the person with MS and identify relevant workplace modifications (77,89,131,159).

Regarding the underlying mechanisms, early intervention was recommended to remove workplace barriers before they become unmanageable and affect their overall performance at work (60,77,107,160). However, in practice there are challenges associated with early intervention as (i) there is a lack of VR services available for people with MS and (ii) it is common for people with MS to underestimate the impact of the condition on their employment, and only when a crisis arises, do they look for support (77,131,156). In fact, the majority of people are employed or studying when they are diagnosed with MS; however, they leave the workforce prematurely (4).

In the last few years, the UK Government has introduced some initiatives to support people with disabilities to RTW (e.g., Pathways to Work<sup>4</sup>, Access to Work<sup>5</sup>); however, these do not necessarily meet the needs of people with a chronic progressive neurological condition who would benefit from more long-term support to address issues as the condition or workplace characteristics change over time (60,161).

It is also worth noting that the majority of interventions were implemented in the USA. In fact, only one intervention was implemented in the UK; highlighting the lack of specialist employment services for people with MS in the UK (54).

These findings are in line with the literature available on the topic, which recognises a lack of RCT evidence to demonstrate the effectiveness and cost-effectiveness of VR interventions for people with MS (146).

#### 2.4.1. Study limitations

Unfortunately, a full description of ten interventions was not available even after contacting the authors. Because we could not access the full report of some interventions, information about the participants involved and outcomes measured

<sup>&</sup>lt;sup>4</sup> Service to support people with illness or disability to return to work.

<sup>&</sup>lt;sup>5</sup> Publicly funded employment support programme to help disabled people to remain or return to work.

were not available. We understand reporting complex interventions such as VR can be challenging, but better reporting of these interventions can help other researchers to build new interventions based on previous research (142).

Another limitation is that we did not complete a thorough search of grey literature. We only contacted the National Multiple Sclerosis Society (USA) from outside the UK to obtain further information about the interventions that we found in the searches.

#### 2.4.2. Future directions

There is a need for studies evaluating the effectiveness and cost-effectiveness of VR interventions for people with MS. Researchers should consider what are the most adequate research designs to build enough evidence about the effectiveness of these interventions before conducting further RCTs. Because the evidence about what interventions work to support people with MS at work is not clear; future research should explore what intervention components and underlying mechanisms are beneficial to supporting people with MS at work.

These interventions should be reported following frameworks that allow future researchers to understand the procedures and reasoning behind the development of the intervention. In this review, we only found enough information to complete the TIDieR checklist of three interventions.

In conclusion, this review presents an overview of VR interventions that have been implemented for people with MS. As part of the systematic review, I identified the main intervention components, and underlying mechanisms to understand how these interventions work. The term VR is broad and encompasses multiple approaches, making it difficult to compile all the evidence together.

Identifying the intervention components and underlying mechanisms is necessary to develop an intervention based on the evidence identified. The findings from this review have informed the development of the following studies and the knowledge gaps from the systematic review will be complemented with further research.

# Chapter 3: Experiences of people with MS at work: Towards the development of a job retention VR intervention

# 3.1. Chapter overview

The findings from Chapter 2 highlighted the fact that there is limited evidence about effective VR interventions for people with MS. Furthermore, poor reporting of the interventions identified made it difficult to understand the VR processes followed and intervention components.

The MRC framework recommends complementing the evidence available on a topic with further primary research to develop a theoretical understanding of why an intervention might work (133). Qualitative research methods can provide additional knowledge about the needs and preferences of the population investigated (133).

The PBA also recommends collecting qualitative data to complement the knowledge from the literature with the views of relevant stakeholders (139).

This chapter presents a qualitative study about the VR needs for people with MS and the potential barriers and enablers to an intervention targeted at supporting them in remaining in work. The findings from this study were mapped to the ICF (59) and Behaviour Change Wheel (BCW) (162). Therefore, this chapter also introduces the BCW (162).

#### 3.1.1. Behaviour Change Wheel.

The BCW is a framework that can be used to design interventions aimed at behaviour change (162). The BCW helps in understanding how an intervention should be designed to target behaviour in a given context. It has three key components (*capability, motivation* and *opportunity*) that can influence one another to produce the desired *behaviour*, known as the COM-B system (Figure 5) (162).



Figure 5 BCW Components

The diagram represents the "behaviour system" that can be modified by the interaction of the components. The direction of the arrows reflects how the components interact and affect each other (162).

In the BCW, *capability* is defined as the psychological and physical capacity that an individual has to engage in an activity. *Motivation* refers to those factors that direct a behaviour, such as the decision-making process that leads a person to conduct an activity. Finally, *opportunity* refers to those factors independent of the individual that make a behaviour possible (162). Identifying and understanding these components is key to developing interventions and removing potential barriers to increase the acceptability of the intervention.

## 3.2. Rationale

People with MS tend to become unemployed a few years after diagnosis (5). Unemployment or reduced working hours can lead to economic difficulties and negatively impact the individual's self-esteem (41). Furthermore, high unemployment increases the economic burden of MS nationally (55).

The causes of unemployment in MS are complex and caused by a mixture of disease and context-related variables (41,138). Most research to date on employment and MS has focused on barriers and facilitators to working (41,138,163–165). Sweetland et al. (2007) conducted a focus group study with people with MS to understand their preferences for VR support. Two key findings were reported, the need to manage performance at work so that people with MS can cope with the demands of their role, and the need to help employers have realistic expectations about the individual's work performance (138).

# 3.3. Aims and objectives.

The primary aim of this study is to explore the experiences of people with MS at work, and how VR support could help them remain at work. The secondary aim was to understand the barriers and facilitators to delivering the support.

This study differs from Sweetland et al. (2007) in that this study not only reports the views of people with MS, but also the views of healthcare professionals that support people with MS at work, and employers (including Human Resources, HR) who had experience working with people with MS or supporting other employers in managing relationships with their employees with MS. Furthermore, I conducted semi-structured interviews to collect in-depth information as opposed to focus groups.

To my knowledge, no study has linked the difficulties with which people with MS present at work with the support that matches their needs, and at the same time understood the potential barriers and facilitators of delivering the support. Understanding this could inform the development of interventions with increased acceptability and effectiveness.

# 3.4. Methods

# 3.4.1. Participants

I used convenience sampling to recruit participants through local charities and personal contacts. I included as participants people with MS, healthcare professionals and employers. The inclusion criteria for the participants with MS were:

- Diagnosis of MS.
- Currently employed.

The inclusion criterion for the healthcare professionals were:

• Experience working with people with MS and/or experience supporting people with MS at work.

The inclusion criterion for the employers were:

- Experience supporting line managers or employers in managing the relationships with their employees.
- Line managers.

Other inclusion criteria for all participants:

- Between 18 and 65 years of age.
- Can communicate in English.

I obtained ethical approval from the ethics committee of the Division of Psychiatry and Applied Psychology, University of Nottingham (Ethics Reference Number 0281).

# 3.4.2. Study design

I used a phenomenological approach to qualitative research conducting semistructured interviews to explore the views and needs of people with MS at work. I selected semi-structured interviews because they allow collecting in-depth information about personal experiences (166). Although more time consuming than a focus group, the conversational character of this method allowed us to explore in more detail the personal experiences and thoughts about the issue being investigated (166).

The interviews were conducted in person or via telephone according to the participant's preference. At the beginning of the interview, I presented a summary of the research study and aim of the interview to the participants. The interviews were audio-recorded, and I transcribed them verbatim. I handled the data using NVivo v.12 (167).

The topic guide of the interviews was informed by the two theoretical frameworks, the ICF and BCW. A Patient and Public Involvement (PPI) advisor was consulted about the wording of the topic guide to ensure it was written in lay language and not difficult to understand or misleading; furthermore, I used open-ended questions (where possible) to expand the range of responses participants could provide to express their experience. Appendix E presents the topic guides used during the interviews.

A member check was performed during the interviews by summarising the participant's answer and questioning the participant about the accuracy of the summary to ensure the validity of the data (168).

# 3.4.2.1. Framework Analysis

Data were analysed using a framework analysis method, selected for its suitability for research studies addressing predetermined objectives such as developing an intervention (169,170). The framework method involves five steps (familiarisation, identifying a thematic framework, indexing, charting the data, and mapping and interpretation) to analyse the data leading to a systematic and structured summary of the findings (171).

After transcribing the interviews, I read the transcripts several times and listened to the audio recordings to *familiarise* myself with the content of the interviews. While reading the interviews, I took notes when I found a key message or idea in the transcript.

After familiarisation with the interview content, I developed a *framework* to categorise the information in a meaningful way. To develop the thematic framework, I organised the data iteratively following the research objectives, headings of the ICF (59), and BCW (162). The ICF was selected to describe the impact of MS at work and the BCW to describe the barriers and facilitators of implementing the proposed VR support. Table 7 presents the coding framework for the interviews.

Code	Definition	Framework/ Rationale
Working with MS		
Activities and Participation Mobility Domestic life General tasks and demands	<ul> <li>Activity is the execution of a task or action, and participation is involvement in a life situation.</li> <li>Mobility: Changing body position or transferring from one place to another.</li> <li>Domestic life: Carrying out domestic and everyday actions and tasks.</li> </ul>	ICF

Table 7 Coding framework for interviews with rationale

Code	Definition	Framework/ Rationale
• Interpersonal	• General tasks and demands: Carrying out	
interactions and	tasks, organising routines, and handling stress.	
relationships	• Interpersonal interactions and relationships:	
• Work and	Carrying out actions and tasks required for	
Employment	interacting with people.	
• Transport to work	• Work and employment: Engaging in all aspects	
	of work (e.g., performing required tasks,	
	attending work on time, or supervising others)	
	• Transport to work: Using transportation to and	
	from work.	
<ul> <li>Body Functions</li> <li>Energy and drive</li> <li>Bladder issues</li> <li>Memory</li> <li>Attention</li> <li>Emotions</li> </ul>	<ul> <li>Body functions are the physiological functions of a body and body structures are anatomical parts of the body (e.g., organs).</li> <li>Energy and drive: Physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs.</li> </ul>	
Emotions	• <b>Bowel and Bladder:</b> Functions of eliminating	
• Pain	waste.	
• Sleep	• Memory: Specific mental functions of	
	registering and storing information and retrieving	ICF
	it as needed.	
	• Attention: Specific mental functions of focusing	
	on an external stimulus or internal experience for	
	the required time.	
	• <b>Emotions:</b> Mental functions related to the	
	feeling (e.g., fear, anxiety, joy).	
	• <b>Pain:</b> Unpleasant feelings indicating potential or	
	actual damage to some body structure.	
	• <b>Sleep:</b> Amount of sleep, sleep cycle, etc.	
<b>Environmental Factors</b>	Physical, social, and attitudinal environment in which people live and conduct their lives.	
• Products and	• <b>Products and technology:</b> Equipment and	
technology	technology in an individual's immediate	
• Relationships with	environment (e.g., assistive technology for	ICF
colleagues	employment)	
• Relationship with	• <b>Relationship with colleagues:</b> Relationships	
employer	with individuals at work who share demographic	
• Attitudes	features.	

Code	Definition	Framework/ Rationale	
• Services, systems, and policies	<ul> <li>Relationship with employer: Relationship with individuals in a position of authority who have decision-making responsibility for others.</li> <li>Attitudes: Observable consequences of ideologies that influence the behaviour and relationships between individuals.</li> <li>Services, systems, and policies: Services, systems and policies designed according to established governments that meet individual's needs.</li> </ul>		
<ul><li>Personal Factors</li><li>Acceptance</li><li>Profession</li><li>Experience</li></ul>	<ul> <li>Background of an individual's life and living and including the features of the individual that are not part of a health condition.</li> <li>Acceptance: Relates to the acceptance of the diagnosis and implications of having a chronic progressive condition.</li> <li>Profession: Characteristics of the job (e.g., office-based, organisation's culture)</li> <li>Experience: Past experiences at work that influence behaviours and ideologies of an individual.</li> </ul>	ICF	
The Intervention			
Mechanisms Components Outcomes	Drivers of the intervention that bring about a change. The mechanisms are the characteristics of the intervention that help achieve the desired outcomes. Services or support are required to help a person with MS remain at work. Behaviours or traits that the intervention aims to change	Research Question	
Barriers and Facilitators to future implementation			
Opportunity Capability	All the factors that lie outside the individual that make the behaviour possible or prompt it The individual's psychological and physical capacity to engage in the activity concerned. It includes having knowledge and skills.	BCW	
Motivation	Brain processes that energize and direct behaviour, not just goals and conscious decision-making. It includes habitual processes, emotional responding, and analytical decision-making		
Once I identified the framework, I applied the transcripts of the interviews to the categories of the framework to *index* the data. Because I used NVivo to code the interviews, after indexing the interviews I explored the relationship between the themes and the participants who mentioned the themes in the interviews. Using NVivo, I created matrices of each of the issues discussed in the interviews and have an overview of the content discussed in each theme by participants. I summarised the information included in these charts and identified the most relevant quotes from each theme. This step is known as *charting the data* and involves summarising the data of each category of the framework (169).

After charting the data from each theme identified, and understanding the data together as a whole, I *mapped and interpreted* the data to establish the relationship between the concepts and integrate the findings to answer the research questions (171).

I used Yardley's framework to maintain the quality of the data collected and analysed (172). This framework highlights the need of understanding the relevant literature (*sensitivity to context*), collect in-depth data through adequate research methods (*commitment and rigour*), present the methods and data clearly (*transparency and coherence*), and provide a discussion of the impact that the research has (*impact and importance*) (172).

### 3.5. Results

Twenty participants completed the semi-structured interview. All the participants who expressed an interest in the study agreed to participate. Interviews lasted between 35 and 70 minutes.

The participants recruited include ten people with MS, six healthcare professionals and four employers. The majority of participants (n=18) worked for a large size company (>250 employees), and only two participants worked for a medium-size company (<50 employees). Most participants worked for a public company (n=17), and only three (2 MS and 1 professional) worked in the third sector (i.e., charities).

In total, ten participants (7 women and 3 men) were included in the employers and healthcare professionals group. All participants in this group were from a white ethnic background. They were working full-time and had on average 16 (7.48) years

of working experience in their respective fields. The group included four OTs, two neurologists, one programme manager, and three HR managers (two employer relations advisors and one project manager). The demographic characteristics of participants with MS are shown in Table 8.

Participants with MS					
Demographic characteristics					
Women/men	8/2				
Age [mean (SD)]	47.5 (7.74)				
Ethnicity					
White	9				
Mixed (white-asian)	1				
MS Characteristics					
Years MS [mean (SD)]	9.51 (8.58)				
Primary Progressive	1				
Secondary Progressive	4				
Relapsing-Remitting	5				
Education Level					
Post-graduate	3				
Degree	3				
College	3				
A Levels	1				

Table 8 Demographic characteristics of participants.

The majority of participants with MS (n=8) had an office-based job, and two had a physical job (midwife, and teacher assistant). Three participants with MS were working full-time and seven part-time. Overall, they had jobs classified as professional (n=6), semi-professional (n=2) and semi-skilled (n=2) according to the Standard Occupational Classification (SOC) 2020 (173).

Below, I present the results in three interrelated sections (working with MS, VR for people with MS, and barriers and facilitators), in which nine major themes are divided, which also contain sub-themes. In total, I found 30 meaningful sub-themes which are numbered with a superscript to facilitate the reading.

### 3.5.1. Working with MS

Four themes about the experiences of working with MS were identified, and mapped to the four components of the ICF, as presented in Table 9.

ICF Component	Theme	Sub-theme	Exemplar Quotes	
Body Functions and Structures	Common MS symptoms at work	Cognition and memory problems <sup>1</sup>	"There are several quite subtle cognitive problems that are coming out [at work]. I think the fatigut seems to be the largest impact so kind of from the body level, fatigue and cognitive problems seems be the main issues [of people with MS at work]" (P13, OT)	
			"My memory is shocking, so I need to write everything down, set reminders for when to complete it." (P4, MS)	
		Fatigue <sup>2</sup>	"I have to approach my job differently because it has a real impact on my fatigue levels. I mean teaching is hard on anybody. So, I have to manage my fatigue levels at all times." (P14, MS)	
			"I do find that quite often I struggle to concentrate, and I have to take breaks, and it affects the rest of my day because I am tired." (P20, MS)	
		Physical factors <sup>3</sup>	"Before I could sit at my desk for two to three hours typing away, and then be able to go somewhere else. I can't do that now. I can sit and type for two to three hours. I can sit there on the phone, but when I get up, I can't just move, it takes a while out ofthings seem tothe way I describe it is as if me telling my legs to moveit's almost as if the message isn't getting there." (P11, MS)	
		Psychological factors <sup>4</sup>	"I have lost my confidence in doing that [work]. Because I was good at it [work]and it is just the time factor, and the fatigue." (P7, MS)	
			"Fatigue is one of the main symptoms that people with MS complain about. It is also one of the invisible symptoms, and hence, that can cause a lot of psychological distress I think in particular people feel that they do not want to be treated differently for an invisible symptom" (P10, Neuro)	
Environmental Factors	Work-related factors	Workplace characteristics <sup>5</sup>	"I have always worked 12-hour shifts, where we do not get a lunch break and stuff like that, so that side of things can be quite difficult." (P3, MS)	

# Table 9 Impact of MS at work according to ICF.

ICF Component	Theme	Sub-theme	Exemplar Quotes
	affecting performance	Co-workers attitudes <sup>6</sup>	"I think when people can see a condition it's easier for them to understand it. But when they can't see it is very difficult for them to comprehend it." (P17, HR)
		Transport to and from work <sup>7</sup>	"It is such a big building, and I am trying to get to meetings and that can be a challenge and getting myself around which it makes me tired, it makes my left leg to drag more. Which then I worry in case because I have I can fall a lot easier" (P6, MS)
Activities and participation	Support provided at work	Role modifications <sup>8</sup>	"I do not do school trips anymore, and I do not do playground dutyalso I have more of a sitting down job. I don't walk up and down the corridors all the time between classes" (P7, MS)
Personal Factors	Importance of work	Economic situation <sup>9</sup>	"I think I would personally struggle if I didn't have wages. I had to pay for accommodations and stuff, but if I didn't have a job, I wouldn't be in a very good place" (P1, MS)
		Satisfaction of work <sup>10</sup>	"For somebody with MS that is like the fatigue and the memory and the mobility, you know, yes, they are those things, but you are still a person, a working brain. But you have to work your brain I want the fatigue to come from something else [work] that I enjoy" (P7, MS)
PX= Participant 1	number, MS= Mu	ltiple Sclerosis. HR	= Human Resources; Neuro= Neurologist

### 1. Common MS symptoms

The participants discussed four aspects of their MS that caused them difficulties at work. Complaints suggestive of *cognitive deficits*<sup>1</sup> were common among participants with MS. Problems with memory were the most prevalent, but several people were using techniques to manage these difficulties. The presence of *fatigue*<sup>2</sup> at work also made the participants concerned about their ability to meet deadlines and complete their work.

*Physical factors*<sup>3</sup> such as numbress and stiffness were reported as impacting their workday, with the most common complaints being difficulties using their hands or increased pain after a day of sedentary work.

The increased difficulties at work, the unpredictability of MS, and thoughts about the future made the participants feel anxious or depressed. The participants considered these *psychological factors*<sup>4</sup> as affecting their work performance.

2. Work-related factors

Environmental factors appeared to interact with MS symptoms facilitating or hampering performance at work. Participants reflected on the environmental factors affecting their performance.

Workplace characteristics<sup>5</sup> sub-theme encapsulated several participants' experiences of the physical and environmental obstacles they face when conducting their work duties such as attending a meeting in a distant conference room or being productive at work while experiencing intense pain. This sub-theme also encapsulated issues managing high workloads and lack of flexibility in the workplace leading to a worsening of MS symptoms. This was reflected in a trend across participants to move from smaller companies, or physically demanding jobs, to office-based jobs in larger companies.

The second sub-theme identified was *co-workers' attitudes*<sup>6</sup>. Participants with MS felt that one of the greatest problems they faced at work was the lack of understanding about MS by those around them (e.g., colleagues, line managers). Their experiences were in line with the views of the HR professionals, who mentioned how the "visibility" of the condition played a crucial role, as people with more obvious

symptoms (e.g., mobility problems requiring wheelchair use) were better supported than those with invisible symptoms (e.g., fatigue or pain).

*Transport to and from work*<sup>7</sup> was seen as a problem. For some, travelling to work, finding parking, and/or work schedule (e.g., leaving the workplace late at night) were challenging and exhausting tasks.

### 3. Support provided at work

Participants described how they had received *role modifications*<sup>8</sup> such as reducing working hours, reducing the number of physical activities at work, or even flexibility to work from home when required. These modifications were implemented to help them manage their condition at work.

Those with a better relationship with their line manager or well thought of at work were relatively satisfied with the modifications received at work, as their employers seemed to be more accommodating. Unfortunately, even those who were managing their condition well at work felt that they had fewer opportunities to progress in their career because of MS.

4. Importance of work

I elicited two sub-themes regarding the importance of work. The *economic situation*<sup>9</sup> of the person with MS was seen as important, as they were concerned about the minimum number of hours, they needed to work to cover their needs. Also, although they faced challenges at work, the *satisfaction of work*<sup>10</sup> and the social aspect of work was a positive aspect of their lives, therefore, they wanted to remain employed for as long as possible.

#### 3.5.2. VR for people with MS

After discussing the experiences and challenges at work of people with MS, I asked the participants what type of support people with MS and their employers require to support the person with MS to remain at work. A summary of the themes identified regarding the VR needs of people with MS is presented in Table 10.

Table 10	<b>Characteristics</b>	of VR for	people	with MS

Intervention Attributes	Themes	Supporting Quotes
Intervention Components	Education <sup>11</sup>	"Some of the [VR] intervention has to be around education, about MS, the impact of MS and again that might be for different stakeholders, obviously for the person with MS and their family, and their employer, but it might be educating their GP" ( <b>P2, OT</b> )
		"For me, it [the VR support] just starts with awareness; I think there is a real lack of awareness or knowledge [from employers] of certain conditions but also how those conditions play out in reality." (P18, HR)
	Employer engagement <sup>12</sup>	"Having the managers understand what MS is and then look at the ways that they can have you at work. Because MS isn't, right, everybody is in a wheelchair, everybody has bladder issues, everybody gets the fatigue, and is not, and I think this is the problem when people don't realise that MS is very personal." ( <b>P6, MS</b> )
		"Sometimes we [MS neurologist] do a letter to explain to the employer what their [the person with MS] needs are or what to expect or not to expect from them [at work]. So it is more like a support letter to help the employer to understand more and show more support to the patient." (P12, Neuro)
	Reasonable accommodations <sup>13</sup>	"I am not sure what [VR support] is available my employer has asked me what support do I need [at work] but I don't know what to tell them" ( <b>P4, MS</b> )
		"I think having that flexibility to say tomorrow, I just can't come in because I am too tired. Or I am going to come in later on today [to work]. You know flexibility around the hours that you work would be a huge help [to manage MS at work]" ( <b>P15, MS</b> )
	Symptom management <sup>14</sup>	"We did a lot of fatigue management; we looked at symptom management, so sometimes we will refer them [the people with MS] back to the nurses for issues." ( <b>P5, OT</b> )

Intervention Attributes	Themes	Supporting Quotes
	Support with disclosure <sup>15</sup>	"When people get diagnosed, they might go to their workplace and disclose to their employer. They are going back to their work and they are like "oh, I got MS", and then the moment you share that [the diagnosis], you can't take it back" ( <b>P5</b> , <b>OT</b> )
		"I didn't know [what support I needed] until I started having problems. There is all sort of things that they can do [to support people with MS at work], and I never knew that. Andthen I am going to say support with how you tell [the diagnosis of MS] your colleagues?" ( <b>P16, MS</b> )
Attributes	Early intervention <sup>16</sup>	"I think that [providing VR support soon after diagnosis] is crucial as soon as you are diagnosed. You can go to google and get lots of rubbish information, but if you are told to go to one or two places That [support] is crucial, everything to somebody that is newly diagnosed" (P1, MS)
		"The format of the MS clinic is that we offer yearly reviews to the MS patients, so it [employment] is not something that it will be discussed at first diagnosis generally, because there is a lot of clinical information to get across, and treatment decisions need to be made" ( <b>P10, Neuro</b> )
	Timely support <sup>17</sup>	"I think self-referral would be good. Because a lot of time patients do have to wait to see a clinician [to address clinical problems]" (P12, Neuro)
		"People need to be able to access it [VR support] at different time points, they need to be able to frequently access the service because things [employment situation or problems at work] might change with time." ( <b>P8, OT</b> )
	Tailored support <sup>18</sup>	"So, people with MS are all unique they can present a variety of symptoms that require you [the therapist] to have a variety of different solutions in terms of VR program. So, this [intervention] can't be one-size-fits-all." ( <b>P9, PM</b> )

Intervention Attributes	Themes	Supporting Quotes
		"There is no shortage of information outside [about support with employment]. But we have to make it accessible and helpful and just find it quickly and easily" (P19, HR)
Intervention outcomes	Job retention <sup>19</sup>	"I think the easiest outcome [of VR] is if someone maintains the job, but I think there are bigger outcomes than that. So do people maintain a sense of self-worth, do they feel valued, I do not know how you measure this, but are they knowledgeable and equipped to self-manage in the future." ( <b>P5, OT</b> )
	Improved work experience <sup>20</sup>	"That is what you want [when working], job satisfaction. To realise that just because you sit in a chair all day you are doing a worthwhile job" ( <b>P7, MS</b> )
	Psychological outcomes <sup>21</sup>	"I think [the most important outcome of VR is] becoming more confident overall. Their confidence to manage themselves in the workplace and at home, but this is VR so at the workplace mostly. And a sense of quality of life" ( <b>P2, OT</b> )
	Goal attainment <sup>22</sup>	"That the person has met the goalswell that would be the main thing [of the intervention], that they met the goals." ( <b>P2, OT</b> )
PX= Participant nu Neuro= Neurologis	mber; VR= Vocational R st.	Rehabilitation; MS= Multiple Sclerosis; HR= Human Resources; OT= Occupational Therapist; PM= Programme Manager;

### 1. Intervention Components

Five main intervention components of VR for people with MS were identified. The participants felt that *education*<sup>11</sup> for both the person with MS and their co-workers should be included to raise awareness about the impact of MS at work, invisible symptoms, and support available.

The data suggested that *engaging the employer*<sup>12</sup> in discussions around MS and the support they can provide to their employee was an important part of VR. The healthcare professionals explained that this may be beneficial for a long and prosperous relationship between employer and employee. Employers were keen to receive information about *reasonable accommodations*<sup>13</sup> that their employees may need.

The data suggested including *symptom management*<sup>14</sup> in the intervention to support the person with MS to manage pain, cognitive deficits, and fatigue. Although the participants had disclosed their condition to their employer, they explained how *support with disclosure*<sup>15</sup> can be beneficial to empower the person with MS in the decision.

2. Attributes

The data suggest that providing support with employment and raising awareness about support available for people with MS at work should occur soon after diagnosis *(early intervention<sup>16</sup>)*, as it is crucial to identify early those environmental factors or MS symptoms that might become a barrier to job retention. Furthermore, the participants explained the need for support to be *tailored<sup>17</sup>* to the needs and experiences of each individual.

Along similar lines, the healthcare and HR professionals identified the need for *timely support*<sup>18</sup>, to address issues as they appear and which was responsive, including having reviews because the individual's needs changed.

### 3. Intervention Outcomes

When discussing the appropriate outcomes, it was clear that *job retention*<sup>19</sup> was the overarching goal of the VR intervention. However, some participants (the OTs) discussed how people with MS might benefit from reduced hours or finding a job

that better matched their needs. Therefore, the data suggested other outcomes that could be equally beneficial.

*Improving the work experience*<sup>20</sup> was considered crucial for job retention. The participants saw this outcome as a combination of better relationships in the workplace and improved self-efficacy to address workplace barriers.

Improving *psychological outcomes*<sup>21</sup> was also seen as key for job retention, with a focus on improved mood, quality of life, and work self-efficacy.

Finally, the participants discussed the challenges of measuring the impact of these interventions. For this reason, they believed that including *goal setting*<sup>22</sup> could be beneficial to target and identify areas that are important for them as an individual.

### 3.5.3. Barriers and facilitators

At this point in the interviews, the participants discussed employment problems and recommended support that meets the needs of people with MS and their employers. Taking this into consideration, participants were asked about the barriers and facilitators to implementing the support. A summary of the barriers and facilitators are presented in Table 11.

Themes	Classification	Sub-Themes	Supporting Quote
External factors	Barriers	Lack of resources <sup>23</sup>	"It's just general availability [of VR support], there isn't much therethen lots of the community teams, they do not provide VR. Although only provided if people are referred for something else, and they might discuss it with them maybe a little bit, but they will not necessarily accept a referral kind of purely for that (employment issues)." (P8, OT)
		Employer's approach <sup>24</sup>	"An added complication [at work] is that people don't always have one direct manager who takes the responsibility for them. So, they might have a manager over here that supports them with this bit and a manager over there who supports them with that bit. When it comes to who do I need to tell about this [a work issue] and who is going to take the responsibility, and ownership to help me with this, which can cause complications. And when it becomes tricky there is deflection: "Oh, I didn't know that was my responsibility." (P17, HR)
	Facilitator	Flexible support <sup>25</sup>	"Whenever I went somewhere and I saw leaflets about MS, I pick them up, and I've read every one that I've got. There is more in there that I can relate to if I'm honest. And I think it is because there is such a broad range of [symptoms] in the population thatit's not just one simple pointing thing saying this [symptom] is going to happen." (P11, MS)
		Safety net <sup>26</sup>	"You've got to have some sort of safety net during the initial assessment process, that picks up on does that individual have additional support needs? And there has to be something in place to support that individual, then you can refer them within the program or within the suit of services that the organisation is operating." ( <b>P9, PM</b> )
Individual's characteristics	Barriers	Coping mechanisms <sup>27</sup>	"Interviewer: what would stop people with MS from participating? Participant: Probably pride, maybe a misplaced understanding, that they know everything, and they do not need to be told anything else" ( <b>P1</b> , <b>MS</b> )
		Worsening of MS symptoms <sup>28</sup>	"Interviewer: What would stop people with MS from participating? Participant: If they are feeling generally unwell." (P4, MS) "A potential negative effect is that you've got a therapist that is dead keen to keep somebody in work. And so that might cause more stress [to the person with MS] and then that lead to potentially more frequent relapses for somebody." (P2, OT)

Table 11 Barriers and facilitators to future implementation.

Themes	Classification	Sub-Themes	Supporting Quote
		Consequences of the intervention <sup>29</sup>	"The only thing is that I want this [the intervention] to be confidential. So, there is no repercussion" ( <b>P7, MS</b> ) "The things that might get on the way might be the people's perception that this service is forcing people to stay at work or forcing people into work, that in some way is connected to welfare benefits claims, I can see that being suspicious for some people, and then not being able to get help." ( <b>P2,</b> <b>OT</b> )
	Facilitators	Managing expectations <sup>30</sup>	"It is not guaranteed when someone moves on to one of this [VR] programs they will move into permanent employment, they will not face additional challenges in the workplace going forward, and you must be very mindful of building up somebody's expectations too high and then not be able to deliver on that." ( <b>P9, PM</b> )
PX= Participant nu	umber, MS= Multipl	e Sclerosis, HR= Hum	han Resources, OT= Occupational Therapist, PM= Programme manager, VR= Vocational rehabilitation.

### 1. External Factors

Several participants reported how external factors can facilitate or hamper the implementation of VR support for people with MS. The main barrier identified to deliver this support was the *lack of resources*<sup>23</sup> such as funding, multidisciplinary teams, and staff to follow-up the clients. This also encompasses the lack of an experienced therapist aware of the support available.

The *employer's approach*<sup>24</sup> and relationship with the employee are relevant here as some employers might feel forced to participate or unwilling to accommodate the needs of the employee.

Participants believed that providing *flexible support*<sup>25</sup> in the intervention could overcome these barriers. These could involve signposting the participant to relevant resources when the support is not easily available, and reducing the interference of the intervention with the work or personal commitments of the person with MS. The participants also believed that there should be a *safety net*<sup>26</sup> to identify issues early and refer people with unmet needs to organisations that provide more specialised support.

### 2. Individual's characteristics

The participants described how their circumstances and views could impact the intervention. The main barrier was maladaptive *coping mechanisms*<sup>27</sup>, as this may lead to people having unrealistic expectations of the intervention or even reject the support.

The data also suggested that *worsening of MS symptoms*<sup>28</sup> such as a relapse or being too fatigued to participate could act as barriers to job retention.

Finally, participants reported a fear of the *consequences of the intervention*<sup>29</sup>. This could make people reject the support for fear of losing benefits or the employer becoming aware of their needs. Therefore, it was seen as important that the therapist can *manage expectations*<sup>30</sup> of both the employer and employee to ensure they understand what can be achieved with the intervention and the amount of support required to address the problems.

### 3.6. Discussion

This study explored how MS symptoms, co-worker attitudes, and physical barriers led to challenges at work for people with MS. The findings of this study also highlight the need for VR support for both people with MS and their employers to help them better understand (and/ or self-manage) their condition, manage workplace relationships, develop employers' knowledge and confidence in managing the person with MS.

Currently, there is a lack of provision of VR services in the UK for people with LTNC (174). The participants with MS had not previously received VR support, despite feeling that it would have been beneficial to them.

These findings align with the literature that underlines that work can be beneficial for the health and wellbeing of a person (110). The participants with MS considered employment as a highly important part of adult life. Not only economically but also socially (e.g., interacting with other adults) and cognitively (e.g., mentally challenging and rewarding). The participants with MS acknowledged that a good reputation at work led to their employer being more accommodating, which has been reported elsewhere in the MS and employment literature (41).

In terms of MS symptoms, concerns about cognitive deficits and fatigue were mentioned by most participants with MS. Thus, VR interventions should address these concerns, as fatigue is one of the major factors leading to work-related difficulties and change in work status (e.g., reduced working hours) for people with MS (41).

Regarding the implementation of reasonable accommodations, there are a large number of professionals involved in recommending reasonable accommodations, such as HR, OH, or OTs. Some employers asked the person with MS what support they needed at work; however, people with MS do not always know what support they might need at work or what sorts of things they could ask e.g. in terms of flexible or home-based working, equipment, or adaptations. This approach to reasonable accommodations seems problematic as the professionals making the decisions might not be aware of the nuances and fluctuating nature of MS.

Interestingly, HR professionals were focused on the physical aspects of work such as providing ergonomic and workplace accommodations; however, people with MS were more troubled by the attitudes and support they received from their co-workers. This is reflected by the fact that most of the participants with MS had already had workplace modifications, however, they complained about the lack of understanding from their co-workers. Therefore, educating employers and co-workers about MS could help them better understand the impact of MS at work, and by extension create a more supportive workplace.

Participants discussed the possibility of engaging the employer in the intervention. There is evidence that involving the employer or a colleague of a person with MS in the intervention can be beneficial for the person with MS because it raises awareness of the condition, the hidden nature of some symptoms (e.g., sensory impairments), and how the condition fluctuates (53). This has also been found to be beneficial for other long-term conditions such as spinal cord injury (175), stroke (176), and traumatic brain injury (177,178).

The findings suggest that when understanding the problems someone with MS faces at work, it is important to understand the workplace characteristics. Sometimes, the culture of an organisation that promotes competition or tight deadlines can exacerbate MS symptoms. Another factor to take into consideration is the size and the type of organisation, as some employers may not have the resources or infrastructure to support people with more complex needs. Some participants with MS were working in an environment where colleagues or line managers were not aware of what MS is and how it affects a person. For this reason, they were keen to have the option of contacting an expert in MS to explain the array of symptoms that MS causes to their employers and colleagues. The healthcare professionals also highlighted the need to create a supportive environment in the workplace. This finding supports previous research into VR and MS highlight the relevance of addressing complex issues through a collaborative approach (138).

To date, there is inconclusive evidence about the effectiveness of VR for people with MS (146), potentially due to the lack of RCTs and longitudinal studies assessing the impact of these interventions, and the progressive character of MS, as people with MS may need different support at different time points (146). Unfortunately, as the

participants in this study reported, the accommodations implemented for people with MS are rarely reviewed over time to map the progression of the condition.

All participants had disclosed their condition to their employer, but very few had disclosed to their colleagues. Furthermore, those who had disclosed their condition to their employer had not explained to their employer how MS impacts their work (and vice versa). Therefore, support with disclosure should be included in the intervention. Evidence from VR for people with mental health issues recognises that explaining how the condition impacts the performance at work can be a facilitator to support a person to remain at work (179).

The findings of this study also highlighted the main mechanisms of VR. Interestingly, the mechanisms discussed by the participants align well with the BSRM recommendations for VR for people with MS, that highlight features such as early intervention, rapid response, open access, and individualised support (60). *Early intervention*, should be a top priority of the intervention because some people experience MS symptoms even a few years before they are diagnosed (180). The second mechanism is associated with *tailored support*. Due to the variability in symptoms, the culture of the company and the person's responsibilities in the workplace, the intervention needs to be tailored to the needs of the person with MS. Furthermore, employers and people with MS need to receive information that relates directly to them to increase their willingness to participate. The last mechanism referred to was *timely* support; due to the progressive character of the condition, people with MS present changing needs in the workplaces, which should be reviewed periodically. However, the main barrier identified in this study was the lack of resources, such as funding or multidisciplinary teams to deliver VR support, which is widely acknowledged in the literature as essential for people with LTNC in the UK (181).

Finally, the participants were flexible in their views about where the intervention should be delivered, suggesting a combination of remote intervention complemented with meetings in person. However, when discussing the location of the sessions, all participants agreed that this should not be conducted in a clinical setting such as the hospital. The practicalities of going to the hospital, along with the emotional attachment of being in a hospital made the participants reject this as a potential

setting for the intervention. This finding aligns with previous research that suggests that the best context to deliver VR interventions is the workplace and not in a medical clinic (182).

#### **3.6.1.** Limitations

These findings should be considered in terms of the limitations of the study. One limitation is the lack of variability across participants. Even though twenty participants were included, I only recruited four employers, and the group of healthcare professionals only represent the views of Neurologists and OTs. The study would have benefited from including the views of other healthcare professionals such as GPs who issue fit notes<sup>6</sup> (116) and provide advice regarding RTW after a relapse, or relevant stakeholders from DWP services such as Jobcentre Plus or Disability Employment Advisors. The reason why the sample of healthcare professionals does not represent the larger multidisciplinary team of MS experts is that OTs were particularly keen on participating in this study and I did not receive responses to participate in the study from Nurses or Psychologists, potentially because employment might not be directly aligned with their expertise.

Another limitation refers to the participants with MS included since most participants with MS from this study were diagnosed with MS several years ago, there was a lack of diversity in terms of ethnicity and socioeconomic status, only two participants had a physical job, and several had received ergonomic modifications in the workplace. For these participants, the main challenges at work were associated with their colleagues' and employers' attitudes. Had the sample also included newly diagnosed or unemployed participants, the results may have highlighted different employment issues such as discussion around disclosure or understanding different career paths or career progression. However, this study aimed to gather information to develop a job retention intervention; hence, the participants included were employed. Another limitation is the fact that all participants with MS were working in the public sector, and I could not recruit participants from the private sector. Those employed in the private sector may face different and unique challenges (90).

<sup>&</sup>lt;sup>6</sup> Note written by doctors providing advice about the fitness for work of a person.

# 3.7. Conclusion

The findings from this study suggest that VR interventions for people with MS should offer individually tailored, re-accessible support, and a collaborative approach. The aim should be to remove barriers before they appear to prevent difficulties at work from evolving into a more complex situation. To achieve this, the employer and/or colleagues of the person with MS should be included in the intervention. Furthermore, to improve the management of MS, healthcare professionals should record a patient's employment status routinely to identify those in need of support soon after diagnosis.

Finally, information and resources about working with MS should be provided even to those who do not experience problems at work, so they can start thinking about what could happen in the future, provide them with the skills to identify barriers before they appear, and signpost them to resources and/or people offering support to address them.

# **Chapter 4: Development of a VR intervention**

# 4.1. Chapter overview

In this chapter, I present the development of a job retention VR intervention for people with MS following the recommendations of the MRC framework and the PBA (133,140). The MRC framework does not provide sufficient information to guide intervention development; therefore, I complemented it with the PBA.

The intervention was developed through a complex, dynamic, and iterative process to ensure data from different processes are collated to refine the intervention as new information appears, as presented in Table 12. This table was adapted from the manuscript by Yardley et al. (2015) to reflect how the PBA was mapped to the different stages of this PhD thesis.

Intervention development stage	Output	Person-based approach process	Complementary activities	Chapter
Planning	Identify problems that intervention must address and needs of people with MS at work	Qualitative research with relevant stakeholders	Review previous evidence	Chapters 2 & 3
Design	Guiding principles	Develop guiding principles	Develop intervention logic model	Chapter 4
Development and evaluation of acceptability	Evaluate intervention and refine based on user's feedback	Mixed-methods case study to evaluate intervention	Mixed methods evaluation of acceptability and feasibility	Chapter 5

### Table 12 Overview of Person-based approach.

Because at the inception of this thesis I did not know the interventions that had been previously developed to support people with MS at work; I first conducted a review of previous evidence of the literature of VR for people with MS (Chapter 2) before collecting further qualitative evidence of the experiences of people with MS at work (Chapter 3).

# 4.2. Logic Model

In line with the MRC framework, the final step of the development of a preliminary intervention involves modelling the processes and outcomes of the intervention before implementing it (133). I used the logic model development guide from Kellogg et al. (2004).

A logic model is a visual representation of the intervention to describe how the intervention will work in practice (183,184). The logic model depicts the resources needed to carry out the activities of the intervention, as well as understand how the activities will lead to the desired change (184). The logic model has five elements:

- <u>Resources:</u> Refers to all the resources (experts, organisations, and community resources) available to conduct the planned activities (184).
- <u>Activities:</u> This component comprises the process and actions that are part of the intervention.
- <u>Mechanisms</u>: The logic model presents the changes that the activities should cause to achieve the desired outcomes of the intervention. Identifying these mechanisms was quite complex, but they are the key to understand how the intervention works. At the same time, if the intervention is not effective, the mechanisms can be refined to learn what did not work (185).
- <u>Outcomes</u>: The outcomes are those changes caused by the intervention.

# 4.3. Aims and objectives.

This study aimed to develop a job retention VR intervention based on extant literature and stakeholder involvement. To achieve this, I developed:

- 1. Guiding principles that summarise the objectives and key features of the intervention following the PBA.
- 2. Logic model of the preliminary intervention visually describing how the intervention works.

### 4.4. Methods

The intervention was developed in two phases. Phase 1, focused on the development of guiding principles and intervention logic model based on the findings from the systematic review (Chapter 2) and qualitative study (Chapter 3).

Phase 2 involved collecting further stakeholder feedback to refine the guiding principles and intervention logic model.

### 4.4.1. Methods Phase 1

Before intervention development, I combined the information from the systematic review and the qualitative study to identify knowledge gaps in terms of intervention components and attributes.

### Development of guiding principles

Following the steps of the PBA, I formulated guiding principles to support and inform the development of the intervention. The guiding principles were made of two elements, the *intervention design objectives* and *features* to achieve the objectives (139). The *objectives* were selected according to the needs identified that people with MS and their employers experience in the workplace, as discussed by the stakeholders in the interviews (Chapter 3). The *features* were those characteristics that the intervention should have to help people with MS to remain at work (140). The guiding principles were refined as the intervention development progressed to ensure they capture the main issues identified as new information appeared.

#### Intervention Logic Model development

The logic model was developed at this stage to plan and design the structure of the intervention and understand how the different components will integrate (184).

To develop the logic model, I reviewed the information available about the activities that should be included in the intervention, these were identified in the guiding principles, qualitative study, and findings of the systematic review. This was followed by planning the resources that are required to conduct the activities, as well as understand which resources were available in our context. Once the information about the activities and resources was clear, the next step involved describing the outcomes of the proposed activities based on the outcomes identified in the previous two studies. This was done through an iterative process that led to changes in the logic model as the intervention evolved.

The final step involved identifying the outputs that are the direct result of the activities of the intervention. These outputs appear in the logic model as the mechanisms of the intervention.

### 4.4.2. Methods Phase 2

The second phase of intervention development involved refining the guiding principles and intervention logic model based on feedback from stakeholders.

Participants were recruited using convenience sampling through personal contacts. The same inclusion and exclusion criteria of the qualitative study were applied to the stakeholders. Participants included those who participated in the qualitative study and requested an update on the findings from the interview; and healthcare professionals with an interest in employment and MS.

Because NHS professionals from personal contact were included in this stage, I completed the Health Research Authority (HRA) self-assessment to identify the need for NHS ethical approval, and the assessment reported that there was no need for NHS approval. No personal data were collected apart from publicly available data (e.g., name, job title), the issues discussed were not sensitive or confidential, and there was no risk for potential disclosure or reporting obligations. Therefore, this study did not require formal ethical approval.

Before the discussion, the participants received a document describing the intervention and the logic model to familiarise themselves with the content. The discussion was conducted in person or via telephone according to the preference of the participants, and the discussions lasted between 40 to 60 minutes. I took notes during the discussion to keep a record of the ideas discussed.

On the day of the discussion, participants were presented with a short description of the research findings and intervention. The discussion aimed to guide the participants through the stages of the intervention describing the following sections:

- Delivery mode and intensity of the intervention (e.g., how many hours, where)
- Intervention components (e.g., identifying reasonable accommodations)
- Relevant outcomes (e.g., improved relationship with employer)
- Guiding principles and logic model

The participants were asked about their views and gaps in the intervention. These gaps could be in terms of missing components or attributes of the intervention that should be included to achieve the desired outcome.

After discussing the intervention, the logic model was presented. Each component was first described to facilitate the understanding of the participants. Then, participants were asked about their views of the logic model. The final intervention is reported following the TIDieR checklist.

# 4.5. Results

# **4.5.1.** Intervention Development (Phase 1)

The following section describes the Phase 1 guiding principles and logic model.

# 4.5.1.1. Identifying guiding principles

The primary objective of the intervention is to support people with MS to remain at work for as long as they wish. During the qualitative study (Chapter 3) I identified the target behaviours that the intervention aims to address. The design objectives and key intervention features to address the target behaviours were developed based on evidence from the literature (Chapters 1 and 2). The target behaviours identified were the following:

 An interaction between MS symptoms, environment and workplace characteristics can create barriers that hamper the performance of the person with MS at work (186). The mismatch between the capacity of an individual and the job requirements is known as "work instability" (WI) (187). Research has shown that people with higher "work instability" are at risk of losing their jobs (188,189). Therefore, the intervention should aim to reduce WI levels.

- 2. Overall, there is a lack of awareness about MS, legal rights, and how to manage MS in the workplace. It is common for people with MS to not seek support at work until the problems are too difficult to manage (77,180). Recent figures show that more than a third of people with MS keep their diagnosis secret from their employer for fears of discrimination or the impact it would have on their career (190). On similar lines, colleagues and employers do not fully understand the array of MS symptoms, especially those that are not visible (e.g., fatigue, physical pain) (191). Therefore, the intervention should educate people with MS and their employers on relevant topics and help them self-manage symptoms.
- 3. VR interventions for people with MS are characterised by high drop-out rates (148). Common reasons for dropping out are high level of disability and high workload or stress at work (148). Therefore, the intervention should offer flexibility on the timing and delivery of the intervention to facilitate the participation of people with MS in the intervention.

Taking into consideration the aforementioned information, I developed the Phase 1 guiding principles presented in Table 13.

Target behaviour/ Problematic behaviour	Design objective	Key intervention features		Supporting evidence
The experiences of people with MS at work are different according to their MS and work environment.	To improve the work ability of employed people with MS	<ul> <li>Provide support tailored to the needs of each person.</li> <li>Provide support soon after diagnosis.</li> <li>Prioritise relevant/urgent issues.</li> </ul>	•	<ul> <li>VR interventions for people with long-term neurological conditions and by extension MS need to be individually tailored due to the variability on employment and disease-related factors causing difficulties at work (60).</li> <li>Early intervention is recommended for people with chronic illness can be understood as providing support soon after diagnosis or before a crisis arises (6,77,148,154,160,180).</li> </ul>
			•	Urgent issues should be prioritised in the intervention to reduce work instability (60).
People with MS are not always aware of the support they need at work or their legal rights at work.	To empower people with MS at work	<ul> <li>Inform and advise people with MS about topics such as disclosure and legal rights.</li> <li>Educate people with MS about strategies to self-manage MS symptoms (e.g., fatigue).</li> <li>Educate people with MS,</li> </ul>	•	Educating the person with MS about their legal rights and symptoms will empower them to address future problems at work (77,192). Symptom management is a common intervention component to help the person manage their condition at work (130,138).
		employers, and colleagues about MS.	•	Employer engagement has been recommended for these interventions and can lead to improved workplace relationships (6.131).

### Table 13 Guiding Principles Phase 1

Target behaviour/ Problematic behaviour	Design objective	Key intervention features	Supporting evidence
Lack of time as a result of high workload, family responsibilities, and impact of MS symptoms can hamper the participation of people with MS in the intervention.	To facilitate participation in the intervention	<ul> <li>Flexible support including <i>face-to-face</i> support plus <i>telephone</i> and/or <i>email</i> contact.</li> <li>Appointments are booked according to the person's availability.</li> <li>Re-accessible support.</li> </ul>	<ul> <li>Telerehabilitation is an acceptable method to support people with MS with employment (127,129).</li> <li>People with MS should be able to access the VR intervention as required without having to request additional referrals to the intervention (60).</li> </ul>

### 4.5.1.2. Developing a Logic Model

This section presents an overview of the key elements of the logic model:

1. <u>Resources:</u> For this intervention, the essential resources are the employed person with MS and a therapist with experience working with people with MS and delivering VR to deliver the intervention. To recruit people with MS for the intervention, they need to be aware of the existence of this support. Therefore, as resources in the logic model, I included local charities and relevant clinical areas where information about the intervention can be advertised.

Employer and colleagues have also been included as resources because involving them in the intervention can be beneficial to improve the work situation of the person with MS. The rest of resources are related to information about services available and informational resources that can be useful to support the person with MS at work.

2. <u>Activities:</u> The activities included in this logic model present what the intervention entails. The first step involves identification of potential users. This is followed by a detailed assessment of personal circumstances and assessing further needs, as some people will need to be referred to other specialists. The intervention will target the needs identified in the initial assessment, and intervention components (activities) will vary according to the needs of the person with MS. The final stage of the intervention involves signposting the person with MS to relevant organisations that provide further support. This stage was included because some people might have unmet needs at the end of the intervention.

3. <u>Mechanisms</u>: For this intervention, the main mechanisms identified were around early intervention and increasing awareness of the person with MS and the employer. It is also important that this intervention focuses on collaboration between the person with MS, employer, and therapists, as this can increase the likelihood of achieving the intervention outcomes. A good relationship between therapist and person with MS, as well as a therapist capable of managing the expectations of what can be realistically achieved in the intervention, are also key mechanisms of the intervention.

4. <u>Outcomes</u>: The primary outcome of this intervention refers to supporting the person with MS to remain at work for as long as they wish. However, measuring job retention can be challenging due to the timeframe available to measure this outcome. Other relevant outcomes that are easy to measure and can be evaluated in a short timeframe have been included in the logic model as relevant indices of the effectiveness of the intervention. These outcomes target achieving work-related intervention goals set by the person with MS and improving functional outcomes.

The preliminary Phase 1 logic model is presented in Figure 6.

Resources	Activities	Mechanisms	Outcomes
Assistant Psychologist (AP)	Identify employed person with MS and refer to intervention	Trust between AP and person with MS	Person with MS remains employed
Employed person with multiple sclerosis	AP screens person with MS for eligibility	AP understands impact of MS at work and identifies useful	Person with MS meets intervention goals
(MS)	AP assess current work situation, needs at work, and set intervention goals	strategies to reduce the impact of MS	Improved emotional well- being
to share information about the intervention	Person with MS that requires psychological support or report cognitive problems is referred	Newly diagnosed person with MS understand what to look for in the future	Improved quality of life
Employer and colleagues willing to support the person with MS at work	to relevant organisations		Reduced fatigue
	AP delivers flexible and tailored support to the needs identified in the assessment	Person with MS understands impact of MS at work and coping strategies	Reduced risk to lose job and improved productivity
MS services to refer the person with MS	AP provides education and advice to the person with MS about working MS, legal rights, fatigue, and disclosure	Person with MS aware of support available and how to access it	Participant able to manage workplace difficulties (self- efficacy)
Signposting leaflets		Employer and colleagues aware of	
	AP and person with MS communicate throughout the intervention to solve queries and track progress AP provides education to the employer or colleagues as to how to support the person with	impact of MS and support the person with MS at work	employer and employee
		Managing expectations of person	Employer better informed about how to support the person with MS at work
		with MS and employer	
	MS at work	Early intervention	
	AP signposts participant to relevant organisations and local and national resources		

Figure 6 Logic Model Phase 1

### **4.5.2.** Intervention Development (Phase 2)

Hitherto, I have described the processes that led to the development of a preliminary guiding principles and logic model, which were used to develop a preliminary version of the intervention.

The following section of the chapter describes Phase 2 of intervention development. This phase involved presenting the intervention to relevant stakeholders to refine the guiding principles, logic model, and preliminary intervention. This part of the study was also used as an opportunity to conduct a members check of the themes identified in the qualitative study to achieve validity, as several participants from the qualitative study were also involved in this stage of the study.

The next step following the PBA involved refining the intervention with stakeholders' feedback. This step was necessary to ensure the processes of intervention development were thorough and to reduce the chances of developing an intervention that is not feasible and by extension less effective.

### 4.5.2.1. Participants

Ten participants (8 women, 2 men) were recruited for this study, including three people with MS and seven healthcare professionals (6 OTs, 1 Neurologist). Half of the participants included in this study were recruited from the previous qualitative study (Chapter 3). Five further participants from the qualitative study were contacted but did not participate in the study because they were not available (n=1) or were lost to follow-up (n=4).

### 4.5.2.2. Guiding principles Phase 2

At this stage, the stakeholders noted the relevance of relationships with co-workers (including the employer) on the job performance and satisfaction of the person with MS. This issue was previously included as part of the design objectives, but the stakeholders explained that it should be a separate issue. Therefore, the guiding principles were refined to incorporate this change.

A further target behaviour for the intervention was identified in the discussions with stakeholders. It refers to the fact that few people with MS are not always aware of reasonable accommodations that could facilitate their work performance. There is also a lack of awareness about the support available to remain at work, as well as the legal responsibility of the employer of a person protected by the Equality Act 2010 (119).

On similar lines, employers commonly request support from OH (where available), where the professionals might not understand the nuances of MS, and might provide advice that only partially addresses the needs of the employee with MS. Therefore, the participants explained the need for education about the Equality Act 2010 (119), and support identifying and requesting reasonable accommodations.

The phase 2 guiding principles are presented in Table 14.

Target behaviour/	Design objective	Key intervention features		Supporting evidence
The experiences of people with MS at work are different according to their MS and work environment.	To improve the workability of employed people with MS	<ul> <li>Provide support tailored to the needs of each person.</li> <li>Provide support soon after diagnosis.</li> <li>Prioritise relevant/urgent issues.</li> </ul>	•	<ul> <li>VR for people with MS needs to be individually tailored due to the variability in employment and disease-related factors causing difficulties at work (60).</li> <li>Early intervention is recommended for people with chronic illness can be understood as providing support soon after diagnosis or before a crisis arises (6,77,148,154,160,180).</li> </ul>
			•	Urgent issues should be prioritised in the intervention to reduce work instability (60).
People with MS are not always aware of the support they need at work or their legal rights at work.	To empower people with MS at work	• Inform and advise people with MS about topics such as disclosure and legal rights.	•	Educating the person with MS about their legal rights and symptoms will empower them to address future problems at work (77,192).
		• Educate people with MS about strategies to self- manage MS symptoms.	•	Symptom management is a common intervention component to help the person manage their condition at work (130,138).
Co-workers are not considerate with people with MS because they do not understand the impact of MS on their colleague	To increase the awareness of MS and MS-related symptoms for colleagues and employers.	• Educate employers, and colleagues about MS	•	Employer engagement has been recommended for these interventions and can lead to improved workplace relationships (6,131).

### Table 14 Guiding Principles Phase 2

Target behaviour/ Problematic behaviour	Design objective	Key intervention features	Supporting evidence
Not all companies have an OH department to recommend support at work, and employers do not always provide the support.	To identify reasonable accommodations for the person with MS	<ul> <li>Assessment of needs at work.</li> <li>Support the employer and person with MS by identifying reasonable</li> </ul>	<ul> <li>Conducting a detailed assessment of employment needs can identify barriers to job retention and support to reduce the barriers (60,130,138).</li> <li>People with MS are protected under the Equality Act 2010, and their employers are obliged to provide</li> </ul>
		accommodations.	them with reasonable accommodations (119).
Lack of time as a result of high workload, family responsibilities, and impact	To facilitate the participation in the intervention	• Flexible support including <i>face-to-face</i> support plus <i>telephone</i> and/or <i>email</i>	• Telerehabilitation is an acceptable method to suppor people with MS with employment (127,129).
of MS symptoms can hamper the participation of		contact.	• People with MS should be able to access the VR intervention as required without having to request
people with MS in the intervention.		• Appointments are booked according to the person's availability.	additional referrals to the intervention (60).
		• Re-accessible support.	

### 4.5.2.2.1. Logic Model Phase 2

Unlike the guiding principles, the logic model of the intervention changed substantially from Phase 1 to Phase 2. The logic model was refined iteratively as the stakeholders review the different sections. Figure 7 presents the Phase 2 logic model with the modifications suggested by the stakeholders.

Once the stakeholders had a clear picture of the intervention, the discussion around the logic model started. When discussing the logic model, the stakeholders were asked to focus on one column of the logic model at a time.

The resources necessary to implement the intervention were relatively straightforward to discuss with the participants. These resources were refined and extended by mapping the activities to the resources and identifying gaps in the resources presented in the preliminary logic model.

The activities column was discussed at length to ensure all relevant activities were included. To achieve this, the activities were organised as they were meant to happen in the intervention from recruitment to discharge.

The participants expressed interest in individual sessions as opposed to group intervention, as the topic of employment issues is highly individualised to the person with MS and their workplace characteristics.

The idea of providing an "end of intervention package" emerged at this stage. This involves providing the person with MS with top tips and a summary of the intervention in the last appointment. This package was included in the resources section of the logic model.

The stakeholders believed that 10 hours of support would be sufficient support to address the most common employment concerns; but those with further needs (e.g., psychological support, employment tribunal) might need longer support. The timeframe of the intervention was set at 3 months for practical reasons (i.e., PhD timeline) and based on previous interventions identified in the systematic review that ranged between 12 months to 4 weeks.

Resources	Activities	Mechanisms	Outcomes
Assistant Psychologist (AP)	Identify employed person with MS and refer to intervention	Trust between AP and person with MS	Person with MS remains employed
Employed person with Multiple Sclerosis (MS)	AP screens person with MS for eligibility	Early intervention	Better relationship between employer and employee
Charity groups willing to share information about the intervention	AP assess current work situation, needs at work, goal setting, and intervention content (up to 10 hours)	Responsive service Timely support	Person with MS meets intervention goals
	Person with MS that requires psychological support or report cognitive problems is referred to relevant	Managing expectations of person with	Improved emotional well-being
Employer and colleagues willing to support the person	organisations	MS and employer.	Improved quality of life
with MS at work	Constant communication throughout the intervention to	Collaboration between parties	Reduced fatigue
letter	Information for the parson with MS about working MS	Employer engagement	Person with MS able to manage workplace difficulties (self efficacy)
MS services to refer the person with MS	legal rights, disclosure, fatigue management, and cognitive impairment	Awareness about resources available	Increased productivity Person with MS aware of support available and how to access it Person with MS understands impact of MS at work, coping strategies, and what to look for in the future
Sign posting leaflets		Understand impact of MS at work	
Polovant stokoholders willing to	AP signposts participant to relevant organisations	Individually tailored support	
get involved	AP provides education to the employer/colleagues about MS, invisible symptoms, and how to support the person	Re-accessible support	
End of intervention package with	with MS	Flexible content and structure	
top ups	Support identifying and requesting reasonable accommodations		Reasonable adjustments implemented
	Advice about how to prioritise work and career paths		Improved work-ability
	Person with MS receives a summary letter after each		Person with MS feels supported at the end of the intervention
	session with topics and actions discussed		Transport to work
	Final session- referral to social MS group and other services		Employer better informed about how to support the person with MS

Figure 7 Logic Model Phase 2
For those people with MS with complex needs, it might not be possible to address all their work-related concerns in the timeframe of the intervention. For this reason, providing each person with a summary of the content learnt, and a list of organisations to seek further support was recommended to ensure the person with MS felt supported at the end of the intervention. Furthermore, those people with complex issues could be referred to other professionals to address their needs.

Regarding the outcomes and mechanisms, new ideas were discussed when reviewing the logic model that led to a clearer differentiation of individual and measurable outcomes, as well as mechanisms that were underrepresented in the preliminary logic model. This was further refined by reviewing the underlying mechanisms of VR interventions for people with other long-term neurological conditions. Mechanisms such as collaborative approach, early intervention, and tailored support have been commonly described for this type of intervention and they represent the mechanisms that can help achieve the desired outcomes of the intervention (107,123).

# 4.6. Final Intervention

The previous sections of the chapter presented a description of the process followed to develop a job retention VR intervention for people with MS.

VR is considered a complex intervention; it can be challenging to describe the resources and processes that are effective at supporting people at work (133). In fact, in the systematic review about VR for people with MS (Chapter 2), only three out of thirteen interventions reported a complete description of the intervention.

The missing information from the interventions made it challenging to build up this intervention from previous interventions. In an attempt to reduce the missing information from the intervention description, this intervention is presented following the TIDieR checklist (142). An overview of the intervention is presented in Appendix F.

#### **4.6.1.** Intervention description following TIDieR.

#### 4.6.1.1. Brief name

Full Title: Job retention vocational rehabilitation intervention for employed people with multiple sclerosis.

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Short title: Preventing job loss for people with MS.

#### 4.6.1.2. Rationale

#### The problem:

MS affects approximately 700,000 people in Europe and 130,000 people in the UK (4,5). People are usually still employed when they are diagnosed with MS (6); hence, people affected by MS would benefit from an intervention that supports them to remain at work (160).

The BSRM recognises four different situations that people with MS can face regarding their employment situation. As can be seen in Figure 8, people with MS can be classified as newly diagnosed, working yet worried, in a work crisis, and unemployed but wanting to RTW (60).



Figure 8 Characteristics of people with MS (BSRM, 2010)

# The theory:

This VR intervention was developed following a biopsychosocial approach addressing the characteristics of this progressive condition, and environmental and disease-related factors (59), paradigms of work disability prevention (135), and a series of anti-discrimination legislation (Equality Act 2010) to ensure the person with MS is adequately supported in the workplace with reasonable accommodations (119). The intervention follows a problem-solving process tailored to the needs of the person, with an iterative process reviewing the progress made by the person (105). The intervention aims to adapt the environment and accommodate the person with MS at work. It also aims to educate the person to self-manage the condition at work. This approach was selected because MS is a chronic progressive condition where symptoms fluctuate, and people can experience increased disability over time. Supporting the person by adapting the environment can be beneficial to accommodate the difficulties that the person experiences, especially if these are reviewed over time to match the needs of the person.

People with illness or disability can experience "work disability" when their condition impacts their work performance (193). Traditionally, work disability used to be attributed to the medical factors that lead to disability; however, we have mounting evidence that it is indeed the psychosocial factors and context that cause most work disability (135,193,194). To avoid work disability, it is necessary to understand the complex environment of work, where the person with illness or disability is included in the context along with the workplace system, healthcare system, and legislative system (135). These interact with each other creating or removing disability, therefore, interventions supporting individuals to return or remain at work should include these variables in the intervention (135).

Regarding the type or intensity of support, people with MS will have different needs according to their employment, MS, and personal characteristics among other variables. Stratified interventions with different levels of support are recommended for people with LTNC (123). This type of stratified intervention is quite common in complex interventions, and there are examples from interventions for cancer survivors (195). In a stratified intervention, the lower intervention level addresses basic needs, and complex problems can be addressed at the higher levels (180). This idea is congruent with a theme discussed in the qualitative study (Chapter 3), indicating that an intervention to support people with MS to remain at work cannot be designed as "one size fits all".

Previous research into MS and VR suggests that most employment issues that people with MS experience, could be addressed with information, signposting to relevant organisations, and supporting the individual to self-manage MS-related symptoms (151,180). This is especially the case for those who are newly diagnosed and need support understanding how MS will impact them in the future (180,196). Those who have complex issues at work or conflict with their employer will require higher levels of intervention through specialist VR services (146,180).

Because of the variability in the MS population and lack of evidence about the effectiveness of these interventions, we do not have enough information to understand exactly what levels of support that each person with MS will require

(146,180). Due to the divergence in variables such as MS symptoms, disclosure in the workplace, and years with MS among other variables, there is a blurred line in terms of the intensity and content required at each level of the intervention. To address this, instead of developing a stratified intervention, the intervention will be individually tailored according to the needs of the person. The intervention levels will be defined after the intervention has been assessed in practice.

The VR services available for people with LTNC are divided according to how generic or specific they are. The lowest level involves a generic VR service that mainly identifies vocational needs and signposting to other services (174). The highest level involves specific VR services, characterised by multi-disciplinary teams, with trained professionals that deliver a wide range of services from assessment of vocational needs to assist with job seeking or job retention (108,174). The rest of services typically fall into a middle category that provides the services while the person is in a hospital or after discharge; these are typically VR support provided by a neuro-rehabilitation service (174).

Currently, there is a lack of specialist employment services for people with MS in the UK (54,181). Therefore, a job retention intervention to support people with MS to remain at work can add to the evidence of VR and improve methodological considerations such as relevant outcome measures and intervention content.

#### 4.6.1.3. What materials?

Considering the variety of employment issues that people with MS can present due to the disease itself and context/environmental variables, this intervention covers a comprehensive menu of components. Appendix G includes a list of resources for the intervention organised according to the topic they cover. This section describes some of the materials that will be used in the intervention:

 Initial interview: To explore the work situation, type of MS and most common symptoms, and screening for workplace issues. The interview was extracted from "Employment and Multiple Sclerosis: A guide to vocational exploration for OTs" from the MS Society of Ireland (197). Due to the nature of this job retention intervention, we tailored the interview excluding the sections relating to RTW.

- Living with fatigue: Fatigue management for people with MS (MS Trust). This booklet covers information about what is fatigue, causes of fatigue, how to manage fatigue, and strategies to build up energy levels and using energy effectively (198).
- 3. Work toolkit: A series of forms and documents from the UK MS Society to help people with MS to understand their work situation, where they might need reasonable adjustments, support about disclosure, and understanding their strengths and weaknesses at work (199).
- 4. MS in the workplace, an employer's guide: Booklet from the UK MS Society addressing topics such as what MS is and how to support the person with MS at work from the employer's perspective.
- 5. MS workbook: This guide covers topics such as disclosure to employer, asking for reasonable accommodations and understanding MS (200).
- 6. Working with MS: Employment Resource for People with Multiple Sclerosis: Document from the UK MS Society that provides information about relevant topics such as disclosure, how MS will affect career progression and legal rights among other topics.
- Educational resources from academic publications and MS charities about MS, common symptoms, cognitive impairment, and legal rights (further information on Appendix G).
- 8. Educational videos from MS charities showing the experiences of other people with MS and discussing topics such as management of cognition in the workplace, assistive technology in the workplace and disclosure (further information on Appendix G).
- Information about resources available and organisations that support people with disabilities at work or provide legal advice such as Access to Work, Citizens Advice Bureau, MS Benefit Advisors, charities, or Disability Advice Centre.

10. MS and your Emotions: Understanding and dealing with your feelings. This booklet describes how MS can affect the way a person feels and how to manage emotions.

### 4.6.1.4. What procedures?

Because this is a job retention intervention, the intervention focuses on the first three groups of people with MS presented in Figure 8, excluding only unemployed people with MS. The intervention pathway is presented in Table 15.

#### Table 15 Intervention Pathway

Community	An employed person with MS is informed about the
	intervention by a healthcare professional.
Referral to	Person with MS contacts the MS Clinic to show interest, ask
intervention	further questions about the intervention, and person screened for eligibility.
Interview	Assessment of the impact of MS in the workplace, relevance of work for the person with MS and selection of three intervention goals.
Intervention	The intervention includes up to ten hours of support. The meetings can be arranged at the convenience of the person with MS (in person, via telephone, or videoconferencing). The person with MS can decide to include the employer in the intervention. Employers will receive up to three hours of support.
Re-assessment	Discussing progress made, review of goals and future steps

#### Stage Action

The person with MS will be involved in a three-month intervention that includes an initial interview, and up to ten hours of individually tailored support dependent on their needs and/or goals. The content of the intervention will be selected from a menu of interventions addressing common problems at work, and a final appointment to discuss the progress made and future steps.

The intervention will be delivered by an assistant psychologist (PhD Researcher) who will receive mentoring and monitoring by an OT with experience delivering VR to address complex cases.

The assistant psychologist will have the role of case coordinator, referring the person with MS to the relevant organisation and supporting them with the referral process, and an educational role, providing information and addressing relevant issues such as support with applications and identifying reasonable accommodations.

<u>Initial Appointment</u>: This step involves the completion of the initial interview and will last approximately one hour. The aim is to understand the following aspects:

- Demographic and professional information.
- MS characteristics (e.g., years with the condition, symptoms, impact of symptoms).
- Work characteristics: Information regarding the job duties, and support received from employer.
- Discussing what is important for the person with MS at work.
- Identify problems at work (barriers to remain at work).

After completing the initial interview, the person with MS with the support of the assistant psychologist will select three goals to achieve with the intervention. The goals should be SMART (specific, measurable, achievable, realistic/relevant and timed) and will be evaluated at the end of the intervention (201,202). The person with MS with the help of the assistant psychologist will select the content of the intervention to achieve the goals.

The initial appointment can be split in two if the person with MS feels fatigued after the interview. At this appointment, the person with MS will be asked if they are interested in involving their employer in the intervention.

In the initial interview, the person with MS and assistant psychologists will book the date for the next session in the preferred modality (in person, via telephone or Microsoft Teams). The initial interview is relevant because it will structure the whole intervention.

<u>Programme:</u> The intervention involves between 1 and 10 hours of individually tailored support on relevant topics for the person with MS. The support will be divided into sessions that will typically last 1 hour; the sessions can be shorter

according to how the person with MS feels. We estimate that the sessions will range between 30-60 minutes.

The person with MS will select from a menu of intervention components to address relevant topics such as the ones presented in Table 16.

Intervention components									
Understanding MS	Signposting to local and national resources	Cognition in MS							
Education about legal rights	Signposting to organisations	MS and emotions (anxiety, stress)							
Support with disclosure	Advice about reasonable accommodations	Long term career planning							
Fatigue management	Employer engagement	Referrals							

Table 16 Menu of intervention components.

Each appointment will start by reviewing the progress made to date and addressing queries. The content of the appointments is individualised to the person's characteristics to address those areas of concern relevant for them.

After the session, the person with MS will receive a letter via email or post describing the topics discussed in the intervention and techniques that they need to try before the next session.

We estimate that not all people with MS will need 10 hours of support because this will vary according to their situation at work. Therefore, this intervention is reaccessible so that people can opt to receive information on the first session and decide later if they would like to receive further support.

The employers will have the opportunity to receive information that they deem useful and receive support in topics such as reasonable accommodations or understanding MS. We expect employers to be involved for an initial interview and up to three hours over the three months of the intervention.

The topics covered in the intervention are:

- Understanding MS: This topic is particularly relevant for newly diagnosed people who are not aware of what MS is or how it will progress with time. This subject also covers the key features of the condition and the most common symptoms and progression.
- Education about legal rights: Discussing the Equality Act 2010, what are reasonable adjustments and their rights at work.
- **Support with disclosure:** Discuss what is disclosure, and advise about whether it is necessary to disclose the condition to their employer. The support provided on this topic involves role-playing, as an opportunity to practice how to tell the employer, reading materials and educational videos.
- **Fatigue management:** For those who experience fatigue in the workplace, they will be thought strategies to reduce their fatigue in the workplace. This subject also includes advice on how to organise and prioritise tasks throughout the day.
- Signposting to local and national resources: Discussing organisations and resources that are locally available to provide support to people with MS. Examples of these are social MS groups or online peer support (e.g., Shift.ms). This component includes providing booklets to complement the knowledge gained in the intervention.
- Signposting to organisations that support people with disabilities: Information about the services available to facilitate their work experience (e.g., Access to Work, Disability Advisors). Those who decide to access schemes such as Access to Work will receive support to complete the applications.
- Advice about reasonable accommodations: For those who are experiencing problems at work but do not know what can be done to improve their situation, they will be provided with resources and have a discussion to identify the accommodations that can be useful for them according to their work environment and role.
- Employer engagement: This includes support with reasonable accommodations, understanding MS, and their legal responsibilities, among others. For those who do not want to involve the employer, there is a possibility of providing the employer with a letter presenting reasonable accommodations that could be

useful to support the person with MS or resources that include information useful for the employer.

- **Cognition in MS:** The intervention will cover several aspects of cognition such as what is cognition, how MS can affect memory and thinking and tips to deal with memory and thinking problems.
- **MS and emotions:** Discussing feelings such as anxiety, depression, and stress. Those who experience clinical levels of depression or anxiety will be referred to the appropriate professional.
- Long-term career planning: This subject focuses on understanding the current work situation, and the future of working with MS. This content can be useful for those who are worried about whether they will be able to continue working.
- **Referral to other professionals:** We will refer people who present complex employment issues to the appropriate professional to address these concerns.

<u>Final Appointment:</u> This appointment includes discussing the content learnt through the intervention and a summary of the intervention with further resources and top tips. The document will also include information about social MS groups that offer peer support. At the end of the intervention, those with further needs will be referred to the relevant organisation or professional that can address their situation. This appointment will last approximately 1 hour.

### 4.6.1.5. Who provided?

An Assistant Psychologist will deliver this intervention but will be mentored by an OT with experience delivering VR. The Assistant Psychologist will also refer people with complex needs to relevant professionals (e.g., OT, Psychologists, Neurologist, etc.).

### 4.6.1.6. How, where, when and how much?

This intervention has been designed to involve employed people with MS. The first stage of the intervention consists of an interview that can be conducted either *face-to-face*, via telephone or Microsoft Teams.

After the initial interview, the researcher and person with MS will agree on the date for the following appointment. The person with MS can select to have the appointments distributed according to their preference and can receive up to ten hours of support.

They will have the opportunity to select the delivery mode of the sessions to facilitate the inclusion of the intervention in their personal and professional lives. The intervention was designed to be flexible in its delivery and content to ensure the inclusion of people with time restrictions or difficulties travelling. Furthermore, allowing people to have sessions over the telephone will reduce the levels of fatigue, as it does not require the person to travel to extra appointments.

The distribution of the sessions of the intervention will be adapted to the individual's needs and availability. While some people will need intensive support to manage employment issues such as a disciplinary meeting, others might need a less intense intervention that allows them to put into practice the content learned in the sessions.

The timing of the intervention (i.e., stage after diagnosis) will vary according to the clinical characteristics of the person recruited. We expect different needs in the intensity of the intervention because if a person has been out of work (e.g., sick leave) for a few weeks, they might need shorter sessions until they feel ready to engage in the support.

The intervention has been designed to be conducted either remotely (e.g., telephone, Microsoft Teams) or in-person in a quiet place or at the workplace according to the preference of the person.

### 4.6.1.7. Tailoring

This intervention is designed to be tailored to the needs of each person with MS. The areas that can be tailored have been described throughout the intervention description. Overall, the tailoring involves selecting delivery mode and frequency of sessions, the content of the intervention, involvement (or not) of the employer, and length of the sessions.

#### 4.6.1.8. How well planned?

The assistant psychologist will measure intervention adherence by recording information regarding the completion of the initial interview, number of sessions offered to both the person with MS and their employer, number of sessions received, their length and content will be recorded using a proforma. The proforma used for this intervention was an adapted version of a proforma previously used to measure the delivery of VR interventions for people with stroke and traumatic brain injury (203,204). I adapted the proforma to include the main intervention components identified during the intervention development phase, as the original proforma did not include all relevant components. This proforma captures information about the dose, intensity, and content of the intervention.

The proforma includes a section with predetermined intervention components to help code the topics discussed. These predetermined components were those identified during the intervention development process. During the sessions, the topics discussed should be recorded in units of 10 minutes and categorised within the main intervention components along with a brief description of the topics discussed.

The proforma provides the opportunity to record face-to-face contact (direct contact), which refers to the topics discussed during each session with the person with MS (or employer); and indirect contact, which includes all the activities conducted outside of the session to complement the session such as liaison with other professionals and communications. The proforma also includes a section to record time spent travelling to visit the person with MS or employer (if required).

For each person included in the intervention (MS and employer), a proforma should be completed describing the information discussed and activities conducted after the session (indirect contact). The proforma should be completed soon after the session to increase the accuracy of the content.

### 4.7. Discussion

This chapter presented the steps followed in developing a job retention VR intervention to support people with MS at work. The intervention was developed using a combination of evidence available through a systematic review and primary research through a qualitative study. To increase the acceptability and adherence of the intervention, I followed the PBA and the MRC framework (133,140). The intervention development process also involved developing guiding principles and an intervention logic model depicting how the intervention will work in practice.

The findings of this study have provided valuable insight into the understanding of how the intervention components will help people with MS and their employers in identifying and addressing common problems at work. This showed that it is important to provide support tailored to the needs of the person with MS.

Developing the logic model and in particular selecting the underlying mechanisms of the intervention was exceptionally complex, as the line between the underlying mechanisms and outcomes of the intervention is not always clear. Thus, even after refining the intervention logic model, some outcomes could be considered as a mechanism and vice versa.

The intervention development process helped identify several underlying mechanisms that were seen as important to support people with MS at work. These mechanisms align with the mechanisms identified in the systematic review about VR for people with MS (Chapter 2).

The next step focuses on understanding how this intervention will work in practice. Since the intervention is still in the early stages of its development, the intervention will be tested on a small scale (e.g., case studies) to help us refine the content and logic model before implementing it on a larger scale (133).

# Chapter 5: Implementing a job retention VR intervention for people with MS: A mixed-methods case study design.

# 5.1. Introduction

The present VR intervention addresses the most common employment issues that people with MS experience at work. The barriers and facilitators to implementing this support were identified in the qualitative study (Chapter 3) and were taken into consideration in the intervention development (Chapter 4) to increase its acceptability.

# 5.2. Aim and objectives.

The overall aim of this study was to assess the feasibility of delivering a job retention VR intervention for people with MS and evaluate the perspectives and experiences of people with MS, healthcare professionals, and employers. Specifically, I wanted to assess the:

- Feasibility of recruiting participants using the recruitment strategy developed for this study.
- Length of time to recruit the sample.
- Feasibility of delivering up to 10 hours of VR.
- Feasibility of delivering VR alongside existing treatments people with MS received.
- Practical issues in delivering the intervention.
- Participant attrition and reasons (if provided).
- Spectrum of MS severity among participants.
- Appropriateness of study methods and procedures.

# Additional objectives were to:

(i) Determine whether receiving this job retention VR intervention was associated with changes in quality of life, mood, fatigue, functional outcomes, employment situation, and work instability, and degree of goal attainment.

(ii) Understand the experiences and perspectives of the participants (people with MS and employers), and healthcare professionals of the intervention, at three months post-intervention.

### 5.3. Methods

#### 5.3.1. Ethical Approval

This study was granted ethical approval by the Division of Psychiatry and Applied Psychology at the University of Nottingham, reference number 1582 (April 2019). Ethical approval was also granted by the NRES Committee East Midlands Nottingham 2, reference number 20/EM/0113. The Research and Development (R&D) department approved by Nottingham University Hospitals (NUH).

#### 5.3.2. Study Design

This was a mixed-methods n-of-1 case study design (single-case study design) with embedded qualitative study; selected for its suitability to investigate the efficacy of an intervention and experiences of those receiving the intervention. Moreover, it allowed us to understand the impact of the intervention for each participant individually (205). This approach is recommended by the MRC framework for developing and evaluating complex interventions (133) to understand the connections between the intervention components and the outcomes achieved during the intervention before implementing it at a larger scale. The information from the case study also provides further insight to refine the intervention logic model (133,184).

I selected a mixed-method approach to obtain a more comprehensive understanding of the impact of the intervention. The purpose of a mixed-methods study is to collect and analyse quantitative and qualitative data within one study (206). The quantitative data included data from questionnaires and the qualitative data are the post-intervention interview; allowing us to obtain a comprehensive picture of the impact of the intervention (206,207).

The findings from the case study design are presented following the CARE Checklist for reporting case reports from the Equator Guidelines (208). This includes 13-items covering the most important aspects that should be reported when describing case studies.

The CARE Checklist is structured for manuscripts reporting one case study; thus, the checklist was modified to allow reporting each case study individually and avoid

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repetition. To achieve this, items 1-3 (title, keywords, abstract) were not reported for individual case studies. Item 9 (therapeutic intervention) was substituted for the TIDieR checklist for intervention description (see Chapter 5) to allow a more comprehensive description of the intervention (142).

# 5.3.2.1. Sample Size

As this was a case study, no power calculations were conducted. This type of research study involves examining closely the data from a limited number of individuals. I anticipated that not all people with MS recruited in the study would be interested in including their employer, therefore, I aimed to recruit 15 people with MS, up to 10 employers and up to 10 healthcare professionals. I aimed to recruit participants over three months. I felt that this sample size would yield sufficient data to achieve data saturation in the post-intervention interviews (209). Furthermore, I aimed to recruit a sample of participants with a wide range of employment, clinical and demographic characteristics to explore whether the intervention meets the needs of participants with different needs (210).

# 5.3.3. Participants

Three types of participants were included in this study: people with MS, their employers, and a member of their healthcare team.

### Person with MS

People with MS could be included in the intervention regardless of the presence of employment issues, as the intervention could help them discuss their current employment situation or address questions they may have about working with MS. The inclusion criteria were:

- Diagnosis of MS.
- Between 18 and 65 years of age.
- Currently employed.
- Living within reasonable distance from recruitment centre (1-hour travel by train).
- Can give informed consent.
- Can communicate in English.

Exclusion criterion of people with MS:

• Planning to retire due to age or take early retirement within the next six months.

# Employers and healthcare professionals

The participants with MS had the opportunity to involve their employer in the intervention and/or a healthcare professional from their usual care team. The inclusion criteria were:

- Willing to consent to participate in the study.
- Over the age of 18 years.

# 5.3.4. Recruitment

Participants were recruited from three sources: NUH, relevant charities (MS Society and MS Trust), and self-referrals from publicly available information about the study.

For those recruited through the NHS, the initial approach was from a member of the patient's usual care team, and information about the study (an advertisement) was on display in the relevant clinical areas. This advertisement included the email address of the primary researcher, therefore, those interested in the study contacted the PhD student, who provided them with further information about the study.

I contacted local charities to ask them to share the advertisement of the study with the members of their group and contacted those who were interested in the study.

Once a potential participant with MS expressed their interest in the study, they were informed of all aspects of the study and provided with a Participant Information Sheet (PIS) and a consent form.

Consenting participants with MS were asked about the possibility of including their employers and a member of their healthcare team in the intervention. This was optional, and they were only contacted if the person with MS agreed to include them. The healthcare professionals and employers were provided with a separate PIS and consent form before consenting to participate in the study.

#### 5.3.5. Study Flow

The first contact with the participants with MS aimed at screening for eligibility and signing the consent form. Oral consent was obtained over telephone or Microsoft Teams, as the participant and PhD student could not meet in person. The participants were sent a copy of the consent form signed by the PhD student at the end of the initial conversation. After completing the consent form, participants with MS were invited to nominate a designated healthcare professional and employer to be included in the study. The following diagram represents the path that the participants followed (Figure 9).



Figure 9 Participant involvement and study flow diagram.

Consenting employers were asked to complete an initial interview (Appendix H), a three-month intervention with up to four hours of support, and an interview at three months post-intervention to discuss their experiences receiving the support, and to help us refine the content.

The healthcare professionals were involved in an initial interview (Appendix H) about their role in the care team of the person with MS and an interview at three months post-intervention to understand their perspectives of the intervention and its future implementation.

Participants with MS were asked to complete the baseline assessment (A1). This was followed by the initial interview (Appendix H) and setting the intervention goals. The measures that participants completed and the time-points can be seen in Table 17.

	Assessment and time-point								
Measures	Baseline		Post-intervention	3 months Follow-Up	6 months Follow-Up				
Participant with Multiple Sclerosis (MS)									
Initial Interview (includes demographic information)									
Goal Attainment Scaling	Х	X X	х	X					
Perceived Difficulties Questionnaire (PDQ)	X		Х	x	Х				
Work Productivity and Activity Impairment Questionnaire (MS)	X	]	Х	x	X				
MS Work Instability Scale (MS-WIS)	X		Х	X	X				
Hospital Anxiety and Depression Scale (HADS)	X		Х	X	X				
Modified Fatigue Impact Scale -5 Items version	X	tior	X X X	X	X				
European Quality of Life-5D (Euro-QOL)	X	/ent		X	X				
Work Self-efficacy Scale (WSES)	X	erv		X	X				
Workplace Accommodations	Х	Int	Х	х	X				
Qualitative Study	VR								
Post-intervention interview				x					
Intervention Compliance	X	X		Х	X				
Observations	X		Х	х					
Employer									
Initial Interview (includes demographic information)	X								
Post-intervention interview		]		Х					
Healthcare Professional									
Initial Interview (includes demographic information)	X								
Post-intervention interview				Х					

#### Table 17 Summary of assessments and time points.

After completion of the baseline assessment and initial interview, I booked the first appointment for the intervention. The intervention assessed in this study is described in Chapter 4 following the TIDieR checklist. This was a three-month VR intervention for employed people with MS including an initial interview, and up to 10 hours of individually-tailored support.

The participants received an email before each session to remind them of the appointment, and an email after each session with a summary of the topics discussed. The final session reviewed the content covered during the intervention and participants were provided with a document with further resources to address new problems as they appear.

For those participants with MS with unmet needs at the end of the intervention, the final session involved discussing the content addressed and future steps. The intervention sessions could range between 30-60 minutes according to the topic discussed, and participant needs and availability.

Initially, it was intended that the sessions were conducted in person or via telephone according to the preference of the participant. However, because of the national regulations associated with Covid-19, all sessions and stages of the study were conducted remotely via telephone or Microsoft Teams, according to the participants' preference. Guidelines from the British Psychological Society (BPS) were followed to deliver the intervention remotely to ensure the confidentiality of the discussions (e.g., therapists using headphones), and to agree on an alternative delivery method with the participant should the video consultation fail (e.g., continue via telephone) (211).

Participants with MS were asked to assess their intervention goals and complete the post-intervention assessment (A2) at the end of the intervention.

At three months post-intervention, the participants with MS were contacted to complete the three months follow-up assessment (A3) and a semi-structured post-intervention interview (appendix I) to understand their experiences during the intervention and explore the barriers and facilitators to embedding this intervention in the current services available. The interview was conducted via telephone or Microsoft Teams.

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The participants with MS were also contacted for a follow-up questionnaire at 6months post-intervention (A4). The follow-up time points were selected following the recommendations of the BSRM of collecting follow-up measures (196).

#### 5.3.6. Endpoints

#### Primary endpoint

For the participants with MS, the primary endpoint was the completion of an assessment at the end of the intervention and an interview at three months post-intervention. For healthcare professionals and employers the endpoint was the completion of an interview at three months post-intervention.

#### Secondary endpoint

For the participants with MS, the secondary endpoint was the completion of questionnaires at 3 and 6-months post-intervention.

### 5.4. Quantitative methods.

Participants with MS were asked to complete a booklet of questionnaires at different time points as presented in Figure 9. Initially, they were going to have the opportunity to complete the booklet face-to-face, via telephone, or sent by post with a pre-paid return envelope according to their preference. This approach was selected to facilitate the completion of questionnaires. Because of the Covid-19 restrictions, participants only received the questionnaire via email; but they also had the opportunity to complete it via telephone with the PhD student.

Participants were contacted either via telephone or email if there was missing data in the returned questionnaires.

The intervention goals were set during the initial interview. Participants with MS were asked to select three goals, and these were used to guide the topics for the intervention. Participants were urged to select SMART goals (Specific, measurable, achievable, realistic, and timed). The assistant psychologist (PhD student) supported the participants in selecting the goals and transformed them into SMART goals were possible. The timeframe to achieve most of the intervention goals was at the end of the intervention.

The intervention timing and content was measured using a proforma that measured the direct (e.g., discussions during sessions) and indirect contact (e.g., administrative tasks) of the intervention. The proforma was presented in Chapter 4.

Given that this was a case study design, the results present first the quantitative findings of each case separately, and then the combined quantitative results of all participants to explore the impact of the intervention on the outcomes measured.

# 5.4.1. Baseline Assessment

Before the involvement in the study, participants were asked to complete a booklet of questionnaires. The measures collected are presented in Table 18.

Questionnaire:	Time:		
Demographic information	Within initial		
Goal Attainment Scaling (202,212)	interview		
Perceived Difficulties Questionnaire (PDQ) (213)	5 minutes		
Work Productivity and Activity Impairment Questionnaire	2 minutes		
MS Work Instability Scale (MS-WIS) (188)	4 minutes		
Hospital Anxiety and Depression Scale (HADS) (215)	5 minutes		
Modified Fatigue Impact Scale -5 Items version (216)	1 minute		
EQ-5D (Euro-QOL) (217)	2 minutes		
Work Self-efficacy Scale (WSES) (218)	2 minutes		
Workplace Adjustments (219)	2 minutes		
Total Time:	23 minutes		

Table 18 Time required to complete questionnaires of the case study.

Demographic and MS characteristics were collected during the initial interview. Participants were asked their EDSS (56), those who did not know it completed the scale online (www.clinicspeak.com).

# 5.4.2. Justification of outcome measures

I selected questionnaires that had been validated with people with MS (where possible), and that was easy and quick to complete.

# 5.4.2.1. Perceived Difficulties Questionnaire (PDQ)

The Perceived Deficits Questionnaire (PDQ) explores the perceived cognitive difficulties and measures four sub-scales within the questionnaire: attention/concentration, planning/organisation, retrospective memory and prospective

memory (213). The PDQ is a 20-item scale scored with a 5-point Likert scale ranging from 0 (never) to 4 (almost always). The total score for the scale ranges between 0-80 points, and the domain sub-scales range from 0-20; where a higher score represents a greater perceived cognitive deficits (213). There is no cut-off score for the sub-scales, but a score of  $\geq$ 40 on the PDQ is considered as being in a "risk range" (220).

The sub-scales have good reliability and internal consistency: Cronbach's alpha .78 (attention/concentration), .84 (planning/organization), .83 (retrospective memory), and .76 (prospective memory) (213).

# 5.4.2.2. Work Productivity and Activity Impairment Questionnaire- Multiple Sclerosis

The Work Productivity and Activity Impairment Questionnaire (WPAI) measures impairment due to health illnesses, and there is a version that assesses in particular, the impairment at work as a result of MS (WPAI:MS) (214). This questionnaire includes questions about the employment situation of the person with MS, hours missed at work as a result of MS, and two numerical scales measuring how MS affects their productivity at work and conducting everyday activities (214). The numeric scales range from 0 (no impact) to 10 (unable to perform an activity), where a higher score represents a larger impact of MS at work and conducting everyday activities (214).

#### 5.4.2.3. MS Work Instability Scale (MS-WIS)

The MS Work Instability Scale (MS-WIS) was selected to measure work instability in patients with MS (188). Work instability refers to the impact that a condition (such as MS) has on the professional life of a person; this is caused by a mismatch between the demands of a job and an individual's abilities (188). This scale was first developed for people with rheumatoid arthritis and then adapted for people with MS (187).

The MS-WIS is a 22-item scale with true or false questions. Each "true" answer is awarded 1 point, and the total score for the scale ranges between 0-22 points, where a higher score represents greater work instability. Two cut-off points are representing an increase in the severity of work instability. The first cut-off ( $\geq$ 11) representing low to medium work instability, and the second cut-off ( $\geq$ 17) representing medium to high risk (188). This questionnaire has good internal consistency with a Cronbach's alpha of .89 (188).

#### 5.4.2.4. Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a questionnaire with two subscales measuring anxiety and depression. The HADS is a 14-item scale scored with a 4-point Likert scale ranging from 0 to 3 (215). The total score of each scale is obtained by the sum of all items included in each scale, and ranges from 0 to 21 points, with a higher score suggesting higher levels of anxiety or depression (221).

For the general medical population, a score of  $\geq 8$  on either subscale is considered as indicative of possible anxiety or depression, and a score above 10 reflects probable depression or anxiety (215,221). For the population with MS, previous studies have used different cut-off scores ranging between 8 to 11 to consider the score as possible depression or anxiety (221). However, a cut-off score of  $\geq 8$  in the depression sub-scale is considered as having good sensitivity (78.0%) and specificity (77.8%) for the MS population (221).

The recommended cut-off for the anxiety sub-scale is not as clear as for the depression sub-scale, however, a cut-off score of  $\geq 8$  seems to have high levels of sensitivity (88.5%) and specificity (80.7%) (221).

This questionnaire has been previously validated for people with MS and used to measure depression and anxiety in employed people with MS (84,221,222).

#### 5.4.2.5. Modified Fatigue Impact Scale -5 Items version

The Modified Fatigue Impact Scale -5 items (MFIS-5) was selected as an MSspecific scale to measure fatigue developed by adapting the Fatigue Impact Scale (FIS) (216,223). The extended version includes 21-items, however, for this study I selected the 5-item version to reduce the strain on the participants (224). The 5-item version is a self-reported scale with a 5-point Likert scale ranging from 0 (never) to 4 (almost always). The total score ranges between 0-20 points, where a higher score represents greater levels of fatigue. This scale has good internal consistency of .80 (216). There is no cut-off score for the scale, but a difference of 4 points between assessments is considered clinically meaningful with a confidence interval (CI) of .70 (225).

#### 5.4.2.6. EQ-5D (Euro-QOL)

The EQ-5D-5L is a self-completion questionnaire suitable to complete face-to-face or via post. This is a standardised questionnaire to assess health-related quality of life and provides a profile of the quality of life of the person with MS and an index value of their health status (217,226). This measure was selected to identify changes in quality of life overtime associated with receiving the intervention.

The questionnaire measures five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) according to the level of perceived difficulties or problems from "Level 1 - no problem" to "Level 5 - unable to or extreme problem". The value of each domain creates a five-digit code indicating problems in the five domains, and an index value can be derived from the five-digit code (217). The measure also includes a "health today" thermometer from 0 (worst health you can imagine) to 100 (best health you can imagine). This questionnaire has been used in several research studies as a measure of quality of life for people with MS (227–230).

#### 5.4.2.7. Work Self-efficacy Scale.

The Work Self-Efficacy Scale (WSES) assesses perceived work self-efficacy; which refers to the beliefs a person has about their capability of conducting the duties associated with their role (218). The WSES is a 10-item scale scored with a 5-point Likert scale ranging from 1 (not well at all) to 5 (very well). The score of the scale range between 10-50 points, with a higher score representing higher levels of work self-efficacy. The factorial structure of this scale shows two main factors measured with the scale: "relational willingness" (predisposition towards or attention to relationships with colleagues) and "commitment" (views on the capability of achieving objectives at work) (218). Both internal factors have good internal consistency with a Cronbach's alpha of 0.85 and 0.82, respectively.

This scale has not been validated in clinical populations but was included to understand the perceptions of the participants with MS about their abilities managing relationships and problems at work, as the qualitative study presented in Chapter 3 identified work self-efficacy as an enabler to remain at work.

#### 5.4.2.8. Workplace Adjustments

The questions included regarding workplace accommodations were extracted from a published manuscript reporting workplace accommodations that stroke survivors received following a RTW intervention (219). These questions were included because no questionnaire assessed the most common workplace accommodations that people with MS receive at work. Furthermore, they are a good indication of the support that the person with MS is receiving at work.

#### 5.4.2.9. Goal Attainment Scale

Goal attainment was included to measure the ability of the intervention in supporting participants to achieve their goals. Goal Attainment Scale (GAS) is commonly used in rehabilitation interventions (202,212) and has been used in rehabilitation intervention for people with MS (231).

Goal attainment was reported as a relevant outcome of the intervention for the participants with MS in the qualitative study presented in Chapter 4. Furthermore, because a key characteristic of this intervention was to tailor the support to the participant with MS, selecting goals that are relevant for the person is a good step to drive the intervention according to the preferences of the participant with MS.

During the initial interview, the participants with MS selected three intervention goals they wanted to achieve with the intervention. Participants were asked to evaluate whether or not they met the intervention goals using a 5-point scale from -2 (goal not met, much worse than expected) to +2 (goal met, much more than expected) (212). Using the goal attainment standardised formula, a GAS T score was calculated (212). The goals were considered as met if the GAS T score was >50 (Table 19).

Performance	GAS T score
Better than expected	50-60
Much better than expected	>60
Less well than expected	40-50
Much less than expected	<40

Table 19 Goal attainment sco	re range.
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#### 5.4.3. Quantitative analysis

#### 5.4.3.1. Statistical analysis.

The quantitative data of the study were analysed using Statistical Package for Social Sciences (SPSS) version 24.0 (232).

For the individual case studies, descriptive statistics [Mean, standard deviation (SD)] were calculated for the different variables measured. The Leeds Reliable Change Index was used (where possible) to determine whether the change in questionnaires scores was clinically significant and reliable (233). For those measures with a cut-off score (such as HADS, PDQ, and MS-WIS), the performance of the participants with MS over the different time points was plotted on graphs to illustrate whether the scores on the tests crossed the clinical cut-off boundaries.

To compare the performance of the participants as a group at different time points (baseline, post-intervention, three months follow-up), I selected paired *T*-tests and Wilcoxon signed-rank test (for parametric and non-parametric data respectively). I present the mean, SD, associated p values, and effect sizes (r). I have not used Bonferroni correction for multiple tests because of the increased chance of Type II error, the adjustments are concerned with the null hypothesis, and the adjustment implies that the comparison between measures will be different according to the number of comparisons performed (234). Therefore, I interpreted the results from the statistical tests with caution.

I used graphs illustrating the fluctuation over time in the different measures included in the study for the participants as a group.

Quantitative analyses were used to evaluate the perceived change in quality of life, mood, fatigue, work instability and functional outcomes for the participants with MS. The response rates and completeness of returned questionnaires were assessed.

### 5.5. Qualitative methods

#### 5.5.1. Semi-structured interviews.

At three months post-intervention, the participants took part in a semi-structured interview either via telephone or Microsoft Teams. The interviews aimed at understanding the experiences of the participants and identification of barriers for future implementation.

I selected this methodology because the conversational nature of this method enabled us to complement the quantitative findings by exploring the views and experiences of the participants involved in the study (166).

There were three interview topic guides according to the participant group (MS, employer, and healthcare professional). The topic guides (Appendix H) were informed by the ICF (59), and BCW (162), as this methodology proved to be useful in the previous qualitative study presented in Chapter 3.

Because this study also aimed to assess the feasibility of delivering an intervention that was developed through research, the topic guide was also informed by the Consolidated Framework for Implementation Research (CIFR; 215). This is a comprehensive implementation framework that identifies five relevant domains (intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and progress of implementation), and can be beneficial to identify what aspects of the intervention work and why. Furthermore, it can complement the theories that underpin the intervention (235).

Following the PBA, the intervention will be refined based on the findings from the post-intervention interviews. Information regarding issues identified during the intervention will be recorded on a table of changes along with the recommended changes to refine the intervention.

#### 5.5.2. Framework analysis.

Following the lines of the initial qualitative study (Chapter 3), the analysis was informed by the framework method (169,170). I selected this approach for its suitability for studies with a predetermined objective such as supporting the

development of a refined intervention; furthermore, this approach has proved to be useful in addressing a similar research question in the population of MS (236).

Framework analysis includes five stages of analysis (transcription, familiarisation, coding, developing a framework and applying framework) (169). The interviews were audio-recorded, transcribed verbatim and handled using NVivo v.12 (167). I familiarised myself with the data by reading the transcripts to get an overview of the topics discussed and take notes about relevant ideas present in the interview.

The interviews were coded following an iterative process using a coding matrix (Appendix J) previously developed following the relevant theoretical frameworks.

After the transcripts were coded, I identified the key themes to address the objectives of the interview. These codes informed the framework for analysis that was systematically applied to all interviews. Anonymised quotes from the participants were extracted to depict the participants' experiences in the intervention.

#### 5.5.3. Data Synthesis

The data from the qualitative and quantitative findings were synthesised following the convergence coding matrix strategy (237,238). This method was selected for its suitability to analyse mixed methods when there are quantitative and qualitative data from the same participants (237). For this study, the same participants with MS completed the questionnaires and the post-intervention interview; therefore, data from these two methodologies were integrated to obtain an in-depth representation of the impact of the intervention.

To synthesise the data, I identified the key factors that provide insight into the acceptability and impact of the intervention. The convergence matrix allowed me to compare the findings from the quantitative and qualitative data and identify areas of agreement and disagreement between the two types of data, using a coding strategy. The coding strategy included the following four possible codes (238):

- Convergence: The findings from both methodologies agree.
- Complementary: The findings from one methodology complement or provide further insight into the findings of the other methodology.
- Disagreement: The findings from each methodology contradict each other.

• Silence: This code was used when only one of the methodologies offered information about a relevant factor, and there was no data available in the other methodology.

#### 5.6. Results

Figure 10 presents an overview of the pathway that the participants followed through the study. In total, 26 people were screened to participate and 22 consented to the study, of whom 15 were people with MS, three employers, and four NHS healthcare professionals. The participants with MS were recruited from NHS (n=3), and self-referral from publicly available information (n=12).



#### Figure 10 Study flow-chart

Four participants were lost to follow up from the study after screening because (i) one person with MS could not be contacted, (ii) two employers got ill, and (iii) one employer was too busy to participate in the intervention.

One participant with MS and one employer were lost at follow-up for the postintervention interview. One of the participants with MS did not have time to complete the post-intervention interview but returned the booklet of questionnaires at three months post-intervention. Three participants with MS were lost to follow-up at six months post-intervention.

# 5.6.1. Participants Characteristics

# 5.6.1.1. Participants with multiple sclerosis

In total, 15 participants with MS were recruited (12 women, 3 men). The participants with MS had an average age of 46.13 years (SD=9.58) and had relatively high educational levels (Figure 11). Regarding their relationship status, 12 participants with MS were in a relationship, two were separated and one was single. Most participants were White British (n=14), and one participant was Black British Caribbean.



Figure 11 Educational level of participants with MS.

#### **Clinical characteristics**

There were nine participants with RRMS, and six with SPMS. The participants with MS as a group were relatively newly diagnosed with an average of 5.87 (SD=4.83) years with MS. However, there was considerable variability in the number of years they had been living with MS, ranging from 6 months to 16 years with MS. Interestingly, when asked about years experiencing symptoms suggestive of MS before diagnosis, the average years with MS symptoms doubled to 14.87 (SD=10.42) years.

Regarding the level of physical disability, their EDSS ranged from 0 (no disability) to 7.5 (severe disability), with an average EDSS of 4.57 (2.10).

Participants were asked about the most common MS symptoms affecting them in the workplace. All participants reported fatigue as one of the main symptoms affecting their performance at work. This was closely followed by memory problems, as well as difficulties walking. Feelings of anxiety were also reported, as their anxiety was closely related to the progression of the condition and the impact that MS was having in their everyday activities.

#### **Employment characteristics**

All the participants with MS were employed; however, at the time of recruitment three of them were on furlough as a result of the Covid-19 pandemic. Six participants with MS were working full-time, and on average all participants with MS were working 29.43 (SD=10.65) hours per week.

Regarding the size of the companies employing the participants with MS, 12 were working in a large company (>250 employees), two in a small company (10-49 employees), and one in a medium-size company (50-249 employees). Company size was defined following UK Government guidelines (239).

The participants' with MS job was categorised in four levels following the SOC 2020 (173) as presented in Table 20.

Job Category	All participants with MS (n=15)
Unskilled	2 (13.3%)
Semi-skilled	4 (26.7%)
Semi-professional	5 (33.3%)
Professional	4 (26.7%)

Table 20 Job classification of participants with MS.

#### 5.6.1.2. Employers

Three employers (line managers) were included in the study (1 woman, 2 men). All the employers identified as White British and had high educational levels, including degree (n=2) and postgraduate qualifications (n=1). The employers had been supervising the person with MS for a relatively short time, ranging between two months to three years.

# 5.6.1.3. Healthcare professionals

Four healthcare professionals (2 women, 2 men) were included. The healthcare professionals included two neurologists and two MS nurses with an average of 14.25 (SD=6.65) years of experience working with people with MS. Three of the healthcare professionals were working for the NHS and one of them working for a private company.

# 5.6.2. Baseline characteristics

Table 21 presents an overview of the baseline data for the 15 participants with MS.

ID	Gender	Age	PDQ					HADS				MFIS-	EQ-5D-5L *		WSES	<b>a</b> . <b>a</b> .
			Att	Plan	R. Mem	P. Mem	Total	Anx	Dep	Total	MS-WIS	5	INDEX	Health Today	*	GAS*
MS_01	М	51	5	4	3	4	16	4	7	11	14	6	0.73	85	43	43.2
MS_02	F	36	13	12	10	8	43	12	5	17	15	11	0.78	45	42	46.9
MS_03	F	55	16	15	20	16	67	8	13	21	16	13	0.70	64	32	38.6
MS_04	F	50	9	12	10	7	38	7	6	13	16	12	0.50	40	38	43.2
MS_05	F	44	11	9	5	8	33	3	4	7	10	12	0.88	63	39	43.2
MS_06	F	39	15	16	12	13	56	21	17	38	19	20	0.21	20	36	41.9
MS_07	F	33	14	12	13	11	50	13	9	22	18	12	0.70	70	47	43.2
MS_08	F	52	14	11	11	13	49	11	10	21	18	15	0.65	60	33	38.6
MS_09	F	57	10	8	5	4	27	14	12	26	17	15	0.28	20	34	43.2
MS_10	F	55	8	6	4	6	24	4	2	6	16	10	0.76	70	40	43.2
MS_11	М	45	9	11	11	8	39	4	6	10	8	14	0.51	35	40	43.2
MS_12	F	47	13	15	13	14	55	17	15	32	18	14	0.62	50	35	43.2
MS_13	М	31	11	6	4	7	28	7	1	8	10	4	0.86	96	42	43.2
MS_14	F	35	14	12	8	7	41	10	11	21	14	11	0.85	45	32	38.6
MS_15	F	62	14	7	11	13	45	9	11	20	13	11	0.62	60	46	45.1
Mean	-	46.13	11.73	10.4	9.33	9.27	40.73	9.6	8.6	18.2	14.8	12	0.63	54.87	38.6	42.57
(SD)		(9.58)	(3.06)	(3.62)	(4.58)	(3.77)	(13.67)	(5.19)	(4.69)	(9.3)	(3.32)	(3.76)	(0.20)	(21.59)	(4.87)	(2.34)
Min		_	0	0	0	0	0	0	0	0	0	0	0	0	10	_
score	_	_	0	U	0	0	0	0	0	0	0	0	U	0	10	
Max	_	_	20	20	20	20	80	21	21	42	22	20	1	100	50	_
score			20	20	20	20	00	21	21	72	22	20	1	100	50	
Cut-off		-	-	-	-	-	40	8	8	-	Low (<10) Medium (11-16) High (17>)	-	-	-	-	-

#### Table 21 Baseline Data

MS: Multiple Sclerosis, SD: Standard Deviation, F: Female, M: Male, Min: Minimum; Max: Maximum; PDQ: Perceived deficit questionnaire, Att: Attention, Plan: Planning, R.Mem: Retrospective Memory, P.Mem: Prospective Memory, HADS: Hospital Anxiety and Depression Scale, Anx: Anxiety, Dep: Depression, MS-WIS: Multiple Sclerosis Work Instability Scale, MFIS-5: Modified Fatigue Impact Scale -5 items, EQ-5D-5L: EuroQol 5-dimensions, 5 levels, WSES= Work Self-efficacy Scale; GAS: Goal Attainment Scale. \*Questionnaire where a higher score is a positive outcome.

The baseline data shows a diverse group of participants with MS. At baseline, the mean score for the PDQ was 40.73 (SD=13.67). A score above 40 suggests significant cognitive deficits. The scores of the participants with MS on the PDQ ranged from 16 to 67, with eight participants scoring above the cut-off ( $\geq$ 40).

The mean HADS anxiety score at baseline was 9.6 (SD=5.19). Nine participants scored above the cut-off score of probable anxiety ( $\geq$ 8). The mean HADS depression score at baseline was 8.6 (SD=4.69). Eight participants scored above the cut-off score of probable depression ( $\geq$ 8). The same participants with MS that scored above the cut-off score of the HADS depression, scored above the cut-off score of the HADS depression, scored above the cut-off score of the HADS anxiety. These figures suggest that most participants were experiencing moderate levels of anxiety and feelings of depression.

Regarding work instability, the mean MS-WIS baseline score was 14.8 (SD=3.32). Three participants with MS were experiencing a low risk of work instability, with a score at or below the cut-off score of 10 points. Seven participants experienced moderate risk of work instability with scores ranging between 11-14 points, and five participants scored above the cut-off score of 17 points, suggestive of a high risk of work instability.

The participants with MS experienced moderate to high levels of fatigue, with an average MFIS-5 baseline score of 12 (SD=3.76). The median score for this test was 12 points, and only two participants scored below 10 points (out of a maximum of 20), suggesting low fatigue levels. One participant scored at the ceiling (20 out of 20), suggesting severe levels of fatigue.

In terms of quality of life, the participants reported an average health index on the EQ-5D-5L of 0.63 (SD=0.2) at baseline; and an average health today of 54.87 (SD=21.59), reflecting a moderate to low quality of life.

The participants experienced moderate work self-efficacy with an average score of 38.6 (SD=4.87) at baseline. All the participants scored above 30 points (out of 50), and their performance as a group in this measure was more homogeneous than in the rest of the measures.
### 5.6.3. Case Study

Table 22 summarises the scores of the participants with MS on the outcome measures over six months. These will be referred to through the individual case study results.

For all participants with MS, the intervention was delivered by an assistant psychologist (PhD researcher) with experience working with people with MS who was mentored by an OT with experience delivering VR. The sessions were delivered individually and remotely (telephone or Microsoft Teams) because of Covid-19 restrictions. The intervention content was tailored according to the intervention goals and participant's needs.

Intervention fidelity was not assessed. However, information about sessions offered and received, as well as length and topics covered were recorded and reported in the sections describing the intervention for each participant with MS.

Me	easure	MS_01	MS_02	MS_03	MS_04	MS_05	MS_06	MS_07	MS_08	MS_09	MS_10	MS_11	MS_12	MS_13	MS_14	MS_15	Mean (SD)
	Baseline	16	43	67	38	33	56	50	49	27	24	39	55	28	41	45	40.73 (13.67)
ğ	Post-int	19	38	61	45	25	48	33	56	25	42	41	45	25	32	37	38.13 (11.97)
Ы	3M FU	27	31	60	41	32	N/A	52	47	26	38	38	41	23	25	45	37.57 (10.99)
	6M FU	29	41	64	52	22	N/A	40	44	28	35	27	N/A	27	N/A	40	37.42 (12.09)
	Baseline	4	12	8	7	3	21	13	11	14	4	4	17	7	10	9	9.60 (5.19)
DS DS	Post-int	9	9	5	11	4	15	7	15	13	5	5	16	7	16	10	9.80 (4.33)
HA	3M FU	5	12	2	12	3	N/A	14	13	13	6	6	10	6	4	9	8.21 (4.12)
4	6M FU	6	13	7	13	4	N/A	9	11	13	7	5	N/A	5	N/A	10	8.58 (3.37)
	Baseline	7	5	13	6	4	17	9	10	12	2	6	15	1	11	11	8.60 (4.69)
DS da	Post-int	9	9	10	10	5	10	5	10	11	4	4	11	3	12	12	8.33 (3.18)
ΡH	3M FU	8	7	10	8	4	N/A	11	9	12	5	8	6	1	6	14	7.79 (3.38)
	6M FU	11	9	14	8	6	N/A	7	9	12	3	5	N/A	3	N/A	11	8.17 (3.51)
	Baseline	14	15	16	16	10	19	18	18	17	16	8	18	10	14	13	14.80 (3.32)
IS S	Post-int	12	12	15	17	13	17	13	21	19	14	9	20	9	11	15	14.46 (3.74)
MW	3M FU	15	17	14	14	14	N/A	14	20	18	10	14	16	10	9	13	14.29 (3.12)
	6M FU	16	17	19	14	15	N/A	13	20	17	14	13	N/A	9	N/A	15	15.17 (2.95)
ŝ	Baseline	6	11	13	12	12	20	12	15	15	10	14	14	4	11	11	12 (3.76)
-S-	Post-int	10	8	16	11	14	12	8	15	15	6	14	14	5	13	13	11.6 (3.46)
Æ	3M FU	10	12	14	18	12	N/A	15	13	15	8	13	10	7	9	13	12.07 (3.02)
~	6M FU	13	10	19	14	10	N/A	6	11	15	8	12	N/A	8	N/A	11	10.54 (4.63)
4	Baseline	0.73	0.78	0.70	0.51	0.89	0.21	0.70	0.65	0.28	0.77	0.51	0.62	0.86	0.85	0.62	0.65 (0.20)
Ġ.	Post-int	0.66	0.86	0.46	0.51	0.72	0.44	0.75	0.62	0.39	0.77	0.39	0.62	0.88	0.85	0.52	0.63 (0.17)
Š 2	3M FU	0.73	0.81	0.46	0.43	0.83	N/A	0.6	0.65	0.39	0.72	0.46	0.66	1	0.92	0.59	0.66 (0.19)
щ	6M FU	0.65	0.87	0.62	0.37	0.89	N/A	0.76	0.67	0.36	0.67	0.7	N/A	0.84	N/A	0.36	0.63 (0.18)
*	Baseline	43	42	32	38	39	36	47	33	34	40	40	35	42	32	46	38.60 (4.87)
ES	Post-int	37	46	34	35	40	37	48	34	32	40	44	37	43	35	41	38.87 (4.78)
SN	3M FU	41	46	30	40	37	N/A	41	41	37	42	43	44	42	39	44	40.50 (3.96)
-	6M FU	38	42	27	39	39	N/A	48	36	31	41	43	N/A	39	N/A	42	38.75 (5.53)
	Baseline	43.2	46.9	38.6	43.2	43.2	41.9	43.2	38.6	43.2	43.2	43.2	43.2	43.2	38.6	45.1	42.57 (2.34)
Š	Post-int	72.8	50	63.7	72.8	54.6	60.8	68.3	50	40.9	59.1	59.1	63.7	68.3	63.7	59.8	60.50 (8.85)
GA	3M FU	63.7	50	63.7	40.9	59.1	N/A	50	59.1	40.9	54.6	68.3	45.4	59.1	68.3	68.6	56.55 (9.79_
-	6M FU	77.4	50	68.3	54.6	54.6	N/A	50	54.6	36.3	54.6	68.3	N/A	59.1	N/A	62.3	57.51 (10.66)
Post-In Scleros Standar	6M FU 77.4 50 68.3 54.6 54.6 N/A 50 54.6 36.3 54.6 68.3 N/A 59.1 N/A 62.3 57.51 (10.66) Post-Int: Post-intervention, 3M: 3 months, 6M: 6 months, FU: Follow-up, PDQ: Perceived deficit questionnaire, HADS: Hospital Anxiety and Depression Scale, Dep: depression, MS-WIS: Multiple Sclerosis Work Instability Scale, MFIS-5: Modified Fatigue Impact Scale -5 items, EQ-5D-5L: EuroQol 5-dimensions, 5 levels, WSES= Work Self-efficacy Scale, GAS: Goal attainment scale, SD: Standard Deviation *Ouestionnaire where a higher score is a positive outcome N/A: Not Available i.e. participant lost at follow-up																

### Table 22 Summary participants' scores over 9 months.

## 5.6.3.1. Case Study MS\_01 "Ian"<sup>7</sup>

### Participant information

Ian is a 51-year-old white British man, who was diagnosed with SPMS two years ago, however, he experienced symptoms suggestive of MS up to 23 years before the definitive medical diagnosis. Ian presents with a medium disability level (EDSS=4), and the main MS symptoms that he experiences are difficulties walking and pain.

Ian completed his A-levels and is a Senior Network Analysis for a large public company. He works full-time (37.5 hours); however, he has a busy role and frequently works over 45 hours per week.

Ian lives with his wife and son. He enjoys gardening and cleaning his car, but lately, he is finding these activities more challenging because of the physical difficulties caused by his MS.

### Timeline

A few years ago, Ian had a stressful job in a private company that required him to travel through Europe frequently. As the job was becoming challenging, he moved to his current post where he receives a lower salary, but he is managing his finances well and his quality of life has improved.

Ian initially reported that he did not experience problems at work, as his line manager had provided him with reasonable accommodations such as a flexible working schedule and reduced the physical aspects of his role.

He was interested in the intervention because his role is cognitively demanding and involves solving complex network problems. He also has to take an exam yearly to update a certification to remain at work. As he is relatively newly diagnosed, he had multiple questions about MS and was becoming overly concerned about how the cognitive deficits that MS can cause would affect him.

# Assessment

<sup>&</sup>lt;sup>7</sup>Pseudonyms used to protect the anonymity of the participants.

At baseline, Ian reported that the impact of his MS on work productivity (WPAI:MS 3 out of 10), and his everyday activities (WPAI:MS 2 out of 10) was low.

His perceived cognitive difficulties (PDQ 16 out of 80), fatigue (MFIS-5 6 out of 20) anxiety (HADS anxiety 4 out of 21), and depression (HADS depression 7 out of 21) levels were low, and his work instability score was moderate (MS-WIS 14 out of 22).

In terms of quality of life as measured by the EQ-5D-5L, Ian obtained an index health status of 0.65 (out of 1.0), and an overall health of 60 (out of 100). Ian reported high work self-efficacy (WSES 43 out of 50), addressing problems and managing relationships with colleagues.

At work, Ian was allowed to take more breaks, work from home (even before Covid-19) and was provided with more supervision.

**Intervention reasoning:** The first intervention topic aimed at supporting Ian to better understand MS, its symptoms and progression. The second intervention topic was focus on understanding the impact of cognitive problems at work, and how to manage them better.

#### Intervention

The description of the intervention is presented in Table 23.

Table 23 In	ntervention	Description	MS_01
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Criteria	Description			
WhyIan was concerned about the impact of cognitive problems at we was worried about his ability to work in the future.				
What materials?	<ul> <li>Screening interview</li> <li>Session 2: Fatigue management online course MS Society</li> <li>Session 3: Mobile app (iPrescribe exercise), and Staying Smart website (MS Trust)</li> <li>At the end of each session, Ian received an email with a summary of the main points discussed and the next steps.</li> </ul>			

Criteria	Description			
	The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Ian did not involve his line manager in the intervention, as there was a recent change in management, and he had a new manager.			
	following topics:			
	(i) <u>Understanding MS</u> : This session addressed the progressive nature of MS and its most common symptoms. The session focused particularly on cognitive problems that MS can cause, memory problems he experienced at work, and ideas to manage the difficulties. The session also covered word-finding difficulties, as he became aware of these difficulties when he was tired.			
What procedures	(ii) <u>Reasonable accommodations</u> : The second session discussed what reasonable accommodations are, identified further support for Ian at work, and organisations that provide further support for people with MS. The session finished discussing MS-related fatigue, and ideas to manage fatigue at work. Ian was provided with an online fatigue management course to complement the content of the session.			
	(iii) <u>Cognition in MS</u> : This session reviewed the progress made with the fatigue management course and using the techniques to manage the memory problems at work. In the end, we discussed the relationship between fatigue and exercising, and Ian was provided with a mobile app that created individually tailored exercise plans.			
	<b>Indirect support:</b> The indirect support included the following activities: (i) liaison with participant, (ii) administrative tasks, and (iii) preparation of materials for the session.			
How	The sessions were conducted using Microsoft Teams.			
When and how much?	<ul> <li>The first step involved an initial interview and goal setting (1 hour).</li> <li>Over the three-month intervention, Ian received 3.17 hours of direct support, spread over three sessions, and 0.83 hours (50 minutes) of indirect support. In total, the intervention time plus the interview accounted for 5 hours of support.</li> <li>Direct support: Ian participated in three sessions ranging between 60-</li> </ul>			
now much.	70 minutes. The time spent on each intervention topic was as follows: (i) Cognition in MS (20 mins), (ii) managing cognitive problems at work (40 mins), (iii) discussing word-finding difficulties (20 mins), (iv) fatigue management (40 mins), (vi) understanding reasonable accommodations and needs at work (20 mins), (vii) mobility and MS (10 mins), and (viii) resources for the future (20 mins).			

Criteria	Description
	<b>Indirect support:</b> The indirect support ranged between 10-30 minutes
	per session delivered. The time included on each activity was: (i) administrative tasks (30 mins), and (ii) preparation of materials for sessions (20 mins).
How well?	All the topics agreed upon in the initial interview were discussed. There was an agreed end of the intervention, and Ian received an email three weeks after the final session to see if he needed further support.

#### Follow-up and Outcomes

Table 22 presents an overview of Ian's performance on the different outcome measures included in the study.

At the post-intervention assessment, Ian worsened on all outcome measures except for work instability, where he improvement slightly (MS-WIS from 14 to 12). The productivity impact of his MS at work decreased one point from baseline to postintervention (WPAI:MS from 3 to 2), however, the impact of the MS on everyday activities (e.g., housework, shopping) increased five points (WPAI:MS from 2 to 7), reflecting that MS was almost preventing him from conducting daily activities.

Ian's performance worsened on perceived cognitive deficits (PDQ from 16 to 19), anxiety levels (HADS anxiety from 4 to 9), depression levels (HADS depression from 7 to 9), fatigue levels (MFIS from 6 to 10), and quality of life (EQ-5D-5L Health Index from 0.73 to 0.66). There was no clinically significant change in the levels of anxiety (RIC= -1.88) and depression (RIC= -0.73) on the HADS.

At three months follow-up, Ian worsened again on perceived cognitive deficits (PDQ score from 16 to 27), fatigue levels (MIFS-5 from 6 to 10) and work self-efficacy (WSES score from 43 to 41).

At six months follow-up, Ian also experienced a worsening on perceived cognitive deficits (PDQ score from 16 to 29), anxiety (HADS anxiety from 4 to 6), depression (HADS depression from 7 to 11), fatigue (MFIS-5 from 6 to 13), quality of life (EQ-5D-5L Health Index from 0.73 to 0.65) and work self-efficacy (WSES from 43 to 38).

Ian's scores on the HADS (Figure 12), PDQ (Figure 13) and MS-WIS (Figure 14) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 12 MS\_01 HADS score over 9 months.



Figure 13 MS\_01 PDQ score over 9 months.



Figure 14 MS\_01 MS-WIS score over 9 months.

Intervention Goals: Ian set the following goals at the beginning of the intervention:

• Goal 1: I want to learn what I can do better at work.

**SMART Goal:** To identify at least two reasonable accommodations that can be beneficial for Ian at work by the end of the intervention.

• Goal 2: I want to understand what MS is and its symptoms.

**SMART Goal**: To identify at least two MS symptoms that are causing a significant impact on the personal and professional life of Ian by the end of the intervention.

• Goal 3: I want to understand how to cope with my MS.

**SMART Goal**: To identify at least two strategies to help Ian manage his MS symptoms identified in the previous goal.

Table 24 presents the progress made by Ian over the six months follow-up with regards to his intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	+2 Goal met much more than expected. Ian learnt different approaches to manage the physical and cognitive side of MS at work and saw a positive impact in the way he manages his workload.	+2 Goal met much more than expected. Ian formally requested reasonable accommodations from his line manager, which previously he had	+2 Goal met much more than expected. Ian had received further support at work and was managing well his condition at work.
		do.	
2	+2 Goal met much more than expected. Ian discussed the implications of the MS diagnosis and learnt about the impact that fatigue and memory thinking problems can have at work.	<ul> <li>O Goal met as expected.</li> <li>Ian became more confident identifying when his MS symptoms were getting worst at work.</li> </ul>	+2 Goal met much more than expected. Ian continued learning how to manage his symptoms at work.
3	+1 Goal met more than expected. He learnt strategies to manage MS-related fatigue and started taking breaks at work at regular intervals to manage his fatigue.	+1 Goal met more than expected. He continued learning about MS- related fatigue and has incorporated further strategies in his everyday work to continue improving.	+2 Goal met much more than expected. Ian reported feeling positive about his future working with MS.
GAS	72.8	63.7	77.4

# Patient's perspective

Ian completed a Microsoft Teams interview at three months follow-up explaining his experiences receiving the support (Table 25).

Table 25	Qualitative	findings	MS_01
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Theoretical Construct	Supporting Quotes
Characteristics of	Ian had a positive experience receiving the support:
individuals (CIFR).	"Getting to understand how much I can do before I need to take a break and learning that when I try to push too far, it harms longer, than if I take a break for five minutes and come back. So a lot of those things have been invaluable really. I don't know how I would have found all that information."
	Ian reported a positive impact managing his MS symptoms:
	"I didn't know how to try and manage things and think about taking breaks and stuff like that, and what used to happen was that I used to kind of go down the slope and get worse and worse, but then I will be getting depressed because I was struggling, and then I had problems sleeping and so on. I do not have any of that now. The reason why I don't have that now is that I have self-confidence. I feel like I can manage how I am dealing with things or at least adapt quickly."
Intervention Characteristics	Ian reported the relevance of having a safe environment to share his feelings:
(CIFR).	"The most important characteristics I think is [the therapist] being very personable. What I mean by that is when I have been talking with you [PhD student] at no point I have felt as if you were making assumptions, or snap decisions about me, my life or how I deal with things. I think that is very important because I think you probably have spoken with other people with MS, and we may all be different, and there are so many things out there trying to put people in boxes, in categories. So being personal, and it does feel as if you are talking directly to me, rather than talking to an MS group, that's very important."
Motivation	Using a fatigue diary was not helpful for Ian:
(BCW)	"The fatigue diary that kind of managing how I feel hour to hour, which I did four days I think it was, I felt as if I was well same as last time, same as last time, same as last time. And it almost felt as if I wasn't getting much out of that."
Personal factors	Ian now feels confident about the future:
(ICF)	"So a couple of things one getting a feel for how different people are affected in different ways, but also talking about the techniques for managing that, and dealing with that, what

Theoretical Construct	Supporting Quotes
	that has done for me personally it feels as if in my head there was a roadblock on my career somewhere in the distance. But it feels that I have got more of an idea and information about how to delay that roadblock"

### Summary of case

During the initial interview, Ian reported that he wasn't experiencing problems at work, as his line manager was very supportive, and had provided him with reasonable accommodations. However, as the intervention progressed, it was clear that his lack of understanding of MS was making him anxious about his ability to remain at work in the future, and by extension, the uncertainty was making him depressed.

At the end of the intervention, Ian's scores on all outcome measures worsened, in part because of unexpectedly high demand at work. However, Ian reported in the interview that participating in the VR intervention helped him achieve his intervention goals and made him feel more positive and confident at work.

# 5.6.3.2. Case Study MS\_02 "Sarah"<sup>8</sup>

# Patient Information

Sarah is a 36-year-old white British woman, who was diagnosed with RRMS eleven years ago. Sarah presents with little disability (EDSS=2), and her main MS symptoms are fatigue, memory and word-finding difficulties. Sarah completed a bachelor's degree and is a part-time (21 hours per week) accounts administrator for a large private company, Sarah lives with her partner and enjoys going for walks.

# <u>Timeline</u>

Sarah had been working in her current role for 10 years and was keen on promotion at work. However, she believed that she would not be promoted because of her MS. Sarah reported that she was not experiencing problems at work, as her line manager

<sup>&</sup>lt;sup>8</sup> Pseudonyms used to protect the anonymity of the participants.

had provided her with reasonable accommodations such as reducing her working hours to manage better her fatigue. She was interested in understanding what she could do to manage her memory problems at work.

#### Assessment

At baseline, Sarah reported that the impact of her MS on her productivity at work was very high (WPAI:MS 8 out of 10), and its impact on her everyday activities, medium (WPAI:MS 5 out of 10).

She scored 43 (out of 80) on the PDQ, suggesting considerable perceived cognitive difficulties, and her HADS anxiety score suggested moderate levels of anxiety (12 out of 21). She was experiencing moderate levels of work instability (MS-WIS 15 out of 22), and fatigue (MFIS-5 11 out of 20). However, work self-efficacy was good (WSES 42 out of 50), and scores on the HADS indicated low levels of depression (5 out of 21). In terms of quality of life she obtained high index health of 0.78 (out of 1.0) as measured by the EQ-5D-5L, but a low overall health of (45/100).

At work, Sarah was allowed to take additional breaks and was given extra supervision. Because she had reduced her working hours, this led to a reduction of workload and responsibilities at work. Sarah was not allowed to work from home, but because of the national lockdown, she was temporarily working from home.

**Intervention reasoning:** Sarah was interested in learning about fatigue management and managing cognitive problems at work. The assistant psychologist suggested reviewing what further support she could receive at work, as the baseline data reflected that her MS was negatively impacting her work, and she had medium levels of work instability. However, Sarah rejected the option to discuss reasonable accommodations in the intervention.

#### Intervention

The intervention is described in Table 26.

Criteria	Description
Why	Sarah reported that she was not experiencing problems at work. However, she was interested in receiving VR support to help her manage her fatigue and cognition better at work.
What materia ls?	<ul> <li>Screening interview</li> <li>Session 1: Fatigue management online course MS Society.</li> <li>Session 2: Memory and thinking problems booklet MS Society.</li> <li>At the end of each session, Sarah received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedu res	The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Sarah did not involve her line manager in the intervention and only selected two intervention goals. <b>Direct support:</b> Sarah participated in three sessions addressing the following topics: (i) <u>Fatigue management:</u> This session addressed MS-related fatigue, factors that can cause fatigue, and fatigue management at work. (ii) <u>Cognition in MS:</u> This session addressed the types of cognitive problems characteristic of MS, identify how Sarah experiences these problems at work and ideas to manage them. (iii) <u>Progress made and further questions:</u> This session reviewed the progress made with the fatigue management course, and progress using the techniques to manage the memory problems at work. In the end, we discussed resources for the future should she need further help managing her MS at work. <b>Indirect support:</b> The indirect support included the following activities: (i) liaison with participant, (ii) administrative tasks, and (iii) preparation of materials for the session.
How	The sessions were conducted via telephone.

 Table 26 Intervention Description MS\_02

Criteria	Description		
	The first step involved an initial interview and goal setting (30 mins).		
	support, spread over three sessions, and 0.67 hours (40 minutes) of indirect support. In total, the intervention time plus the interview accounted for 3.3 hours of support.		
When and how much?	<b>Direct support:</b> Sarah participated in three sessions ranging between 30- 50 minutes. The time spent on each intervention topic was as follows: (i) fatigue management (40 mins), (ii) support managing cognitive problems at work (30 mins), (iii) discussing legal rights and Equality Act (20 mins), (iv) reasonable accommodations (10 mins), (vi) anxiety in MS (20 mins), and (vii) resources for the future (10 mins).		
	<b>Indirect support:</b> The indirect support ranged between 10-20 minutes per session delivered. The time included on each activity was: (i) liaison with participant (20 mins), (ii) administrative tasks (10 mins), and (iii) preparation of materials for sessions (10 mins).		
How well?	Sarah was unwilling to discuss reasonable accommodations at work during the intervention and didn't engage much in the discussions. There was an agreed end of the intervention and Sarah received an email three weeks after her final session to see if she needed further support.		

#### Follow-up and Outcomes

Table 22 presents an overview of Sarah's performance on the different outcome measures included in the study.

At the post-intervention assessment, Sarah improved on all outcome measures except for depression levels (HADS depression from 5 to 9). Sarah's self-perceived cognitive difficulties (PDQ from 43 to 38), anxiety(HADS anxiety from 12 to 9) and self-rated work instability reduced (MS-WIS from 15 to 12), as did fatigue levels (MFIS-5 from 11 to 8). She also experienced an improvement in work self-efficacy (WSES from 42 to 46), and quality of life (EQ-5D-5L Health Index from 0.78 to 0.86). There was no clinically significant change in the levels of anxiety (RIC= 1.13) or depression (RIC= -1.46) of the HADS. Sarah reported that the impact of her MS on work productivity had decreased slightly (WPAI:MS from 8 to 7); however, the impact of the MS on everyday activities (e.g., housework, shopping) increased by two points (WPAI:MS from 5 to 7).

At three months follow-up, Sarah experienced a worsening on perceived cognitive deficits (PDQ score from 43 to 31) and work instability (MS-WIS from 15 to 17). She also reported improved quality of life (EQ-5D-5L Health Index from 0.78 to 0.81).

At six months, Sarah's depression levels had increased (HADS depression from 5 to 9); but her quality of life improved (EQ-5D-5L Health Index from 0.78 to 0.87).

Sarah's scores on the HADS (Figure 15), PDQ (Figure 16) and MS-WIS (Figure 17) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 15 MS\_02 HADS score over 9 months.



Figure 16 MS\_02 PDQ score over 9 months.



Figure 17 MS\_02 MS-WIS score over 9 months.

**Intervention Goals:** Sarah set the following goals at the beginning of the intervention:

• **Goal 1:** Understand how to manage fatigue.

SMART Goal: To identify at least two fatigue management techniques that

Sarah can implement at work by the end of the intervention.

• Goal 2: Manage memory problems at work.

**SMART Goal**: To identify at least three strategies that Sarah could implement at work to manage her memory problems by the end of the intervention.

Table 27 presents the progress made by Sarah over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	<b>0</b> Goal met as expected. Sarah learnt about scheduling periodic breaks and reducing the number of non- essential activities that had an impact on her fatigue levels.	<ul> <li>O Goal met as expected.</li> <li>Sarah still uses the fatigue management techniques discussed in the sessions.</li> </ul>	<ul> <li>O Goal met as expected.</li> <li>Sarah reported no changes from the previous assessment.</li> </ul>
2	0 Goal met as expected. Sarah learnt to use memory aids, how to minimise distractions at work and how to structure her work to manage her memory difficulties.	<ul> <li>O Goal met as expected.</li> <li>Sarah continues to learn and implement the techniques to manage memory problems at work</li> </ul>	<ul><li>0 Goal met as expected.</li><li>Sarah reported no changes from the previous assessment.</li></ul>
GAS	50	50	50

Table 27 Goal attainment for participant MS\_02

**Unanticipated events:** Sarah was particularly reluctant to discuss the possibility of identifying further reasonable accommodations that might benefit her at work.

# Patient's perspective

Sarah completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 28).

Theoretical	Supporting Quotes
Construct	
Characteristics of individuals (CIFR).	Sarah was not experiencing problems at work, so she didn't have many questions to address with the support: "I suppose it's been interesting; I don't reallybecause I don't experience problems at work, I wasn't sure if taking part was the right participant for you."

Table 28 Qualitative findings MS\_02

	However, she still managed to find relevant information for her:
	<i>"I think you gave me lots of tips on things that I could use like the app that I need my doctor to use. And a lot of the things that you said about fatigue were quite interesting."</i>
Intervention	Sarah recognised that working part-time helped her to
Characteristics	incorporate the study into her diary:
(CIFR).	<i>"Interviewer: and was it easy to incorporate in your schedule?</i> Participant: yes, more or less, but I don't work full-time, so I have time to do it."
Motivation	She believed that other people with MS could benefit from
(BCW)	learning about the experiences of other people who do not experience problems at work:
	"Maybe you should be telling people who are having problems at work, that there are people who are not having problems, to get reassurance. So those that needed more hours, kind of reassurance that there are people out who don't have problems and get there."

# Summary of case

Sarah reported that she had no problems at work during the initial interview. However, when reviewing the data from the baseline assessment, the data presented a different picture. She was experiencing cognitive difficulties and medium levels of work instability and anxiety.

Overall, she seem to benefit more from reading materials than having the sessions, as during the sessions she was potentially engaging in other activities at home or outside the home, even though the sessions were booked at her preferred time and modality. During the interview, she reported that the intervention was indeed beneficial, and she was using the knowledge she gained.

# 5.6.3.3. Case Study MS\_03 "Lucia"<sup>9</sup>

# Patient Information

Lucia is a 55-year-old white British woman, diagnosed with RRMS three years ago. She has a moderate disability level (EDSS=6.5) suggestive of great difficulties walking. Lucia completed her college education and is working part-time (24

<sup>&</sup>lt;sup>9</sup> Pseudonyms used to protect the anonymity of the participants.

hours/week) as a customer service advisor in a small private company. She has been working in the company for six years. Lucia lives on her own, and experiences economic difficulties, as her salary is just enough to cover her expenses. She engages in few social activities because of the impact of her MS symptoms. Lucia enjoys learning Spanish and gardening, although she finds gardening is becoming more challenging with time.

#### **Timeline**

Lucia was in a work crisis at the time of the assessment. Over the last six years, she had had three different line managers, and only one of them had been supportive of her MS. Before Covid-19, she was having difficulties at work because senior managers did not allow her to discuss her MS at work with other colleagues, because they felt she would distract them. Lucia had also been prompted several times to reduce her working hours; however, for economic reasons, she could not accept a contract with fewer hours.

During the national lockdowns, Lucia was unable to work from home because she did not have internet or a computer/laptop at home to work. The company provided dongles to some employees in her situation, but they reported not have one for her.

Lucia's line manager contacted her during the first lockdown to inform her that they were planning a phased RTW for her, and they reduced 4 hours per week of her contract. This decision was made without Lucia's consent, and she had economic worries because of the change in working hours.

#### Assessment

At baseline, Lucia was employed but unable to work from home because of not having access to the internet or a computer; hence, she had only worked 6 hours on her tablet. She reported that the productivity impact of her MS at work was relatively low (WPAI:MS 3 out of 10); however, her MS had had a negative impact (WPAI:MS 6 out 10) on her everyday activities.

She scored at or above clinical levels on most measures. She was experiencing considerable self-perceived cognitive difficulties (PDQ 67 out of 80), high levels of work instability (MS-WIS 15 out of 22), anxiety (HADS anxiety 8 out of 21), depression (HADS depression 13 out of 21), fatigue (MFIS-5 13 out of 20), and low

work self-efficacy (32 out of 50) suggestive of difficulties addressing problems and managing relationships with colleagues.

In terms of quality of life (EQ-5D-5L), Lucia reported an overall health of 45 out of 100 and obtained an index health status of 0.70. These values indicate a negative impact of MS on her quality of life.

Regarding workplace modifications, Lucia was allowed to take more breaks, had reduced responsibilities (as a result of reducing her working hours) and was only allowed to work from home during the national lockdowns. She had no problems getting to and from work, as she had previously applied to Access to Work and had free taxis to go to work.

**Intervention reasoning:** There were several high priority points in this intervention. The first one related to educating Lucia about her legal rights as a person working with MS; and finding financial support for Lucia, so that she could afford the internet to work from home. The second intervention topic referred to vocational exploration to find alternative employment as the relationship with her line manager had worsened over time. The third intervention topic was concerned with managing cognitive problems at work because she was having great difficulty following telephone conversations with clients. As a result, she received negative feedback from clients who felt she was not listening.

#### Intervention

The intervention is presented in Table 29.

Criteria	Description
Why	Lucia was experiencing a work crisis and needed VR support to help her manage her MS at work and to understand her legal rights.
What materia ls?	<ul> <li>Screening interview</li> <li>Session 1: Disability law service<sup>10</sup>, citizens advice information, ACAS (The Advisory, Conciliation and Arbitration Service).</li> <li>Session 2: Citizens Advice Universal Credit, Turn2Us.</li> </ul>

Table 29 Intervention description Case Study MS\_03

<sup>&</sup>lt;sup>10</sup> National charity providing free legal advice to disabled adults, children and carers.

Criteria	Description
	<ul> <li>Session 4: Document with resources for the future with information to find support for mental health, legal advice, and support with benefits such as Turn2Us.</li> <li>Session 7: NHS every mind matters.</li> <li>Session 8: Fatigue management booklet and online course MS Society</li> <li>At the end of each session, Lucia received an email with a summary of the main points discussed and the next steps.</li> </ul>
	The first step involved an initial interview and goal setting to prioritise the intervention topics according to how urgent they were. Lucia involved her line manager in the intervention.
	<b>Direct support:</b> Lucia participated in eight sessions addressing the following topics:
	(i) <u>Legal Rights:</u> The first session focused on developing an action plan to request further support from her line manager, providing information about legal rights, and exploring the possibility of applying for benefits.
	(ii) <u>Support accessing benefits</u> : This session reviewed the benefits available and the support that she qualified for. Lucia qualified for Universal Credit <sup>11</sup> and Council Tax <sup>12</sup> Covid-19 Hardship relief. She agreed to apply for Universal Credit.
What procedu res	(iii) <u>Working during Covid-19</u> : This session focused on empowering Lucia to have a conversation with her line manager about the phased RTW to ensure her salary didn't change as a result of the change in working hours. This included conversations about her legal rights, work contract, and how to negotiate a change with the line manager.
	(iv) <u>Issues with employer</u> : This session covered the progress made with the phased RTW, difficulties encountered in the conversation with the line manager, and progress made with the benefits applications.
	(v) <u>Issues with employer (2):</u> This session included a follow-up discussion regarding Lucia's RTW; as her line manager finally agreed to pay Lucia's full salary on the phased RTW. The session finished addressing Lucia's worries about her cognitive difficulties.
	(vi) <u>Cognition in MS</u> : This session provided an overview of what cognitive problems are, identified the main problems she was experiencing, such as difficulties managing telephone conversations, and ideas to manage each problem.

 <sup>&</sup>lt;sup>11</sup> Social security payment.
 <sup>12</sup> Local taxation system on domestic properties (applies to England, Scotland and Wales).

Criteria	Description
	(vii) <u>Cognition in MS</u> : This session reviewed the progress Lucia had made in implementing the strategies for managing cognition previously discussed and exploring further cognitive difficulties. This session briefly covered the impact of emotions on cognition.
	(viii) <u>Fatigue management:</u> This session reviewed what MS-related fatigue is, the main factors that cause fatigue, and tips to manage fatigue. The session also included a review of the final steps of the benefits application.
	<b>Indirect support:</b> The indirect support included the following activities: (i) support obtaining financial advice, (ii) preparation of materials for sessions, (iii) support applying for benefits, (iv) liaison with line manager and HR, (v) liaison with the Disability Law Service, (vi) liaison with participant, (vii) administrative tasks, (viii) liaison with OT, and (ix) support with a work emergency.
	<b>Employer's intervention:</b> Sam (pseudonym) agreed to participate in the intervention and completed an initial interview where he reported to be concerned about the cognitive side of MS and how it was affecting Lucia at work.
	Sam completed one session to address his questions about MS and reasonable accommodations at work. This session included a conversation about the possibility of providing Lucia with a dongle and a laptop to allow her to work from home.
How	The sessions were conducted via telephone.
	The first step involved an initial interview and goal setting (1 hour 50 minutes).
	Over the three-month intervention, Lucia received 9.17 hours of direct support, spread over eight sessions, and 7.33 hours of indirect support. In total, the intervention time plus the interview accounted for 18.33 hours of support.
When and how much?	<b>Direct support:</b> Lucia participated in eight sessions lasting on average 70 minutes and ranging between 50-90 minutes. The time spent on each intervention topic was as follows: (i) cognition in MS (150 mins), (ii) support accessing benefits (130 mins), (iii) reasonable accommodations (60 mins), (iv) issues with employer (60 mins), (v) legal rights (40 mins), (vi) fatigue management (30 mins), (vii) RTW plan and working during Covid-19 (30 mins), (viii) mood in MS (30 mins), (ix) review goals and future steps (20 mins).
	<b>Indirect support:</b> The indirect support ranged between 20-170 minutes per session delivered. The time spent on each activity was: (i) Liaison with participant (90 mins), (ii) liaison with healthcare professionals (80

Criteria	Description
	<ul> <li>mins), (iii) administrative tasks (70 mins), (iv) preparation of materials for sessions (50 mins), (v) letter for employer (50 mins), (vi) obtaining legal support (40 mins), (vii) support with benefits application (30 mins), and (viii) work emergency plan (20 mins).</li> <li>Employer's intervention: Sam completed the initial interview (40 minutes) and one session addressing (i) reasonable accommodations (50 mins) and (ii) understanding MS (20 mins). The indirect intervention time was 20 minutes, and it included a report of reasonable accommodations for Lucia</li> </ul>
How well?	Lucia wanted to remain in her current role, therefore she changed the vocational exploration intervention topic to understanding her legal rights.

#### Follow-up and Outcomes

Table 22 presents an overview of Lucia's performance on the different outcome measures included in the study.

At the post-intervention assessment, Lucia's fatigue levels (MFIS-5 from 13 to 16), and quality of life (EQ-5D-5L Health Index from 0.70 to 0.46) worsened. However, the intervention had a beneficial impact on her perceived cognitive difficulties (PDQ from 67 to 61), anxiety levels (HADS anxiety from 8 to 5), depression (HADS depression from 13 to 10) and work self-efficacy (WSES from 32 to 34). Work instability remained relatively stable from baseline to post-intervention (MS-WIS from 16 to 15). There was no clinically significant change in the levels of anxiety (RIC 1.13) or depression (RIC= 1.09).

At three months follow-up, Lucia experienced a reduction in anxiety levels (HADS anxiety from 8 to 2) and depression (HADS depression from 13 to 10). The improvement in anxiety levels was clinically significant (RIC= 2.25). Lucia experienced an improvement in her perceived cognitive difficulties (PDQ from 67 to 60); and a worsening in quality of life (EQ-5D-5L Health Index from 0.70 to 0.46).

At six months follow-up, she remained relatively stable from baseline but experienced a worsening on fatigue levels (MFIS-5 from 13 to 19), work selfefficacy (WSES from 32 to 27) and work instability (MS-WIS from 16 to 19). Lucia's scores on the HADS (Figure 18), PDQ (Figure 19) and MS-WIS (Figure 20) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 18 MS\_03 HADS score over 9 months.



Figure 19 MS\_03 PDQ score over 9 months.



Figure 20 MS\_03 MS-WIS score over 9 months.

**Intervention Goals:** Lucia set the following goals at the beginning of the intervention:

• **Goal 1:** Find financial support.

**SMART Goal:** To support Lucia in identifying and compiling the documents for her benefits application by the end of the intervention.

• **Goal 2:** I find it hard to remember what work I have completed and what I am missing.

**SMART Goal**: To identify at least three aids/strategies to help Lucia manage her memory problems at work by the end of the intervention.

• **Goal 3:** I want to be able to address my problems at work by knowing my legal rights.

**SMART Goal**: To identify relevant legal support and educate Lucia about the Equality Act 2010 and her legal rights at work.

Table 30 presents the progress made by Lucia over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	+1 Goal met more than expected. Lucia applied for	<b>0</b> Goal met as expected. The application to	+1 Goal met more than expected. Because her line
	Universal Credit and the application was still pending.	Universal Credit got rejected. However, her manager provided her with a dongle to have internet at home.	manager provided her with work equipment and a dongle, she did not need further economic help.
2	<b>0</b> Goal met as expected.	+1 Goal met more than expected.	+1 Goal met more than expected.
	Lucia implemented to manage her memory difficulties at work but was still experiencing difficulties at work.	Lucia became more confident managing her memory problems at work and started receiving positive feedback from clients.	Lucia perceived an improvement in her ability to manage cognitive difficulties at work.
3	+2 Goal met much more than expected.	+2 Goal met much more than expected.	+2 Goal met much more than expected.
	Lucia started addressing her problems at work with her line manager to receive the support she needs.	Lucia became more confident in addressing problems at work and managing new issues at work.	Lucia started speaking up for her challenges and felt confident at work.
GAS	63.7	63.7	68.3

#### Table 30 Goal attainment for participant MS\_03

# Patient's perspective

Lucia was interviewed at three months follow-up about her experiences of receiving the support (Table 31).

Table 31	Qualitative findings MS_	_03
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Theoretical	Supporting Quotes
Construct	
Characteristics of	Lucia felt empowered at work as a result of the intervention:
(CIFR).	"I think the best thing I got out of it [the intervention] was the legal advice. Where I stand and my rights, and how my employer, how to deal with my employer better really. So actually that thing helped."
	at work:
	"Lucia: I do still have some [memory] issues occasionallyBut now I find that I speak slower, so the client replies slower to me, which is better because then I have to make some notes. Now I repeat back to them to kind of confirm what they said to me."
	Even though Lucia involved her employer in the study, their relationship continues to be challenging:
	<i>"Interviewer: Has there been any change in the relationship with your manager compared to before the study?</i>
	Lucia: eh yes well no, not really. He is on paternity leave for two weeks now. So I've got the other team manager looking after me now while he is out, and I have had more interaction with him in two weeks than I have in the five months lockdown from my manager."
Intervention Characteristics	Lucia would have liked to have video calls. However, she did not have internet or the necessary software for video calls:
(CIFR).	"Lucia: It would have been nice to have a face-to-face meeting so that you know who you are speaking with, but I did Google you and I know what you look likeI didn't have that [Microsoft Teams] then because of the internet connection. I only got it [Microsoft Teams] now from my work computer."
Opportunity	Lucia found the support provided in the intervention beneficial:
(BCW)	<i>"It [the intervention] was a very good experience and I gained a lot from it [the intervention]."</i>
	However, there were barriers to implementing the content learnt in the sessions:

Theoretical Construct	Supporting Quotes
	<i>"For most of the study that we did, I wasn't working because they [company] wouldn't give me any equipment at home, ironic."</i>

### Summary of case

Lucia reported having benefited greatly from the intervention. She was satisfied with the amount of support received but reported that a follow-up session would have helped her address new issues. Lucia learnt to better manage her memory difficulties during telephone conversations at work and started receiving positive feedback from clients. This was particularly important for her as in the past she had received negative feedback from clients and her line manager was monitoring her performance.

In the first national lockdown (March 2020), Lucia could not work from home because she had no internet or a computer at home. After addressing this topic in the intervention with the line manager, for the third national lockdown (January 2021), Lucia received a dongle and computer at home so that she could continue working.

Overall, Lucia needed more hours of support than initially agreed as a result of a series of issues related to working during Covid-19, and problems with her line manager.

# 5.6.3.4. Case Study MS\_04 "Emily"<sup>13</sup>

# Patient Information

Emily is a 50-year-old white British woman, who was diagnosed with SPMS three years ago, but experienced symptoms suggestive of MS for 27 years before her diagnosis and experienced a moderate disability level (EDSS=5). Emily completed her Higher National Diploma and was working part-time (8 hours/week) as a midday supervisor in a small private school. Her role required her to stand during the day, which caused her overall body pain that worsened the longer she stands. Emily lived with her husband and two children and enjoyed exercising and keeping active.

# Timeline

<sup>&</sup>lt;sup>13</sup> Pseudonyms used to protect the anonymity of the participants.

Emily is an active person who had been working from a young age. She was interested in receiving support at work because she had problems managing the physical aspect of her role. Emily's line manager was not involved because of a lack of time as a result of the Covid-19 regulations.

#### Assessment

At baseline, Emily was employed and reported a moderate (WPAI:MS 4 out of 10) impact of her MS on work productivity and a significant negative impact (WPAI:MS 8 out 10) on her everyday activities.

She experienced medium to high levels of work instability (MS-WIS 16 out of 22) and fatigue (MFIS-5 12 out of 20); and relatively low levels of perceived cognitive difficulties (PDQ 38 out of 80), anxiety (HADS anxiety 7 out of 21), and depression (HADS depression 6 out of 21). She also experienced good levels of work self-efficacy (WSES 38 out of 50).

In the questionnaire measuring quality of life (EQ-5D-5L), Emily reported overall health of 40 out of 100 and obtained an index health status of 0.51. These values represent a reduced quality of life mainly driven by the presence of pain and difficulties walking.

At work, Emily had reduced her working hours, and her role was modified to remove activities that involved walking with items in her hands (e.g., serving tables at lunchtime). Her role did not allow her to work from home, and she had not received support to manage her fatigue and pain during playground duty.

**Intervention reasoning:** Emily saw pain and fatigue as the main challenges to remaining at work. She was unsure what support was available for her and had no knowledge about how to better manage her fatigue.

Her work colleagues did not understand her condition, and were sometimes unsympathetic with her situation; thus, she was interested in learning how to explain her MS to others. The intervention also focused on supporting Emily working during Covid-19 as her school decided that no worker should wear a facemask at the school, and she was concerned because of the close contact with the kids.

#### Intervention

The intervention is presented in Table 32.

Criteria	Description	
Why	Emily needed VR support to help her better manage her MS at work.	
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Information about reasonable accommodations.</li> <li>Session 2: Workplace adjustment agreement form (Business Disability Forum &amp; MS Society)</li> <li>Session 3: iPrescribe exercise, MS Trust activity videos.</li> <li>Session 4: Mental health foundation- managing stress.</li> <li>Session 6: ACAS and Disability Law Service</li> <li>At the end of each session, Emily received an email with a summary of the main points discussed and the next steps.</li> </ul>	
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance.</li> <li><b>Direct support:</b> Emily participated in eight sessions addressing the following topics: <ul> <li>(i) <u>Reasonable accommodations:</u> This session covered an overview of what reasonable accommodations are, the Equality Act 2010, her main responsibilities at work, and reasonable accommodations for Emily.</li> <li>(ii) <u>Requesting reasonable accommodations:</u> The second session focused on developing a plan for Emily to request reasonable accommodations from the employer. This session also addressed the need for a blue badge<sup>14</sup>, parking issues in the workplace and how to address them with her line manager. Because Emily's reasonable accommodations were not formally recorded, we drafted a workplace adjustment agreement form to share with her line manager to record the support she needs.</li> <li>(iii) <u>Fatigue management:</u> This session discussed types of fatigue, factors that lead to increased fatigue, strategies to manage fatigue at work, and exercises to increase physical activity. This session also reviewed the progress made with the workplace adjustment</li> </ul> </li> </ul>	

Table 32 Intervention description Case Study MS\_04

<sup>&</sup>lt;sup>14</sup> Disabled parking permit.

Criteria	Description
	(iv) <u>Fatigue management (2)</u> : This session discussed further fatigue management techniques beneficial for Emily, as she was feeling particularly fatigued at the time because of family issues.
	(v) <u>Progress to date:</u> The session covered information about her MS treatment options, and an update from her neurologist.
	(vi) <u>Working during Covid-19</u> : This session informed Emily about the UK Government regulations for working in a school during Covid-19 and approaches to address her concern with her line manager.
	(vii) <u>Understanding MS</u> : Emily was keen to explain to her colleagues what MS meant for her. However, she was having difficulty understanding some of the symptoms and their causes. This session addressed her doubts about MS and created a structure about what to share with her colleagues.
	(viii) <u>Explaining MS to others</u> : Following on from learning about MS, the final session aimed at creating a presentation for her work colleagues covering the key aspects she wanted her colleagues to understand. This presentation was delayed because of Covid-19 restrictions.
	<b>Indirect support:</b> The indirect support included the following activities: (i) administrative tasks, (ii) preparation of materials for sessions, (iii) liaison with employer, and (iv) liaison with Disability Law Service.
How	Seven sessions were delivered via Microsoft Teams, and one session via telephone.
	The first step involved an initial interview and goal setting (1 hour).
	hours of direct support, spread over eight sessions, and 4.67 hours of indirect support. In total, the intervention time plus the interview accounted for 14 hours of support.
When and how much?	<b>Direct support:</b> The sessions lasted on average 60 minutes and ranged between 20-80 minutes. The time spent on each intervention topic was as follows: (i) reasonable accommodations (110 mins), (ii) explaining MS to others (100 mins), (iii) fatigue management (80 mins), (iv) current issues (60 mins), (v) understanding MS (30 mins), (vi) legal support (20 mins), (vii) resources for the future (20 mins), and (viii) blue badge (10 mins).

Criteria	Description
	<b>Indirect support:</b> The indirect support ranged between 10-70 minutes per session delivered. The time included on each activity was: (i) Liaison with participant (80 mins), (ii) preparation of materials (70 mins), (iii) liaison with employer (50 mins), (iv) administrative tasks (40 mins), (v) workplace adjustment agreement form (20 mins), and (vi) obtaining legal support (20 mins).
How well?	The intervention was tailored to Emily's needs. The intervention finished at the end of the three months.

#### Follow-up and Outcomes

Table 22 presents an overview of Emily's performance on the different outcome measures included in the study.

At the end of the intervention, Emily's perceived cognitive deficits (PDQ from 38 to 45) and anxiety levels (HADS anxiety from 7 to 11), depression (HADS depression from 6 to 10) increased and work self-efficacy (WSES from 38 to 35) decreased. There was a small improvement in fatigue levels (MFIS-5 from 12 to 11), and work-instability (MS-WIS from 16 to 17), and no change in quality of life. There was no clinically significant change in anxiety levels (RIC= -1.5) or depression (RIC= -1.46).

At three months follow-up, Emily experienced a worsening of her perceived cognitive deficits (PDQ from 38 to 41), anxiety (HADS anxiety from 7 to 12), fatigue (MFIS-5 from 12 to 18), and a reduction in quality of life (EQ-5D-5L Health Index from 0.51 to 0.43). The change in anxiety levels was not clinically significant (RIC= -1.88).

At six months follow-up, Emily experienced a pronounced worsening in her perceived cognitive deficits (PDQ from 38 to 52). Emily also experiences increased anxiety (HADS anxiety from 7 to 13) and reduced quality of life (EQ-5D-5L from 0.51 to 0.37). The change in anxiety levels was clinically significant (RIC= -2.25).

Emily's scores on the HADS (Figure 21), PDQ (Figure 22) and MS-WIS (Figure 23) are presented in the following figures. The orange dotted line represents the start of the VR intervention.







Figure 22 MS\_04 PDQ score over 9 months.



Figure 23 MS\_04 MS-WIS score over 9 months.

**Intervention Goals:** Emily set the following goals at the beginning of the intervention:

• **Goal 1:** I want to know what support will help me to remain at work and learn how to ask my employer for help.

**SMART Goal:** To learn and identify what reasonable accommodations could help Emily at work by the end of the intervention.

- Goal 2: The fatigue at work makes it harder.
   SMART Goal: To identify fatigue management techniques for Emily at work.
- **Goal 3:** I want to get my work colleagues to understand and sympathise with my condition.

**SMART Goal**: To prepare a presentation for Emily's work colleagues explaining what MS is by the end of the intervention.

Table 33 presents the progress Emily made with her intervention goals over the six months follow-up.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	+2 Goal met much more than expected.	<b>0</b> Goal met as expected.	+1 Goal met more than expected.
	Emily learnt about the support that would be beneficial for her at work and was starting to address the topic with her line manager.	She is more aware of how to manage her symptoms at work, but her employer has not provided her with extra support during Covid-19.	Emily's employer finally allowed her to have a rollator at work to remove the physical strain of her job.
2	+1 Goal met more than expected.	<b>0</b> Goal met as expected.	+1 Goal met more than expected.
	Emily started identifying the factors that make her fatigue worst and was still learning to manage her fatigue.	Emily was moving home and found it harder to use the fatigue management techniques.	Having the rollator at work removed a significant amount of fatigue at work.
3	+2 Goal met much more than expected.	-2 Goal met much less than expected.	<b>-1</b> Goal met less than expected.

Goal	Post-intervention	3-months follow-up	6-months follow-up
	Emily gained knowledge about MS and prepared a presentation for her work colleagues.	Emily did not have the opportunity to deliver the presentation because of Covid-19 restrictions	Emily still did not have the opportunity to deliver the presentation because of Covid-19 restrictions
GAS	72.8	40.9	54.6

**Unanticipated events:** The change in the Covid-19 regulations led to an increased number of sessions to address new problems.

Patient's perspective

Emily completed a telephone interview at three months follow-up explaining her experiences of receiving the support (Table 34).

Theoretical Construct	Supporting Quotes
Characteristics of individuals (CIFR).	<ul> <li>Overall, Emily had a positive experience during the intervention:</li> <li>"I came into the programme not knowing what was available out there It [the intervention] did help me, and I think a lot of people in my position would have had the same thinking as myself."</li> <li>Because of the support received during the intervention, Emily identified key reasonable accommodations for her role:</li> <li>"I mean it's [the intervention] definitively has had a positive impact for myselfBecause of the intervention, my risk assessment was changed, now it incorporates that I got my fourwheels rollator that I am allowed to use every day now, and I do use it every day now."</li> <li>Emily became more confident understanding her needs at work and asking for help:</li> <li>"Yes, I am definitively I am more confident to go to the office now. You know and tell [line manager] if there is something that I thought I would need."</li> </ul>

Table 34 Qualitative findings MS\_04

Theoretical Construct	Supporting Quotes
Intervention	Receiving support tailored to her needs was one of the most
Characteristics	important characteristics of the intervention:
(CIFR).	<i>"I think it is good that the person with MS that they get given the choice of the goals. Because you [PhD student] asked what goalsI had to set three goals."</i>
	Receiving a summary of the session and reminders were beneficial for keeping track of the work done during the intervention:
	"At the end of the session you [PhD student] used to send the summary of what we covered, and what we will cover in the next session. But then, on the next session, you recapped what we had done the week before, which like I said it is beneficial for us. Because a lot of us [people with MS] don't have a good memory."
Opportunity (BCW)	The Covid-19 restrictions meant that her line manager could not participate: "Covid-19 got in the way. I mean because it stopped the participation of the intervention with the school."

# Summary of case

Emily was concerned about her ability to continue working and considered reducing her working hours even though she was only working eight hours per week. Fortunately, her husband had a full-time job that covered all the economic needs of the household. Therefore, she was willing to reduce her working hours if that meant that she could work for longer.

Although the outcomes reflected that Emily worsen after the intervention in all measures except for work self-efficacy; she reported to have benefited from the intervention, as she gained knowledge about her MS and understood what can make her symptoms worsen. This may have been influenced by the fact that Emily was moving home during the study which she found particularly stressful.
As a result of the intervention, Emily was allowed to use a rollator at work as a reasonable accommodation to help her manage pain and fatigue during playground duty.

# 5.6.3.5. *Case Study MS\_05 "Olivia"*<sup>15</sup> Patient Information

Olivia is a 44-year-old white British woman, that was diagnosed with RRMS four years ago, but experienced symptoms suggestive of MS up to eight years before the diagnosis. Olivia experiences a moderate disability level (EDSS= 4). Olivia completed her Higher National Diploma, and she was working part-time (18.5 hours/week) as a community care office in a large public company. At the time of her MS diagnosis, she had been working for a different company for over 12 years. However, the fast pace of the job, and lack of support from line managers, made her leave and find new employment. She had been working for three years in her current post and was highly satisfied with the support that her company was providing to manage her MS at work. Olivia is a single mum and lives with her two kids. She enjoys doing activities with her kids, but the physical limitations caused by the MS make it harder for her to engage in playing with the kids.

# <u>Timeline</u>

Olivia was working from home at the time of assessment because of the Covid-19 pandemic, and she was meant to continue working from home for the foreseeable future, as they were keeping low numbers of people in the office.

Olivia's employer provided her with reasonable accommodations suggested by OH. However, she was finding it difficult to manage her concentration at work and remembering deadlines. She also struggled to manage her MS symptoms, and works even when she is feeling unwell, because she felt guilty about not working. She was interested in learning how to manage memory problems at work and better understand her MS.

# Assessment

<sup>&</sup>lt;sup>15</sup> Pseudonyms used to protect the anonymity of the participants.

At baseline, Olivia was employed and reported that MS had negatively impacted her work productivity (WPAI:MS 8 out of 10), and everyday activities (WPAI:MS 8 out 10). The MS restricted her from doing activities with her kids and made her work additional hours to meet deadlines at work.

Olivia was experiencing low levels of work instability (MS-WIS 10 out of 22), anxiety (HADS anxiety 3 out of 21), and depression (HADS depression 4 out of 21), and moderate levels of fatigue (MFIS-5 12 out of 20) and perceived cognitive difficulty (PDQ 33 out of 80). She also experienced good levels of work self-efficacy (WSES 39 out of 50).

In terms of quality of life (EQ-5D-5L), Olivia reported a health score of 63 (out of 100) and obtained an index health status of 0.89 (out of 1.0), representing good overall quality of life,

At work, Emily had reduced her working hours, had a flexible schedule to start and finish work and, was allowed to work from home if she was not feeling well.

**Intervention reasoning:** Olivia's main problem at work was the presence of memory problems, and difficulties concentrating. She also had problems understanding her MS, which made her reluctant to request support from her line manager as she did not know how to express her needs.

Finally, Olivia drove to work but she did not have a blue badge. Because of this, she had to walk a long distance to reach her desk, making her fatigued on arrival to work.

Olivia's line manager was not involved in the intervention because she had had a car accident and was off sick for the duration of the study.

# Intervention

The intervention is presented in Table 35.

Criteria	Description
Why	Olivia had received several reasonable accommodations at work; however, she was not confident in managing her MS at work. Therefore, she needed VR support to help her understand and better manage her MS.

Table 35 Intervention description Case Study MS\_05

Criteria	Description
What materials?	<ul> <li>Screening interview</li> <li>Session 2: Work diary</li> <li>Session 4: Blue Badge information.</li> <li>At the end of each session, Olivia received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	<ul> <li>Direct support: Olivia participated in six sessions addressing the following topics:</li> <li>(i) <u>Cognition in MS:</u> Olivia complained about problems concentrating at work and difficulties remembering deadlines and appointments at work. The first session provided an overview of common memory and thinking problems in MS, what causes them, and identifying the most common problems she was experiencing at work.</li> <li>(ii) <u>Cognition in MS (2):</u> The second session focused on identifying techniques to manage the cognitive problems identified in session 1. This session also focused on learning how to keep a work diary to track workload and meetings.</li> <li>(iii) <u>Reasonable accommodations:</u> This session focused on discussing what reasonable accommodations are and understand the barriers to job retention for Olivia. Furthermore, it covers the Equality Act 2010 and how to request disability leave from her employer.</li> <li>(iv) <u>Cognition in MS (3):</u> This session reviewed the progress made incorporating the techniques to manage cognitive problems at work and reviewing the use of the work diary. This session also covered reasonable accommodations, Access to Work, and the application process for a blue badge.</li> <li>(v) <u>Fatigue management:</u> This session discussed types of fatigue, factors that lead to increased fatigue and strategies to manage fatigue at work.</li> <li>(vi) <u>Understanding MS</u>: Olivia had questions about MS and how the symptoms interact and worsen over time. This session covered the most relevant aspects of MS for Olivia, as she had difficulties understanding and explaining to others how MS affected her.</li> <li>Indirect support: The indirect support included the following activities: (i) administrative tasks, (ii) preparation of materials for sessions, (iii) support obtaining information for blue badge application, and (iv) liaison with participant.</li> </ul>

Criteria	Description
How	The sessions were delivered via Microsoft Teams.
When and how much?	The first step involved an initial interview and goal setting (1 hour). Olivia participated in a three-month intervention, and received 7 hours of direct support, spread over six sessions, and 3 hours of indirect support. In total, the intervention time plus the interview accounted for 11 hours of support. <b>Direct support:</b> The sessions lasted on average 70 minutes and ranged between 60-80 minutes. The time spent on each intervention topic was as follows: (i) cognition in MS (100 mins), (ii) understanding MS (70 mins), (iii) fatigue management (60 mins), (iv) reasonable accommodations (50 mins), (v) work diary (50 mins), (vi) blue badge application (40 mins), (vii) legal support (30 mins), (viii) Access to Work information (20 mins), and (ix) issues with employer (10 mins). <b>Indirect support:</b> The indirect support ranged between 10-50 minutes per session delivered. The time included on each activity was: (i) preparation of materials (60 mins), (ii) administrative tasks (60 mins), (iii) liaison with participant (40 mins) and (iv) support with blue badge application (20 mins).
How well?	Olivia cancelled six sessions over the intervention because of the high workload, and healthcare appointments.

# Follow-up and Outcomes

Table 22 presents an overview of Olivia's performance on the different outcome measures included in the study.

At the post-intervention assessment, Olivia reported reduced quality of life (EQ-5D-5L from 0.89 to 0.72) and her "health today" score decreased from 63 to 30 (out of 100). The intervention helped Olivia manage cognitive difficulties, reflected by a decreased PDQ score (from 33 to 25). Her fatigue levels (MFIS-5 from 12 to 14) and work instability (MS-WIS from 10 to 13) worsened at the post-intervention assessment. She remained relatively stable on anxiety (HADS anxiety from 3 to 4) and work self-efficacy (WSES from 39 to 40). There was no change in levels of depression, and the change in anxiety levels of (RIC= -0.38) was not clinically significant.

At three months follow-up, Olivia remained stable from her baseline assessment but reported a worsening on work instability (MS-WIS 10 to 14).

At six months follow-up, she reported a large decrease in her perceived cognitive deficits (PDQ from 33 to 22) and a worsening on work instability (MS-WIS 10 to 15) similar to that experienced at three months follow-up.

Olivia's scores on the HADS (Figure 24), PDQ (Figure 25) and MS-WIS (Figure 26) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 24 MS\_05 HADS score over 9 months.



Figure 25 MS\_05 PDQ score over 9 months.



Figure 26 MS\_05 MS-WIS score over 9 months.

**Intervention Goals:** Olivia set the following goals at the beginning of the intervention:

- Goal 1: I want to learn to keep daily planning.
   SMART Goal: To learn how to keep a work diary to structure her work by the end of the intervention.
- **Goal 2:** I want to tell my employer what is happening to me and understand what additional support I could receive at work.

**SMART Goal**: To identify reasonable accommodations that Olivia can request from her line manager by the end of the intervention.

Goal 3: Understand my MS so that I can tell others what is happening to me.
 SMART Goal: To understand better MS by identifying her main MS symptoms by the end of the intervention.

Table 36 presents the progress made by Olivia over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	<b>0</b> Goal met as expected. Olivia was still learning to keep the work diary and distributing her work according to urgency and relevance.	+1 Goal met more than expected. Olivia became effective at using her diary and distributing her workload	<ul> <li>0 Goal met as expected.</li> <li>Olivia continued experiencing challenges using the diary but felt confident about her ability to structure her work</li> </ul>
2	<b>0</b> Goal met as expected. Olivia was planning on applying for a blue badge to park closer to her building at work.	<ul> <li>0 Goal met as expected.</li> <li>Olivia has not yet applied for the blue badge because she is still working from home.</li> </ul>	<ul> <li>O Goal met as expected.</li> <li>Olivia drafted a plan to start the application once she knows the date to return to the office.</li> </ul>
3	<ul> <li>+1 Goal met more than expected.</li> <li>Olivia addressed all her questions about MS and understood better her symptoms.</li> </ul>	+1 Goal met more than expected. Olivia became confident understanding her MS symptoms and by extension managing them.	+1 Goal met more than expected. Olivia continued mastering her symptom management.
GAS	54.6	59.1	54.6

# Patient's perspective

Olivia completed a telephone interview at three months follow-up explaining her experiences of receiving the support (Table 37).

Theoretical Construct	Supporting Quotes
Characteristics of	Olivia learnt to request further support from her line manager:
individuals (CIFR).	"Something that has changed, I have formally said [to my line manager] you know during my working shift depending on the

Theoretical	Supporting Quotes
Construct	
	work that I am doing, I can very quickly lose brain power, to a point where I don't feel that I am productive, so if it is ok for me to take some time just to reset, re-charge. I have had that formal conversation and it went well, and she [line manager] was open to itI would have probably hidden that before, and just sort of done it myself."
	Overall, Olivia regained her confidence at work:
	"I think, doing the study with you and having an understanding [of MS] I have been more open, and I feel more confident, and I have explained the areas where I am not doing very well, and she [line manager] has been supportive and again I feel empowered, productive, and a valuable member of the team."
Intervention Characteristics	She found it particularly useful that the support was tailored to her needs:
(CIFR).	<i>"I think because it [the intervention] was based around me and my outcomes, I felt it was all valuable."</i>
	Receiving the support remotely was positive:
	<i>"If I had the chance to do this again and we were allowed to meet, I would probably do this [the intervention] remotely."</i>

# Summary of case

Olivia was experiencing some difficulties at work as a result of her MS and had attempted to manage them on her own without requesting much support from her line manager. At the end of the intervention, Olivia felt empowered to manage her symptoms at work and more capable of requesting the support she needed from her new line manager. However, the week before Olivia's post-intervention assessment she had been off sick because of her MS, and she completed the questionnaires when she was ill. This reflected considerably on her intervention outcomes at postintervention assessment, which improved at three- and six-months follow-up.

At three months follow-up, she expressed how she was an expert of her own MS and was managing her symptoms better. Furthermore, she expressed that she was confident and felt empowered at work as a result of the intervention.

# 5.6.3.6. Case Study MS\_06 "Ruth"<sup>16</sup>

# Patient Information

Ruth is a 39-year-old white British woman, who was diagnosed with RRMS four years ago. Ruth has a moderate disability level (EDSS=6), suggestive of great mobility difficulties. Ruth completed college and is working part-time (18 hours/week) as a police call-handler in a large public company. She has been working for over eighteen years in her current job. Her mobility difficulties do not affect her at work, as she has a sitting down job; however, Ruth experiences Generalised Anxiety Disorder (GAD). Her anxiety levels are exacerbated at work as she is constantly dealing with emergency calls that require her to record information about an event and contact the relevant authorities to attend the scene. Ruth lives with her partner and two and enjoys walking her dog and playing with her children.

# **Timeline**

Ruth was working from home at the time of assessment because of Covid-19. She was enjoying working from home, as not travelling to work allowed her to conserve energy for the rest of the day. However, a week before participating in the study, her line manager contacted her to RTW in the office. She was not ready to return to the office, as she had been self-isolating and was concerned about getting Covid-19.

# Assessment

At baseline, Ruth's scores indicated that she was having major difficulties at work and managing her symptoms. She was experiencing high perceived cognitive difficulties (PDQ 56 out of 80), anxiety (HADS anxiety 21 out of 21), depression (HADS depression 17 out of 21), work instability (MS-WIS 19 out of 22), and fatigue (MFIS-5 20 out of 20). She also experienced medium levels of work selfefficacy (WSES 36 out of 50).

Ruth reported that MS had harmed her work productivity (WPAI:MS 8 out of 10), and everyday activities (WPAI:MS 8 out 10). The impact of her MS and the presence of severe anxiety limited her from participating in social activities.

<sup>&</sup>lt;sup>16</sup> Pseudonyms used to protect the anonymity of the participants.

In terms of quality of life (EQ-5D-5L), Ruth reported an overall health of 20 out of 100 and obtained an index health status of 0.21. These values represent a significant reduction in quality of life, driven in particular by the presence of severe anxiety.

At work Ruth had reduced her working hours, she was allowed to take breaks during working hours. However, she reported that she had never taken the breaks, as she was constantly receiving emergency calls, and the idea of not answering a call made her more anxious. Ruth was only allowed to work from home during the national lockdown.

**Intervention reasoning:** Ruth had been informed that she had to return to the office after the first national lockdown, but she was experiencing severe anxiety when thinking about returning to work. She has a stressful role and was concerned about making mistakes when addressing emergency calls. These high levels of anxiety increased her fatigue and made it difficult to concentrate on work tasks. Ruth also had problems concentrating at work and keeping track of her work and was interested in understanding how to manage this. She had previously received Cognitive Behavioural Therapy (CBT) to manage her anxiety but had stopped practising the techniques learnt. In the intervention, she reported being interested in learning about further support to manage her anxiety.

Her RTW was delayed by a month as a result of the pandemic, and her employer was not involved because she was off sick.

# Intervention

The intervention is presented in Table 38.

Table 38 Intervention	description	Case	Study	$MS_{-}$	06
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Criteria	Description
Why	Ruth needed VR support to help manage her anxiety levels and MS symptoms such as fatigue and cognitive difficulties.
What materials?	<ul> <li>Screening interview</li> <li>Session 1: SilverCloud; Mental Health Foundation, NHS Mental health.</li> <li>Session 2: Staying Smart (MS Trust)</li> <li>Session 3: Fatigue Management booklet and fatigue diary</li> </ul>

Criteria	Description	
	• At the end of each session, Ruth received an email with a	
	summary of the main points discussed and the next steps.	
	<ul> <li>Direct support: Ruth participated in five sessions addressing the following topics:</li> <li>(i) <u>Working during Covid-19</u>: The session covered topics such as what to expect when returning to the office and how to request reasonable accommodations such as working from home to manage</li> </ul>	
	fatigue. Because she was previously diagnosed with general anxiety disorder, she was recommended to discuss her situation with her GP and informed about different resources available through the NHS to help her manage anxiety.	
	<ul> <li>(ii) <u>Reasonable accommodations:</u> This session focused on discussing what reasonable accommodations could be beneficial to help her at work, and how to request them from her employer. Finally, Ruth reported to have discussed with her GP her fears and she started using the support recommended in the previous session (SilverCloud app).</li> </ul>	
What procedures	(iii) <u>Fatigue management:</u> This session discussed types of fatigue, factors that lead to increased fatigue, and strategies to manage fatigue at work. Ruth was experiencing fatigue and anxiety in her role; therefore, the session covered vocational exploration to understand how her role could be tailored to reduce the number of emergency calls she has to address. This discussion made her think about the possibility of requesting her line manager to manage the social media accounts of the police, as that would not be as stressful for her.	
	(iv) <u>Overview of progress made</u> : This session reviewed the progress made with fatigue management, and the request to manage social media accounts. At this point, Ruth felt confident to return to the office; thus, this session also reviewed her worries about Covid-19 and how to be safe in the office.	
	(v) <u>Return to Work:</u> This session addressed an update on her experience returning to the office, and the support her employer provided her to RTW. This session also review the fatigue diary and factors that caused her more fatigue.	
	<b>Indirect support:</b> The indirect support included the following activities: (i) administrative tasks, (ii) preparation of materials for sessions. (iii) liaison with participant.	

Criteria	Description
How	The sessions were delivered via telephone.
When and how much?	<ul> <li>The first step involved an initial interview and goal setting (1 hour).</li> <li>Ruth participated in a three-month intervention and received 4.33 hours of direct support, spread over five sessions, and 1.67 hours of indirect support. In total, the intervention time plus the interview accounted for 7 hours of support.</li> <li>Direct support: The sessions lasted on average 52 minutes and ranged between 60-50 minutes. The time spent on each intervention topic was as follows: (i) Working during Covid-19 (70 mins), (ii) fatigue management and fatigue diary (60 mins), (iii) reasonable accommodations (40 mins), (vi) mood in MS (20 mins), (v) cognition in MS (20 mins), (vi) RTW (20 mins), (vii) long-term career planning (20 mins), and (viii) refine goals (10 mins).</li> <li>Indirect support: The indirect support ranged between 10-40 minutes per session delivered. The time spent on each activity was as follows: (i) liaison with participant (30 mins), (ii) administrative tasks (20 mins), (iii) preparation of materials (20 mins), (iv) work emergency plan (20 mins), and (v) working with MS during Covid-19 (10 mins).</li> </ul>
How well?	The intervention was tailored to Ruth's needs. There was an agreed end of intervention after addressing all the relevant topics, and she was contacted three weeks after the final session to see if she needed further support.

# Follow-up and Outcomes

Table 22 presents an overview of Ruth's performance on the different outcome measures included in the study.

The intervention had a positive impact on all clinical outcomes at the end of the intervention. In particular, Ruth experienced a drastic reduction in her self-perceived cognitive difficulties (PDQ from 56 to 48), anxiety levels (HADS anxiety from 21 to 15), depression (HADS depression from 17 to 10), and fatigue (MFIS-5 from 20 to 12). The improvement in both her levels of anxiety (RIC= 2.25) and depression (RIC= 2.55) was clinically significant.

Unfortunately, even though she experienced a significant clinical improvement, she was still experiencing anxiety and depression above clinical levels. She also improved moderately on measures of work instability (MS-WIS from 19 to 17), quality of life (EQ-5D-5L from 0.21 to 0.44) and work self-efficacy (WSES from 36 to 37).

Ruth's scores on the HADS (Figure 27), PDQ (Figure 28) and MS-WIS (Figure 29) are presented in the following figures. The orange dotted line represents the start of the VR intervention. Ruth was lost to follow-up and only completed the post-intervention assessment.



Figure 27 MS\_06 HADS score over 3 months.



Figure 28 MS\_06 PDQ score over 3 months.



Figure 29 MS\_06 MS-WIS score over 3 months.

**Intervention Goals:** Ruth set the following goals at the beginning of the intervention:

• **Goal 1:** I need to get mentally ready to get back to the office, and I am anxious about going back to work.

**SMART Goal:** To support Ruth in managing her return to the office in two weeks.

- Goal 2: Learn to manage my fatigue levels.
   SMART Goal: To identify the factors fatigue management techniques that Ruth can implement at work by the end of the intervention.
- **Goal 3:** I want to learn if there is anything I can do about the memory and thinking problems, and tools that I can come up with that will help me concentrate and focus a little bit more.

**SMART Goal**: To identify at least three techniques to manage cognitive problems at work by the end of the intervention.

Table 39 presents the progress made by Ruth at the post-intervention assessment concerning her intervention goals.

Goal	Post-intervention
1	<b>0</b> Goal met as expected.
	Ruth's RTW got delayed, and eventually, she returned to work voluntarily because she was feeling isolated.

Table 39 Goal attainment for participant MS\_06

Goal	Post-intervention
2	+1 Goal met more than expected.
	Ruth recognised that her anxiety levels led to higher fatigue levels and started treating her anxiety to help her by extension manage her fatigue.
3	+1 Goal met more than expected.
	Ruth learnt to manage the memory and concentration difficulties by using the techniques discussed in the sessions.
GAS	60.8

# Patient's perspective

Ruth did not complete the follow-up interview.

# Summary of case

Ruth reported feeling anxious and fatigued at the beginning of the intervention. These symptoms worsened because of fears of getting Covid-19. In the initial interview, she acknowledged that it was challenging for her to participate in the intervention because of her anxiety levels but having the opportunity to take part via telephone made her ask for support, as she was at a critical point. The intervention made Ruth more confident in addressing the problems she was experiencing, and she decided to review her treatment options to get her anxiety levels under control.

At the end of the intervention, Ruth improved considerably on all of the outcome measures and reported to have benefited from the study. She was working towards becoming more familiar with the support received to maintain the gains over time. Unfortunately, at three-month post-intervention, Ruth did not respond to the emails regarding the follow-up interview to explore her experiences.

# 5.6.3.7. Case Study MS\_07 "Elena"<sup>17</sup>

# Patient Information

Elena is a 33-year-old white British woman, that was diagnosed with RRMS five months before participating in the intervention but has experienced symptoms

<sup>&</sup>lt;sup>17</sup> Pseudonyms used to protect the anonymity of the participants.

suggestive of MS for over ten years. She recently started receiving Tysabri to treat her MS. Elena presents a moderate disability level (EDSS=4), and the main MS symptom she experiences are difficulties using her hands, pain, fatigue, and memory problems.

Elena completed her Higher National Diploma and was working part-time (25 hours/week) at the beginning of the intervention. She works as a hotel assistant in a small private hotel and works in a group of five people where tasks are shared in the group. Her role is quite diverse and includes activities such as vacuuming, cleaning rooms, and attending the entrance desk. Elena lives with her partner who supports her in conducting home duties, especially on the days she feels more fatigued.

#### Timeline

At baseline, Elena was on furlough, as the hotel where she works was closed because of the Government restrictions to manage the Covid-19 pandemic. Elena reported problems at work remembering the things that she had to clean in the room, difficulties using her hands, and getting tired while cleaning.

Her work colleagues were exceptionally supportive and supported her when she was tired. However, she found it emotionally challenging to ask for support and was having difficulties accepting the limitations that MS caused her.

#### Assessment

At baseline, Elena reported a negative impact of MS on her productivity at work (6 out of 10), and everyday activities (7 out of 10).

She was experiencing high levels of anxiety (HADS anxiety 13 out of 21), work instability (MS-WIS 18 out of 22), and perceived cognitive problems (PDQ 50 out of 80); and moderate levels of fatigue (MFIS-5 12 out of 20), and depression (HADS depression 9 out of 21). She also reported high levels of work self-efficacy (WSES 47 out of 50), quality of life (EQ-5D-5L, index health 0.70 out of 1.0), and overall health of 70 (out of 100).

At work, Elena was allowed to take more breaks and reduced responsibilities because she had reduced her working hours. Elena was not allowed to work from home, as the nature of her role was not compatible with working from home. **Intervention reasoning:** Elena was experiencing physical difficulties that were affecting her at work. She was also experiencing memory difficulties, which made her rely on her work colleagues to ensure she completed all her work duties.

Elena works for a small company without an OH department; therefore she had never had an assessment to identify support to manage her MS at work. Thus, the intervention focused on understanding the problems Elena was experiencing at work and identify the support that would help her manage the symptoms (e.g., pain, fatigue, memory) at work.

Elena was on furlough at the beginning of the intervention and was informed to RTW after the first session. She was keen on requesting reasonable accommodations upon her return; therefore, the intervention covered support about how to request reasonable accommodations to her line manager.

# Intervention

The intervention is presented in Table 40.

Criteria	Description			
Why	Elena was recently diagnosed with MS. She was interested in receiving VR because she had a physical job and was starting to experience problems conducting the main duties of her role.			
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Access to Work information.</li> <li>Session 3: Fatigue management online course MS Society.</li> <li>Session 4: Memory and Thinking problems in MS (MS Society).</li> <li>At the end of each session, Elena received an email with a summary of the main points discussed and the next steps.</li> </ul>			
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to how urgent they were. Elena did not involve her line manager in the intervention.</li> <li>Direct support: Elena participated in four sessions addressing the following topics:</li> <li>(i) Pain at work: The session discussed the main triggers of pain at work to identify mechanisms to manage them. She was recommended to contact her MS clinical team to identify adequate treatment for the pain and mobility difficulties. This session also</li> </ul>			

#### Table 40 Intervention Description MS\_07

Criteria	Description			
	informed Elena about the support that Access to Work could provide her to remain at work.			
	(ii) <u>Return to Work</u> : This session covered how to request reasonab accommodations from her line manager, and the accommodations that would be most beneficial for Elena.			
	Upon Elena's RTW, she requested to her line manager to have more of a sitting down job to manage her pain and fatigue.			
	(iii) <u>Fatigue management:</u> During the session, I provided Elena with a fatigue management course and discussing fatigue management techniques at work.			
	(iv) <u>Cognition in MS</u> : This session reviewed the most common memory problems that she was experiencing at work and techniques to manage them better.			
	<b>Indirect support:</b> The indirect support included the following activities: (i) liaising with participants, (ii) administrative tasks, and (iii) preparation of materials for the session.			
How	The sessions were conducted via telephone.			
	The first step involved an initial interview and goal setting (60 mins).			
	Over the three-month intervention, Elena received 2.50 hours of direct support, spread over three sessions, and 1.50 hours of indirect support. In total, the intervention time plus the interview accounted for 5 hours of support.			
When and how much?	<b>Direct support:</b> Elena participated in four sessions ranging between 20-50 minutes. The time spent on each intervention topic was as follows: (i) fatigue management (60 mins), (ii) Cognition in MS (40 mins), (iii) pain at work (30 mins), (iv) RTW plan (10 mins), and (vi) review goals (20 mins).			
	<b>Indirect support:</b> The indirect support ranged between 10-40 minutes per session delivered. The time spent on each activity was: (i) preparation of materials for sessions (40 mins), (ii) liaison with the participant (30 mins), and (iii) administrative tasks (20 mins).			
How well?	There was an agreed end of the intervention, and Elena received an email three weeks after her final session to see if she needed further support.			

#### Follow-up and Outcomes

Table 22 presents an overview of Elena's performance on the different outcome measures included in the study.

The intervention seems to have a positive impact on Elena's performance on the clinical outcomes. She experienced reduced levels of perceived cognitive problems (PDQ from 50 to 33), reduced levels of anxiety (HADS anxiety from 13 to 7), depression (HADS depression 9 to 5), work instability (MS-WIS from 18 to 13), and fatigue (MFIS-5 from 12 to 8). In fact, her perceived cognitive difficulties, anxiety, and depression reduced to normal clinical levels. The improvement in the levels of depression was not clinically significant (RIC= 1.46), but the reduction in anxiety levels was clinically significant (RIC= 2.25).

Elena improved at a lesser degree on her levels of work self-efficacy (WSES from 47 to 48), and quality of life (EQ-5D-5L Health Index from 0.70 to 0.75). Her health today index, however, improved from 70 to 95 at the post-intervention assessment.

Elena also reported a considerable reduction of the impact of MS on her work (WPAI:MS from 6 to 2), and her everyday activities (WPAI:MS from 7 to 3).

At three months follow-up, Elena experienced higher levels of depression (HADS depression from 9 to 11) and fatigue (MIFS-5 from 12 to 15); and lower quality of life (EQ-5D-5L Health Index from 0.7 to 0.6) and work self-efficacy (WSES from 47 to 41). She remained stable on perceived cognitive deficits (PDQ from 50 to 52) and anxiety (HADS anxiety from 13 to 14) but experienced a reduced work instability (MS-WIS from 18 to 14). The changes in anxiety (RIC= -0.38) and depression (RIC= -0.73) were not clinically significant.

At six months follow-up, Elena experienced a reduction in perceived cognitive deficits (PDQ from 50 to 40), anxiety levels (HADS anxiety from 13 to 9), work instability (MS-WIS from 18 to 13) and fatigue (MFIS-5 from 12 to 6). The change in anxiety levels (RIC=1.52) was not clinically significant.

Elena's scores on the HADS (Figure 30), PDQ (Figure 31) and MS-WIS (Figure 32) are presented in the following figures. The orange dotted line represents the start of the VR intervention.







Figure 31 MS\_07 PDQ score over 9 months.



Figure 32 MS\_07 MS-WIS score over 9 months.

**Intervention Goals:** Elena set the following goals at the beginning of the intervention:

• **Goal 1:** I want to be able to work a full shift at work without feeling exhausted at the end.

**SMART Goal:** To help Elena self-manage her fatigue at work by the end of the intervention.

• **Goal 2:** I want to understand what changes I can ask for at work, and what is available to support me.

**SMART Goal**: To identify at least two reasonable accommodations for Elena at work by the end of the intervention.

Goal 3: My memory is going confused at work and I don't know what to do.
 SMART Goal: To identify at least two strategies to help Elena manage her memory difficulties at work by the end of the intervention.

Table 41 presents the progress made by Elena over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	+2 Goal met much more than expected.	<b>0</b> Goal met as expected.	<b>0</b> Goal met as expected.
	Elena started using fatigue management techniques.	Elena experienced low mood and fatigue because she was on furlough.	Elena remained on furlough at this timepoint.
2	+1 Goal met more than expected. Elena asked her employer to reduce her physical activities at work.	<ul> <li>0 Goal met as expected.</li> <li>Elena has been on furlough and is unable to request further support.</li> </ul>	<ul><li>0 Goal met as expected.</li><li>Elena remained on furloughed at this timepoint.</li></ul>

Table 41 Goal attainment for participant MS\_07

Goal	Post-intervention	3-months follow-up	6-months follow-up
3	+1 Goal met much more than expected. Elena was actively using the techniques learned to manage memory difficulties at work.	0 Goal met as expected. Elena has not been able to try the techniques at work, but she now uses them in her everyday	<ul> <li>0 Goal met as expected.</li> <li>Elena remained on furloughed at this timepoint.</li> </ul>
GAS	68 3	activities.	50
GAS	00.5	50	50

# Patient's perspective

Elena completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 42).

Theoretical	Supporting Quotes		
Construct			
Intervention	The support was beneficial and matched her needs:		
Characteristics (CIFR).	<i>"Learning about fatigue and the pain in my arm was also useful when we were talking about that."</i>		
	Having support understanding MS was useful:		
	"Once we were talking about whether I was affected by the heat, and I didn't think I was. And I think that I am. So talking to		
	somebody about the way that things can affect you. Because you don't know until somebody says it."		
	The experience receiving the support remotely was very positive:		
	<i>"I can't imagine you [PhD researcher] doing it better if we would</i>		
	have been able to see each other. It just was a great support."		
Characteristics of individuals	Receiving the support help her regain confidence in her value at work:		
(CIFR).	"You know when we started, I said you know I feel that I should be able to do this, and I should be able to do that. You don't realise that you still have value until somebody tells you "just because		

Table 42 Qualitative findings MS\_07

Theoretical	Supporting Quotes
Construct	
	you can't do it the same way you have always done it, it doesn't mean that you are not a valuable member of the staff"; and I think that was a great thing, especially for somebody who is newly diagnosed."
Opportunity (BCW).	Being on furlough limited how much she could practice the content learnt during the intervention at work: "[The intervention] It's been really good for me. Unfortunately, I have not been able to test it out as much as I wanted because of Covid-19."

# Summary of case

Elena is a young and active person who is determined to continue working. At the beginning of the intervention, she was experiencing problems accepting the limitations that MS causes her, especially because she was newly diagnosed.

She reported that the intervention helped her at work, especially on her approach to problems, and became more empowered to request changes. She continues using the techniques learnt during the intervention; however, not being able to work has made her feel low on mood and she is struggling mentally.

At three months follow-up, Elena deteriorated on all outcome measures. She reported that she was becoming severely depressed because of the isolation of the Covid-19 restrictions, and not being allowed to work. Fortunately, Elena has a supportive employer and colleagues that are happy to support her when she is having difficulties. She expressed how her colleagues are like family and wouldn't want to change her job because she will miss the friendship.

# 5.6.3.8. Case Study MS 08 "Laura"<sup>18</sup>

# Patient Information

Laura is a 53-year-old white British woman, that was diagnosed with SPMS 17 years ago, but experienced symptoms suggestive of MS up to 17 years before the medical

<sup>&</sup>lt;sup>18</sup> Pseudonyms used to protect the anonymity of the participants.

diagnosis. Laura has also been diagnosed with Raynaud syndrome, neuropathic bladder, and a protruding disk. These comorbidities cause her severe pain and mobility difficulties. Laura experiences a moderate disability level (EDSS= 6.5). Regarding her professional life, Laura's completed her A-levels and is working as an information support clerk, in a large public company. She is working part-time, (30 hours/week) over four days, but the working pattern changes from week to week in a work rota. Thus, according to the week, she works early mornings or late evenings. Laura lives with her husband who supports her in conducting the household and dayto-day activities. As a result of the pain, fatigue, and mobilities difficulties, Laura has reduced the number of social activities she conducts and invests most of her energy at work.

# Timeline

At the time of assessment, Laura had broken three ribs in a night accident going to the bathroom. Fortunately, this happened when she was working from home because of the national lockdown and had already used all her sick leave for the year, and she was not allowed to work from home.

A month before the intervention, Laura had an issue with her benefits. Laura was entitled to Disability Living Allowance<sup>19</sup> (DLA) for the last few years, and was receiving the highest bracket of support, which provided her with a mobility car. The DLA is now being replaced with Personal Independence Payment<sup>20</sup> (PIP) for disabled people. When applying for PIP, Laura had an assessment that significantly underscored her difficulties conducting everyday activities. The direct result of this assessment made her lose her mobility car that was essential for her to go to work, as she is unable to use public transport due to mobility problems, fatigue, and work schedule.

#### Assessment

At baseline, Laura was employed and the week before completing the questionnaire she had not missed any hour of work because of her MS or any other reasons. She reported a medium productivity impact of her MS at work (WAIP:MS 4 out of 10);

<sup>&</sup>lt;sup>19</sup> Tax-free benefit for people with disabilities who need support with mobility or care costs. <sup>20</sup> Welfare benefit to help adults with extra costs of living with a long-term health condition or disability.

however, she reported a high impact of MS on everyday activities (WAIP:MS 7 out 10).

She scored 49 (out of 80) on the PDQ, suggestive of significant perceived cognitive difficulties. She also showed high levels of work instability (MS-WIS 18 out of 22), fatigue (MFIS-5 15 out of 20), anxiety (HADS anxiety 11 out of 21) and depression (HADS depression 10 out of 21); and moderate work self-efficacy levels (WSES 33 out of 50).

In the questionnaire measuring quality of life (EQ-5D-5L), Laura reported an overall health of 60 (out of 100) and obtained an index health status value of 0.65.

Regarding workplace modifications, Laura receives more supervision but is not allowed to take more breaks, reduce responsibilities, or work from home.

**Intervention reasoning:** The first intervention topic refers to preparing Laura to compile the documents necessary for the PIP rebate, and the PIP tribunal, as the scoring of the PIP interview did not reflect the problems that she experiences in her everyday activities.

The second intervention topic referred to supporting Laura with the application process to Access to Work to request a taxi to and from work; just in case the PIP tribunal was not successful.

# Intervention

The description of the intervention is presented in Table 43.

Criteria	Description			
Why	Laura needed VR support, as she was experiencing complex problems with her employer and working arrangements.			
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Citizens advice information about PIP tribunal appeal, and MS Society Claiming PIP booklet.</li> <li>Session 2: Citizens Advice information to requesting to work from home, UNISON information about disability leave, PIP diary examples, Access to Work overview.</li> </ul>			

Table 43 Intervention description Case Study MS\_08

Criteria	Description
	<ul> <li>Session 4: Document with resources for the future with information to find support for mental health, legal advice, and support with benefits such as Turn2Us.</li> <li>At the end of each session, Laura received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	The first step involved an initial interview and goal setting to prioritise the intervention topics according to how urgent they were. Laura did not involve her line manager in the intervention, as their relationship was not good. Direct support: Laura participated in four sessions addressing the following topics: (i) Support accessing benefits: This session reviewed the scoring of the PIP benefit assessment and identifying relevant evidence for her PIP tribunal. The session also covered discussing issues with her line manager and information about her legal rights. (ii) Return to work plan and reasonable accommodations: The second session started reviewing the progress made with the evidence for the PIP tribunal; and continued reviewing a RTW plan as she was urged to return to the office after the first lockdown. This included discussing reasonable accommodations and how to request her employer to work from home at least two days per week to help her manage her MS. We also discuss the possibility to apply for Access to Work to obtain funding for taxis to and from work. (iii) Support with a disciplinary meeting: Soon after Laura's return to the office, she had another night fall and end up taking further sick leave. The employer contacted her for a stage two disciplinary meeting. (iv) Support applying to Access to Work: This session started with an update regarding the disciplinary meeting and discussing how to write the application for Access to Work. Laura completed the application and sent it for review by the assistant psychologist. Indirect support: The indirect support included the following activities: (i) review documents for Access to Work application, (ii) preparation of materials for sessions, (iii) review of materials for PIP tribunal, (iv) liaison with the employer, (v) liaison with Disability Law Service, (vi) liaison with participant, and (vii) administrative tasks.
How	The sessions were conducted using Microsoft Teams.

Criteria	Description	
When and how much?	<ul> <li>Laura participated in a three-month interview and goal setting (1 hour).</li> <li>Laura participated in a three-month intervention with 4 hours of direct support, spread over four sessions, and 6.17 hours of indirect support. In total, the intervention time plus the interview accounted for 11.17 hours of support.</li> <li>Direct support: Laura participated in four sessions lasting on average 60 minutes and ranging between 40-80 minutes. The time spent on each intervention topic was as follows: (i) support accessing benefits (80 mins), (ii) RTW plan and support with reasonable accommodations (60 mins), (iii) disciplinary meeting (60 mins), and (iv) support with Access to Work application (40 mins).</li> <li>Indirect support: The indirect support ranged between 70-110 minutes per session delivered. The time included in each activity uses (i) raview documents for Access to Work application (80 mins).</li> </ul>	
	mins), (ii) preparation of materials for sessions (70 mins), (iii) review of materials for benefits applications (50 mins), (iv) letter for employer (50 mins), (v) obtaining legal support (40 mins), (vi) liaising with participant (40 mins), (vii) administrative tasks (40 mins).	
How well?	Laura cancelled one session twice, because she was waiting for further information from her employer regarding her work situation, but all the topics agreed were discussed. The intervention finished at the end of the three months.	

# Follow-up and Outcomes

Table 22 presents an overview of Laura's performance on the different outcome measures included in the study.

Laura's performance worsen at the post-intervention assessment on perceived cognitive deficits (PDQ from 49 to 56), anxiety levels (HADS anxiety from 11 to 15), and work instability (MS-WIS from 18 to 21). The levels of fatigue (MFIS), depression (HADS depression), quality of life (EQ-5D-5L) and work self-efficacy (WSES) remained stable from the baseline assessment. There was no clinically significant change in the levels of anxiety (RIC -1.5) and depression (RIC= 0) of the HADS.

At three months follow-up, Laura experienced an improvement in work self-efficacy (WSES score from 34 to 41), perceived cognitive deficits (PDQ from 56 to 47), anxiety levels (HADS anxiety from 15 to 13), and fatigue (MFIS-5 from 15 to 13). The change in the levels of anxiety (RIC= 0.75) and depression (RIC= 0.36) was not clinically significant at three-month follow-up.

At six months follow-up, Laura remained stable on the outcomes measured; but experienced a reduction of perceived cognitive deficits (PDQ from 49 to 44) and fatigue levels (MFIS-5 from 15 to 11).

Laura's scores on the HADS (Figure 33), PDQ (Figure 34) and MS-WIS (Figure 35) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 33 MS\_08 HADS score over 9 months.



Figure 34 MS\_08 PDQ score over 9 months.



Figure 35 MS\_08 MS-WIS score over 9 months.

**Intervention Goals:** Laura set the following goals at the beginning of the intervention:

• **Goal 1:** I want to work from home.

**SMART Goal:** To request Laura's employer to work from home at least 2 days per week by the end of the month.

• **Goal 2:** I want to get ready for my PIP tribunal.

**SMART Goal**: To complete an evidence file for the PiP tribunal before the deadline in two weeks.

Goal 3: I want to learn about Access to Work.
 SMART Goal: To compile the documents required for the access to work application before the end of the intervention.

Table 44 presents the progress made by Laura over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	<ul> <li>0 Goal met as expected.</li> <li>Laura learned about her legal rights and requested her employer to work from home.</li> </ul>	0 Goal met as expected. The employer denied the request to work from home, but Laura was working on a plan to request	<ul> <li>0 Goal met as expected.</li> <li>Laura's employer rejected her work from home proposal for a second time.</li> </ul>
		it again.	
2	<ul> <li>0 Goal met as expected.</li> <li>Laura compiled and submitted the documents for the PiP tribunal.</li> </ul>	+1 Goal met better than expected. Laura felt confident to face the PIP tribunal but this was delayed because of Covid-19.	<ul> <li>O Goal met as expected.</li> <li>Laura recently received the date for her tribunal and was preparing for it.</li> </ul>
3	<ul> <li>O Goal met as expected.</li> <li>Laura compiled the documents for the Access to Work application.</li> </ul>	+1 Goal met better than expected. Her employer supported her to apply.	+1 Goal met better than expected. Laura's application was under consideration after a delay in the process.
GAS	50	59.1	54.6

# Table 44 Goal attainment for participant MS\_08

# Patient's perspective

Laura completed a Microsoft Teams interview at three months follow-up explaining her experiences receiving the support (Table 45).

Table 45	Qualitative	findings	<i>MS_08</i>
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Theoretical Construct	Supporting Quotes
Characteristics of individuals (CIFR).	Laura found the intervention helpful: "It's been very helpful to have somebody who knows the in-depth side of the law, the Access to Work, reasonable improvements, that sort of things."

Theoretical Construct	Supporting Quotes	
	Both Laura and her line manager were not aware of the support available for her:	
	<i>"I would have not known where to start. My line manager didn't have a clue [about Access to Work]. HR got a department that deals with Access to Work, but nobody knew that."</i>	
Intervention Characteristics (CIFR).	Legal support was the most using intervention component:	
	" To have somebody who understands MS and the law is spot- onTo have somebody who works with you through things and have knowledge about both elements iswowis priceless."	
	Including follow-up sessions after the intervention would have been beneficial for her:	
	<i>"I think the intervention could be 3 months, but I think you need a few re-visits if needed."</i>	
Opportunity	Laura did not fully achieve her goals because of Covid-19 delays:	
(BCW)	<i>"It is not that your help failed in any way, it is that the external people in it [PIP tribunal] have stopped it from progressing."</i>	
Personal factors (ICF)	The lack of support from her manager also affected negatively her goals:	
	<i>"Without Covid-19 I would be in the office. Their [company] answer on that is well we have already given you reasonable adjustments we can't give them to you forever"</i>	

# Summary of case

Laura's intervention focused on addressing the complex relationship she was experiencing with her line manager and how to receive reasonable accommodations.

Laura reported that the intervention was useful to understand her rights and the support available. Laura reported the need for follow-up sessions after the intervention to address new issues as they appear, as she experienced further problems soon after the intervention finished.

# 5.6.3.9. Case Study MS\_09 "Becky"<sup>21</sup>

# Patient Information

Becky is a 57-year-old white British woman, that was diagnosed with SPMS ten years ago but has experienced symptoms suggestive of MS for over twenty-two years. She is receiving Copaxone to treat her MS. Becky presents a high disability level (EDSS=7.5). Becky completed a master's degree and is working part-time (31 hours/week). Becky is a statistician working for a large public university. Her line manager is very supportive and has ensured that Becky received all the support she needs at work. However, Becky's role is quite demanding, and her contract specifies that she should work "as many hours as required" to complete her duties. This means that even though she is working part-time, she usually works more than full-time to complete her work. This is in part caused because she needs a longer time to complete her work, but also because the workload is high.

Becky lives with her husband and daughter, who support her at home, but she conducts several household duties such as cooking, which increase her fatigue levels. A couple of years ago, Becky was referred to an OT to help her manage the fatigue and MS symptoms, but she reported no benefit from the support she received.

# <u>Timeline</u>

At baseline, Becky was working from home for the foreseeable future as a result of the Government regulations to manage the Covid-19 pandemic. Even though working from home was beneficial to manage her fatigue levels, the prolonged exclusion from society harmed her mental health. Becky has severe mobility difficulties, which made it harder for her to meet with other people even if socially distant. Becky was interested in learning how to manage her difficulties concentrating at work and learn what else she could do to manage her workload.

# Assessment

At baseline, Becky reported a surprisingly low impact of her MS at work (2 out of 10); on the contrary, she reported that her MS limited her almost completely from engaging in everyday activities (9 out of 10).

<sup>&</sup>lt;sup>21</sup> Pseudonyms used to protect the anonymity of the participants.

She performed above clinical levels for all measures except for cognitive deficits where she presented low perceived cognitive difficulties (PDQ 27 out of 80). She was experiencing high levels of anxiety (HADS anxiety 14 out of 21) and depression (HADS depression 12 out of 21), work instability (MS-WIS 17 out of 22), fatigue (MFIS-5 15 out of 20), and low work self-efficacy (WSES 34 out of 50). She also reported considerably low levels of quality of life (EQ-5D-5L, index health 0.28 out of 1.0), and overall health of 20 (out of 100).

At work she was allowed to take more breaks, she had reduced her working hours and received more supervision. However, she had not reduced her responsibilities as her role was very demanding. She was receiving support from Access to Work to pay for taxis to go to work.

**Intervention reasoning:** Becky was experiencing significant challenges managing her workload and concentrating at work. Her role is cognitively demanding, and she needs longer hours to complete her work. Her manager allowed her to take breaks at work, but since Becky was already working long hours, taking a break meant that she was finishing work even later.

The first intervention topic aims at identifying further reasonable accommodations that could help Becky remain at work and manage better her workload. The second intervention topic focused on fatigue management, as she was not confident using the techniques she had previously learnt with the OT. Becky was interested in the idea of reducing her working hours, but she was not sure how her line manager would react to it, or how the change will affect her pension plan. Finally, Becky reported to be struggling at work but wanted to remain employed until her daughter finishes school.

# Intervention

The intervention is presented in Table 46.

Table 46 Interve	ntion Descrip	tion MS_09
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Criteria	Description
Why	Becky was experiencing problems at work as her MS was progressing and causing her difficulties concentrating and with mobility. Her line manager was supportive but was concerned about Becky's productivity.

Criteria	Description
What materials?	<ul> <li>Screening interview</li> <li>Session 1: AbilityNet resources.</li> <li>Session 2: Turn2Us, Pension plan information, SilverCloud.</li> <li>Session 3: Fatigue management booklet (MS Society)</li> <li>Session 4: Every mind matters.</li> <li>At the end of each session, Becky received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Becky involved her line manager in the intervention.</li> <li><b>Direct support:</b> Becky participated in five sessions addressing the following topics: <ul> <li>(i) <u>Reasonable accommodations:</u> This session covered discussing the barriers to job retention that Becky was experiencing and identify relevant reasonable accommodations to reduce the impact of MS at work.</li> <li>(ii) <u>Cognition in MS:</u> This session reviewed techniques to manage her cognitive difficulties at work and the possibility of using a diary to distribute her workload. This session also covered the idea of reducing working hours to manage her fatigue and cognitive problems at work.</li> <li>(iii) <u>Fatigue management:</u> This session reviewed the types of MS-related fatigue, factors that cause fatigue, and fatigue management techniques. The session discussed the possibility of taking breaks during the workday and reducing the working hours, as discussed in the previous session.</li> <li>(iv) <u>Fatigue management (2):</u> This session continued reviewing fatigue management techniques at work, and review if the techniques discussed in the previous session were helpful to manage fatigue. This session also discussed tips to support Becky working from home, as she was finding it increasingly challenging to find the motivation to work.</li> <li>(v) <u>Long-term career planning:</u> The final intervention session reviewed alternative employment options for Becky according to her preferences. The session also reviewed the pending actions from previous sessions.</li> </ul> </li> </ul>
	preparation of materials for session, and (1V) resources for participant.

Criteria	Description
	Employer's intervention
	Becky involved her employer Betty (pseudonym) in the intervention.
	Betty completed the initial interview and reported to be fairly confident with her understanding of how MS affects Becky.
	Betty participated in one session identifying and discussing reasonable accommodations for Becky and the reasoning behind them. In particular, the session discussed the possibility of Becky reducing her working hours to help her manage her fatigue better and meet her work deadlines. She believed reducing working hours could have a positive impact on Becky's performance.
How	The sessions were conducted using Microsoft Teams.
	The first step involved an initial interview and goal setting (60 mins).
When and how much?	Over the three-month intervention, Becky received 5.50 hours of direct support, spread over three sessions, and 2 hours of indirect support. In total, the intervention time plus the interview accounted for 8.5 hours of support.
	<b>Direct support:</b> Becky participated in five sessions lasting on average 65 minutes and ranging between 60-90 minutes. The time spent on each intervention topic was as follows: (i) reasonable accommodations (110 mins), (ii) fatigue management (80 mins), (iii) mood in MS (40 mins), (iv) Cognition in MS (30 mins),(v) long-term career planning (30 mins), (vi) working during Covid-19 (20 mins), and (vii) support for the future (20 mins).
	<b>Indirect support:</b> The indirect support ranged between 10-30 minutes per session delivered. The time spent on each activity was: (i) liaison with participant (60 mins), (ii) preparation of materials for sessions (20 mins), (iii) administrative tasks (10 mins), (iv) obtain financial support (10 mins), (v) information about reasonable accommodations (10 mins), and (vi) working during Covid-19 resources (10 mins).
	Employer's intervention
	Betty completed the initial interview (60 minutes) and one session addressing reasonable accommodations (60 minutes). The indirect intervention time spent was 10 minutes to share an email with a summary of the discussion during the session.
How well?	The intervention was tailored to Becky's needs. The intervention finished at the end of the three months.

#### Follow-up and Outcomes

Table 22 presents an overview of Becky's performance on the different outcome measures included in the study.

The intervention did not have an impact on Becky's performance on the outcomes measured. The levels of fatigue remained stable at the post-intervention assessment. She experienced a small improvement in perceived cognitive difficulties (PDQ from 27 to 25), anxiety (HADS anxiety from 14 to 13), depression (HADS depression from 12 to 11), quality of life (EQ-5D-5L Health Index from 0.28 to 0.39), and health score from 20 to 25 at the post-intervention assessment. The improvement in the levels of depression (RIC= 0.38) and anxiety (RIC=0.36) was not clinically significant.

There was a small deterioration in work instability (MS-WIS from 17 to 19) and work self-efficacy (WSES from 34 to 32). Becky also reported a small worsening of the impact of MS on her work (WPAI:MS from 2 to 3) and improvement in her everyday activities (WPAI:MS from 9 to 8).

At three months follow-up, Becky remained stable from the post-intervention assessment, and only showed an improvement in work self-efficacy (WSES from 34 to 37).

At six months follow-up, Becky experienced a small deterioration in work selfefficacy (WSES from 34 to 31), and improvement in quality of life (EQ-5D-5L Health Index from 0.28 to 0.36).

Becky's scores on the HADS (Figure 36), PDQ (Figure 37) and MS-WIS (Figure 38) are presented in the following figures. The orange dotted line represents the start of the VR intervention.






#### Figure 37 MS\_09 PDQ score over 9 months.



Figure 38 MS\_09 MS-WIS score over 9 months.

**Intervention Goals:** Becky set the following goals at the beginning of the intervention:

- Goal 1: I want to know what further support I can get at work to help me.
   SMART Goal: To identify what further reasonable accommodations could be beneficial for Becky by the end of the intervention.
- **Goal 2:** I want to get the right balance between getting enough breaks at work, and getting my work done.

**SMART Goal**: To refine the fatigue management techniques that Becky uses by the end of the intervention.

• Goal 3: I want to ensure I remain at work until my daughter finishes school. SMART Goal: To create a long-term career planning that matches Becky's needs by the end of the intervention.

Table 47 presents the progress made by Becky over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-
			up
1	<b>0</b> Goal met as expected.	<b>-1</b> Goal met less than expected.	<b>-1</b> Goal met less than expected.
	She wants to reduce her working hours but has not reviewed how it would impact her finances.	She could not change her working hours because her husband was made redundant at work.	Becky remained to experience challenges at work.
2	<b>-1</b> Goal met less than expected.	<b>0</b> Goal met as expected.	<b>-1</b> Goal met less than expected.
	She was still having problems getting the right balance between work and breaks.	She reported an improvement in her fatigue levels as her workload was lower.	The challenges at work made Becky experience increased fatigue.
3	<b>-1</b> Goal met less than expected.	<b>-1</b> Goal met less than expected.	<b>-1</b> Goal met less than expected.
	Becky had no time to continue reviewing the alternatives discussed.	Becky stopped reviewing other work alternatives as she	Becky had stopped exploring alternative

Table 47 Goal attainment for participant MS\_09

Goal	Post-intervention	3-months follow-up	6-months follow- up
		needed a higher salary because her husband became unemployed.	employment opportunities.
GAS	40.9	40.9	36.3

# Patient's perspective

Becky completed an interview via Microsoft Teams at three months follow-up explaining her experiences receiving the support (Table 48).

Theoretical Construct	Supporting Quotes
Characteristics of individuals (CIFR).	<ul> <li>The intervention helped Becky keep track of her responsibilities:</li> <li>"I think it's been very good. One, it helped me focus on things that perhapsalthough I have thought of doing, they get pushed down the priority list when you are working."</li> <li>Becky was still experiencing fatigue at work:</li> <li>"The fatigue thing I found it difficult because you know you can take breaks, but the work is still there, and you have to do it; so time doesn't expand If you do take a proper break, I wouldn't get anything done, you know."</li> <li>Becky did not follow up on some of her actions from the sessions:</li> <li>"In my case, when you are working it is difficult [to follow-up on the intervention actions], it would be nice to get it sorted but I am doing all of that and I still have to meet the deadlines for my work."</li> </ul>
Intervention Characteristics (CIFR).	Receiving support tailored to her needs was a positive aspect of the intervention: "It is also nice that someone is focusing on your particular issues, because it does not always fit into other sorts of ways of getting help, and a lot of the support services in the NHS are stretch or almost non-existent."

Table 48 Qualitative findings MS\_09

Theoretical	Supporting Quotes
Construct	
Opportunity	Becky could not request the reduction of working hours to help
(BCW)	her manage the workload and fatigue:
	"I know we talk about reducing my time [working hours]but I
	don't think that will be possible because my partner has been
	made redundant from April so I will have to carry on"

#### Summary of case

The progression of Becky's MS symptoms troubles her deeply causing her to have negative thoughts about the future. At work, she keeps her diagnosis secret to most people as she does not want to be treated differently. Furthermore, the multiple national lockdowns meant that she was feeling isolated and that was affecting her mood negatively.

She was pleased with the support received but explained that she did not meet her intervention goals because her MS keeps getting worst over time. Additionally, she did not find time to follow up on her actions from the sessions therefore she never knew whether the support discussion was useful for her.

Becky's line manager is very supportive; however, she is concerned about Becky's productivity affecting the team, as Becky has a complex professional role with tight deadlines.

# 5.6.3.10. Case Study MS\_10 "Patricia"<sup>22</sup>

#### Patient Information

Patricia is a 55-year-old white British woman, that was diagnosed with RRMS four years ago but has experienced symptoms suggestive of MS for over 23 years. She is receiving Copaxone to treat her MS. Patricia presents a moderate disability level (EDSS=4.5), and experiences difficulties using her hands, pain, and walking difficulties. Patricia completed her A-Levels and is working part-time (23 hours/week) as a sales manager in a large private company. She has a stressful role

<sup>&</sup>lt;sup>22</sup> Pseudonyms used to protect the anonymity of the participants.

where she manages a large team. She lives with her husband and enjoys doing yoga to keep herself active.

#### Timeline

At baseline, Patricia was on furlough as the store where she works was closed because of the first national lockdown. Being furloughed made Patricia realised that she wanted to find alternative employment because the stress she was experiencing at work made her MS symptoms worsen.

#### Assessment

At baseline, Patricia reported that her MS had a moderate impact on her productivity at work (5 out of 10), and everyday activities (5 out of 10). Patricia was relatively stable and experiencing low levels of anxiety (HADS anxiety 4 out of 21) and depression (HADS depression 2 out of 21). She experienced low perceived cognitive difficulties (PDQ 24 out of 80), high levels of work self-efficacy (WSES 40 out of 50), high levels of quality of life (EQ-5D-5L, index health 0.77 out of 1.0), and overall health of 70 (out of 100). She was however experiencing high levels of work instability (MS-WIS 16 out of 22), and moderate levels of fatigue (MFIS-5 10 out of 20).

Patricia had not received any reasonable accommodation from her employer and was unsure as to what could be beneficial for her.

**Intervention reasoning:** The first intervention topic aimed at identifying suitable employment alternatives (vocational exploration) for Patricia that match her needs and skills. The second intervention topic aimed at identifying reasonable accommodations for Patricia's current role. Finally, Patricia complained about the impact of her fatigue at work and home. Thus, the intervention included a component of fatigue management.

#### Intervention

The intervention is presented in Table 49.

Table 49 Intervention	Description MS_10
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Criteria	Description	
Why	Patricia was experiencing difficulties managing the workload and responsibilities at work. Furthermore, she was interested in finding alternative employment.	
What materials?	<ul> <li>Screening interview</li> <li>Session 2: Template cover letter.</li> <li>Session 3: Fatigue management booklet MS Society.</li> <li>At the end of each session, Patricia received an email with a summary of the main points discussed and the next steps.</li> </ul>	
	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Patricia did not involve her line manager.</li> <li>Direct support: Patricia participated in four sessions addressing the following topics:</li> <li>(i) <u>Vocational exploration</u>: This session covered Patricia's skills, and employment preferences, to identify alternative employment options</li> </ul>	
What procedures	<ul> <li>(ii) <u>Vocational exploration (2)</u>: The second part of the vocational exploration aimed at exploring jobs that matched her preferences, identification of companies that would be able to accommodate her needs, and support completing her CV and a cover letter.</li> <li>(iii) <u>Fatigue management</u>: This session reviewed the progress made</li> </ul>	
	<ul> <li>searching for jobs, and discussing types of fatigue, and now to manage fatigue at work.</li> <li>(iv) <u>Future resources:</u> The final session covered relevant organisations to request further support, an overview of the progress made during the intervention.</li> <li><b>Indirect support:</b> The indirect support included the following activities: (i) liaison with participant, (ii) administrative tasks, and (iii) preparation of materials for the session</li> </ul>	
How	The sessions were conducted via telephone.	
	The first step involved an initial interview and goal setting (50 mins).	
When and how much?	Over the three-month intervention, Patricia received 3 hours of direct support, spread over four sessions, and 1.17 hours of indirect support. In total, the intervention time plus the interview accounted for 5 hours of support.	

Criteria	Description		
	Direct support: Patricia participated in four sessions lasting on		
	average 45 minutes and ranging between 20-60 minutes. The time		
	spent on each intervention topic was as follows: (i) vocational		
	exploration (100 mins), (ii) fatigue management (50 mins), (iii) future		
	resources (20 mins), and (iv) issues at work (10 mins).		
	<b>Indirect support:</b> The indirect support ranged between 10-30 minutes		
	per session delivered. The time spent on each activity was: (i)		
	preparation of materials for sessions (30 mins), (ii) liaison with		
	participant (30 mins), and (iii) administrative tasks (10 mins).		
	She cancelled one session because she was unwell, and the final		
How well?	session was shorter than expected because she was tired from work.		
	The intervention finished at the end of the three months.		

#### Follow-up and Outcomes

Table 22 presents an overview of Patricia's performance on the different outcome measures included in the study.

The intervention seemed to have a positive impact on Patricia's levels of fatigue, which decreased by four points (MFIS-5 from 10 to 6), and a smaller positive impact on work self-efficacy (MS-WIS from 16 to 14). Patricia remained stable on levels of anxiety (HADS anxiety from 4 to 5) and depression (HADS depression from 2 to 4) and did not experience any change in work self-efficacy or quality of life. Interestingly, her levels of perceived cognitive deficits almost doubled (PDQ from 24 to 42) at the post-intervention assessment. The change in the levels of depression (RIC= -0.38) and anxiety (RIC= -0.73) was not clinically significant.

At three months follow-up, Patricia's outcome measures followed a similar trend to the post-intervention assessment. The presence of perceived cognitive deficits (PDQ from 24 to 38) remained high. The largest improvement was on the reduction in work-instability (MS-WIS from 16 to 10 points). She experienced a small worsening of anxiety (HADS anxiety from 4 to 6), depression (HADS depression from 2 to 5), fatigue levels (MFIS-5 from 10 to 8), and quality of life (EQ-5D-5L Health Index from 0.77 to 0.72). However, these are small changes in the outcomes, and they remained below clinical levels. The change in scores of the HADS on the levels of anxiety (RIC = -0.38) and depression (RIC = -0.36) was not clinically significant.

At six months follow-up, Patricia remained to experience high perceived cognitive difficulties (PDQ from 24 to 35) and experienced a small reduction in quality of life (EQ-5D-5L Health Index from 0.77 to 0.67).

Patricia's scores on the HADS (Figure 39), PDQ (Figure 40) and MS-WIS (Figure 41) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 39 MS\_10 HADS score over 9 months.



Figure 40 MS\_10 PDQ Score over 9 months.



Figure 41 MS\_10 MS-WIS Score over 9 months.

**Intervention Goals:** Patricia set the following goals at the beginning of the intervention:

• **Goal 1:** I want to learn to manage my priorities better at work to get my work done.

**SMART Goal**: To understand the difficulties that Patricia experiences at work and identify support to manage the difficulties by the end of the intervention.

- Goal 2: I need to learn to manage my fatigue.
   SMART Goal: To identify suitable fatigue management techniques for Patricia by the end of the intervention.
- **Goal 3:** I want to think about my employment possibilities and find a less stressful job.

**SMART Goal**: Vocational exploration to identify suitable employment alternatives for Patricia before she returns to work after the first national lockdown.

Table 50 presents the progress made by Patricia over the six months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	<b>0</b> Goal met as expected.	<b>0</b> Goal met as expected.	<b>0</b> Goal met as expected.
	Patricia returned to work a week ago and did not have time to request support.	Patricia found a new role where she can manage better her MS; therefore, she has not requested any support yet.	Patricia gained more experience in her role and did not need further accommodations.
2	+1 Goal met more than expected.	<b>0</b> Goal met as expected.	<b>0</b> Goal met as expected.
	Being on furlough and using the fatigue management techniques had a positive impact on Patricia's fatigue levels.	She had returned to work and found it harder to be consistent using the fatigue management techniques.	The nature of her new busy role made it challenging for Patricia to manage fatigue but was actively using the techniques.
3	+1 Goal met more than expected.	+1 Goal met more than expected.	+1 Goal met more than expected.
	Patricia learnt about her employment alternatives and was searching for a new job.	Patricia found a new job and was comfortable with the demands of her new role.	Patricia remained satisfied in her new role.
GAS	59.1	54.6	54.6

Table 50 Goal attainment for participant MS\_10

**Unanticipated events:** Patricia was furloughed during most of the intervention; thus, it was difficult to identify reasonable accommodations for her at work.

#### Patient's perspective

Patricia completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 51).

Table 51 Qualitative findings MS\_10

Theoretical	Supporting Quotes
Construct	
Characteristics of	Patricia reported benefits from the intervention:
individuals	<i>"I think really, the help that you gave me to explore…looking for a</i>
(CIFR).	different job that suit better you know my MS, and also you kind
	of helped me with the fatigue kind of thing. Overall, you know I
	think it has been really useful."
	She found that her ability to manage MS symptoms didn't
	change much as a result of the intervention:
	<i>"I don't think so, I think apart from the fatigue side of things that</i>
	to a certain extent you don't have control over that, but I have
	learnt to manage my day better. But I think as far as my MS goes,
	it is probably the same."
Intervention	Future intervention should have a hybrid delivery mode:
Characteristics	<i>"I think in some ways it would be much nicer face-to-face</i>
(CIFR).	[meetings] or certainly in the beginning if that were possible. I
	don't think everything has to be done face-to-face."
	Patricia identified the main barrier to including employers in the intervention:
	<i>"I was a bit concerned in the early stages about including my</i>
	employer. Because I feel like I have a supportive employer anyway,
	I kind of felt that it might be a little bit of a slur on them, that I
	wanted them included on it. It might make them feel that they are
	not being as supportive as they could be."
Personal factors (ICF)	Patricia found a new role following the guidance from the intervention:
	"I think going through options with me about jobs that might be
	better for me, and you also suggested that I had a conversation
	within the company that I am working for and that is sheely take
	what I did in the end."

Summary of case

Patricia was relatively stable on the baseline assessments and reported that being on furlough helped her realised that she needed a change in her professional life to remain at work for longer. At the post-intervention assessment, Patricia experienced an increment of perceived cognitive difficulties, that may have been caused by her RTW after the first national lockdown.

Patricia also found a new role at the end of the intervention and reported to be managing better her MS because she had fewer responsibilities. In fact, her work instability decreased significantly at three months post-intervention as a result of working on a more suitable job.

# 5.6.3.11. Case Study MS\_11 "Robert"<sup>23</sup> Patient Information

Robert is a 45-year-old white British man, that was diagnosed with SPMS 14 years ago. Robert presents a medium to high disability level (EDSS=6), and experiences difficulties walking and using his hands. Robert completed his A-levels and is working full-time (37 hours) as a Business Improvement Officer for a large public company. Robert lives with his partner and keeps himself active by swimming and cycling. Robert has a supportive partner, but his memory problems lead to arguments at home because he forgets about events and activities. Robert is managing well at work. However, he worries that his memory problems are getting worst with time. Furthermore, he has a stressful job, because of an increased workload as a result of redundancies in the company.

#### Timeline

At baseline, Robert was working from home because of the first national lockdown. He was enjoying it, as it helped him manage his fatigue better.

His MS mainly caused him mobility difficulties, but these were not a barrier to remain at work as he was allowed to work from home and has an office-based job. However, the high workload and memory problems were causing him some concerns about working in the future.

<sup>&</sup>lt;sup>23</sup> Pseudonyms used to protect the anonymity of the participants.

#### Assessment

At baseline, Robert reported that the productivity impact of his MS at work was minimal (WAIP:MS 1 out of 10), and it had a small impact on his everyday activities (WAIP:MS 3 out of 10).

Similar to his complaints during the interview, he was experiencing moderate to high levels of fatigue (MFIS-5 14 out of 20), and moderate perceived cognitive deficits (PDQ 39 out of 80). He was however experiencing low levels of anxiety (HADS anxiety 4 out of 21), depression (HADS depression 6 out of 21), work-instability (MS-WIS 8 out of 22), and good levels of work self-efficacy (WSES 40 out of 50).

In terms of quality of life, Robert obtained an index health status of 0.51 (out of 1.0) and overall health of 35 (out of 100), representative of a considerable loss of quality of life mainly driven by the presence of mobility difficulties, and pain.

At work, he is allowed to take breaks and work from home whenever it was required.

**Intervention reasoning:** The main intervention topics aimed at supporting Robert in managing fatigue and cognitive problems at work. Because Robert was working from home, he had become less active, and he acknowledged that this caused him to feel more fatigue but was planning on increasing his activity levels. He reported experiencing problems suggestive of cognitive deficits that were causing him difficulties with his partner and at work. Finally, Robert had multiple falls, associated with balance issues from a new medication, and he was not aware of how to manage it.

#### Intervention

The intervention is presented in Table 52.

Table 52 Interventio	n Description MS_11
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Criteria	Description
Why	Robert was experiencing mild difficulties at work, but he believed that the symptoms he experiences might cause him problems in the future at work.

Criteria	Description
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Fatigue Diary</li> <li>Session 3: Staying Smart website (MS Trust)</li> <li>Session 4: Managing the risk of falls booklet.</li> <li>At the end of each session, Robert received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	The first step involved an initial interview and goal setting to prioritise intervention topics. Robert did not involve his line manager in the intervention. <b>Direct support:</b> Robert participated in four sessions addressing the following topics: (i) Fatigue Management: This session discussed types of fatigue, factors that lead to increased fatigue and strategies to manage fatigue at work. (ii) <u>Cognition in MS:</u> This session review common cognitive problems in MS, identify the areas where he was experiencing more difficulties, and techniques to manage the cognitive problems. (iii) <u>Cognition in MS:</u> The session reviewed the progress Robert had made implementing the techniques to manage his memory problems, and while some of them were beneficial, it was clear that he was experiencing complex problems and it was suggested that he discuss this with his Neurologist to obtain a referral for a neuropsychological assessment. (iv) <u>Mobility in MS:</u> This session provided Robert information about managing the risk of falls and discussing the progress made requesting a neuropsychological assessment with his healthcare team. <b>Indirect support:</b> The indirect support included the following activities: (i) Liaising with participant, (ii) administrative tasks, (iii) liaison with other professionals, and (iv) preparation of materials for the session.
How	The sessions were conducted using Microsoft Teams.

Criteria	Description		
	The first step involved an initial interview and goal setting (1 hour). Over the three-month intervention, Robert received 3.5 hours of direct support, spread over three sessions, and 1.5 hours of indirect support. In total, the intervention time plus the interview accounted for 6 hours of support.		
When and how much?	<b>Direct support:</b> Robert participated in four sessions lasting on average 50 minutes and ranging between 40-60 minutes. The time spent on each intervention topic was as follows: (i) Cognition in MS (100 mins), (ii) fatigue management (50 mins), (iii) managing falls (20 mins), (iv) current work issues (20 mins), (v) understanding MS (10 mins), and (vi) reasonable accommodations (10 mins).		
	<b>Indirect support:</b> The indirect support ranged between 10-50 minutes per session delivered. The time spent on each activity was: (i) liaison with participant (40 mins), (ii) liaison with other professionals (30 mins), (iii) administrative tasks (10 mins), and (iv) preparation of materials for sessions (20 mins).		
How well?	The intervention was tailored to Robert's needs and all the topics agreed upon in the initial interview were discussed. The intervention finished at the end of the three months.		

#### Follow-up and Outcomes

Table 22 presents an overview of Robert's performance on the different outcome measures included in the study.

Robert remained below clinical levels on anxiety (HADS anxiety from 4 to 5) and work instability (MS-WIS from 8 to 9). The intervention, however, seemed to have improved his work self-efficacy levels (WSES from 40 to 44), and mood (HADS depression from 6 to 4). He experienced a small deterioration in perceived cognitive deficits (PDQ from 39 to 41), and quality of life (EQ-5D-5L Health Index from 0.51 to 0.39). The intervention had no impact on fatigue levels.

Interestingly, while the impact of his MS at work remained (WPAI:MS 1) at the baseline levels, the impact of the MS on normal activities (e.g., housework, shopping) doubled from baseline to post-intervention (WPAI:MS from 3 to 6),

indicating greater difficulties at home. Robert's change in levels of anxiety (RIC= -0.38) and depression (RIC= 0.73) was not clinically significant.

At three months post-intervention Robert remained stable on all outcomes except for an increase in work instability (MS-WIS from 8 to 14) and improvement in work self-efficacy (WSES from 40 to 43).

At six months post-intervention Robert experienced a large reduction of cognitive difficulties (PDQ from 39 to 27), and a smaller deterioration on work instability (MS-WIS from 8 to 13) similar to the one experienced at three months post-intervention.

Robert's scores on the HADS (Figure 42), PDQ (Figure 43) and MS-WIS (Figure 44) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 42 MS\_11 HADS score over 9 months.



Figure 43 MS\_11 PDQ score over 9 months.



Figure 44 MS\_11 MS-WIS score over 9 months.

**Intervention Goals:** Robert set the following goals at the beginning of the intervention:

• **Goal 1:** I need help with fatigue, as I am feeling tired all the time and I don't get out of the house.

**SMART Goal:** To identify three fatigue management techniques that can be beneficial to reduce Robert's fatigue levels, so that he can increase his activity levels by the end of the intervention.

• **Goal 2:** I want to understand my memory problems and know what I can do to manage them because I write everything down, but it doesn't work.

**SMART Goal**: To identify three techniques to manage Robert's cognitive difficulties at work by the end of the intervention.

Goal 3: Some healthcare professionals have been very negative about my MS, and I haven't discussed what I can do to manage my condition better.
 SMART Goal: To support Robert in understanding how his MS symptoms can affect him at work by the end of the intervention.

Table 53 presents the progress made by Robert over the six months follow-up with regards to his intervention goals.

Goal	Post-intervention	<b>3-months follow-up</b>	6-months follow-up
1	<b>0</b> Goal met as expected.	+1 Goal met more than expected.	+1 Goal met more than expected.
	Exercising helped him manage his fatigue and he didn't miss a meeting at work for the last three months.	Robert experienced difficulties with fatigue but continues to learn about his fatigue.	Robert became more active and capable of managing his fatigue.
2	+1 Goal met more than expected.	+2 Goal met much more than expected.	+2 Goal met much more than expected.
	Robert was recommended to request a referral to a Neuropsychologist for help as the intervention was not enough for his difficulties.	Robert did not request the referral for the Neuropsychologist, as he learnt to use the techniques discussed in the sessions.	Robert reported fewer memory problems and felt confident about his work capability.
3	+1 Goal met more than expected.	+1 Goal met more than expected.	+1 Goal met more than expected.
	Robert learnt to manage his fatigue and memory problems and addressed other issues with his healthcare team.	Robert continues to manage better his symptoms at work.	Robert continues to make good progress at work and managing his symptoms.
GAS	59.1	68.3	68.3

Table 53 Goal attainment for participant MS\_11

#### Patient's perspective

Robert completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 54).

Theme	Quotes
Intervention Characteristics (CIFR).	Robert believed that it is important to have someone to discuss his issues at work: "I think sometimes you just get involve in living your life and there isn't anybody there, a different perspectiveso it is nice that you [assistant psychologist] can come with suggestions rather than "here is a piece of paper, just do it"."
Characteristics of individuals (CIFR).	The intervention provided Robert with an opportunity to manage his MS at work: <i>"I think talking through it with you, I wouldn't say it made me</i> <i>do it, but it's kind of been a focus because I know I would be</i> <i>talking to you, and you are going to be asking me about it."</i>
Opportunity (BCW).	<b>The intervention helped Robert manage his work better:</b> <i>"From a work perspective, I would say that my job tripled since we started, and I think that by following the stuff [VR intervention] it is making it easier for me to be able to work and I feel as if I am benefiting from it a lot at work."</i>
Contextual factors (ICF)	Robert's manager has also acknowledged his improvements at work: "I had my yearly review from your manager, and he said he has seen that my output has improved, and I am doing more."

Table 54	<i>Oualitative</i>	findings	MS	11

#### Summary of case

Although Robert was managing his MS well at work and had a supportive line manager, the presence of fatigue and cognitive problems were starting to harm his work. During the intervention, Robert learnt techniques to manage his fatigue and memory difficulties and at three months post-intervention, he reported that his line manager and clients had complimented him on his work since he started the intervention.

#### 5.6.3.12. Case Study MS\_12 "Grace"<sup>24</sup>

#### Patient Information

Grace is a 47-year-old white British woman, that was diagnosed with RRMS seven years ago, but experienced symptoms suggestive of MS up to 12 years ago. She is receiving Fingolimod to treat her MS and experiences a moderate disability level (EDSS= 4.5). Grace completed her bachelor's degree and is currently working full-time (38 hours/week) as a nurse in a large public company. Grace is also completing a master's degree part-time. Grace lives on her own and enjoys cooking, walking her dogs, and doing yoga.

#### <u>Timeline</u>

Grace was allowed to work from home during the Covid-19 pandemic. Although, her line manager was not happy about it. While working from home Grace received a much higher workload than usual from her line manager. Grace felt isolated at work because she is not receiving enough support. Grace was also studying for a part-time master's degree which meant she had an additional workload from her studies. Grace reported having difficulties keeping consistent levels of energy throughout the day. Grace also expressed difficulties coping with memory and thinking problems at work.

#### Assessment

At baseline, Grace's was experiencing major difficulties at work and managing her MS symptoms. She was experiencing perceived cognitive deficits (PDQ 55 out of 80), high levels of anxiety (HADS 17 out of 21), depression (HADS 15 out of 21), work instability (MS-WIS 18 out of 22), and moderate to high fatigue levels (MFIS-5 14 out of 20). She also experienced medium levels of work self-efficacy (WSES 35 out of 50). Grace was employed and reported that MS harmed her productivity at work (WPAI:MS 8 out of 10), and a moderate negative impact on her everyday activities (WPAI:MS 5 out 10).

In terms of quality of life (EQ-5D-5L), Grace reported an overall health of 50 out of 100 and obtained an index health status of 0.62. These values represent a modest

<sup>&</sup>lt;sup>24</sup> Pseudonyms used to protect the anonymity of the participants.

reduction in quality of life, driven in particular by the mobility difficulties that by extension cause problems conducting everyday activities.

At work, Grace was working full-time and studying for a master's degree part-time which made her spend her weekends studying. Grace was allowed to work from home during the pandemic to reduce her risk of getting Covid-19.

**Intervention reasoning:** The first intervention topic aimed at empowering Grace to address the problems with her line manager. The second intervention topic focused on managing fatigue and cognition at work and studying. Finally, she addressed the topic of disclosure, as her university supervisors were not aware of her MS, and she wanted to inform them.

#### Intervention

The intervention is presented in Table 55.

Criteria	Description
Why	Grace needed VR support to manage her symptoms and relationships at work.
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Royal School of Nursing Remote Working Guidelines.</li> <li>Session 3: Memory and thinking in MS (MS Society)</li> <li>Session 4: Fatigue management course MS Society.</li> <li>Session 5: SleepStation.</li> <li>At the end of each session, Grace received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Grace did not involve her line manager because they did not have a good relationship.</li> <li>Direct support: Grace participated in five sessions addressing the following topics:</li> <li>(i) <u>Disclosure:</u> This session reviewed how (and whether it was necessary) to disclose her MS to her university supervisors. This also included an overview of the Equality Act 2010, and support that she might need at university. This session also addressed problems with her line manager and how to request further support from work.</li> </ul>

Table 55 Intervention description Case Study MS\_12

Criteria	Description
	(ii) <u>Cognition in MS</u> : This session provided an overview of the cognitive difficulties Grace was experiencing and techniques to manage them better at work. The session also addressed Grace's positive experience disclosing her MS at university, and the support offered by the university as a result of the disclosure.
	(iii) <u>Cognition in MS (2)</u> : This session reviewed the progress made by Grace implementing the techniques discussed and further cognitive difficulties she was experiencing. The session focused on supporting Grace to use a diary to track and distribute her workload.
	(iv) <u>Fatigue management:</u> This session discussed types of fatigue, factors that lead to increased fatigue, and strategies to manage fatigue at work. To complement the knowledge of the session, I referred Grace to an online fatigue management course to re-visit the content learnt.
	(v) <u>Fatigue management (2)</u> : This session reviewed the progress made with the fatigue management course and discussing how to use a fatigue diary.
	<b>Indirect support:</b> The indirect support included the following activities: (i) administrative tasks, (ii) preparation of materials for sessions, and (iii) liaison with participant.
How	The intervention sessions were delivered via Microsoft Teams.
	The first step involved an initial interview and goal setting (1 hour).
	Grace participated in a three-month intervention and received 5 hours of direct support, spread over five sessions, and 1.33 hours of indirect support. In total, the intervention time plus the interview accounted for 7.33 hours of support.
When and how much?	<b>Direct support:</b> All sessions lasted 60 minutes. The time spent on each intervention topic was as follows: (i) Cognition in MS (90 mins), (ii) fatigue management (80 mins), (iii) fatigue diary (30 mins), (iv) disclosure (30 mins), (v) issues with employer (30 mins), (vi) legal rights (20 mins), (vii) reasonable accommodations (10 mins), and (viii) resources for the future (10 mins)
	<b>Indirect support:</b> The indirect support ranged between 10-30 minutes per session delivered. The time included in each activity was: (i) administrative tasks (40 mins), (ii) liaison with participant (30 mins), and (iii) preparation of materials (10 mins).

Criteria	Description
How well?	Grace cancelled one session because of an unexpectedly high workload. She completed the intervention at the end of the three months.

#### Follow-up and Outcomes

Table 22 presents an overview of Grace's performance on the different outcome measures included in the study.

At the post-intervention assessment, the intervention seemed to have a positive impact on managing cognitive difficulties, shown by a decrease in the PDQ (PDQ from 55 to 45). Grace also experienced a reduction of feelings of depression (HADS depression from 15 to 11), and a small improvement in work self-efficacy (WSES from 35 to 37) and anxiety levels (HADS anxiety from 17 to 16). However, Grace deteriorated on work instability (MS-WIS from 18 to 20). The intervention did not affect levels of fatigue, and quality of life. The improvement on the HADS was not clinically significant change on levels of anxiety (RIC= 0.38) and depression (RIC= 1.46).

At three months follow-up, Grace experienced a clinically significant reduction in anxiety (RIC=2.63) and depression (RIC=3.28) levels. She also experienced a change of more than four points on her fatigue levels, which is considered a significant improvement (MFIS-5 from 14 to 10). Grace improved considerably on the perceived cognitive deficits (PDQ from 55 to 41) but remained above the cut-off for risk range. She remained relatively stable on quality of life (EQ-5D-5L from 0.62 to 0.66) and work instability (MS-WIS from 18 to 16). Grace did not complete the six months follow-up as she was on holiday.

Grace's scores on the HADS (Figure 45), PDQ (Figure 46) and MS-WIS (Figure 47) are presented in the following figures. The orange dotted line represents the start of the VR intervention.







Figure 46 MS\_12 PDQ score over 6 months.



Figure 47 MS\_12 MS-WIS score over 6 months.

**Intervention Goals:** Grace set the following goals at the beginning of the intervention:

• **Goal 1:** I would like work to support me to manage my new working arrangements (remote working).

**SMART Goal:** To empower Grace to request extra support from her line manager when working from home before their next meeting in two weeks.

• **Goal 2:** Learn to manage my fatigue levels and what makes me feel exhausted at the end of the day.

**SMART Goal**: To identify at least three fatigue management techniques for Grace by the end of the intervention.

Goal 3: I want to learn if there is anything I can do about the memory and thinking problems, as I find it challenging to focus at work.
 SMART Goal: To identify at least three techniques to manage cognitive problems at work by the end of the intervention.

Table 56 presents the progress made by Grace over the three months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up
1	+1 Goal met more than expected.	-1 Goal met less than expected.
	Grace held a meeting with her line manager and discussed the difficulties she was experiencing. She felt more confident addressing the issue.	Grace reported that her line manager had significantly reduced the contact with her, and their relationship deteriorated.
2	+1 Goal met more than expected.	-1 Goal met less than expected.
	Grace still had problems with her sleep, but she identified the factors that cause her fatigue and learnt techniques to manage fatigue.	Grace was working and studying for a master's degree, which made her more fatigued than usual as a result of the higher workload.
3	+1 Goal met more than expected.	+1 Goal met more than expected.
	Grace learned to use a diary to keep track of her work. She felt more in control of her workload.	Grace had incorporated the use of the diary for personal and professional life and reported great benefits from using it.

Table 56 Goa	l attainment for	· participant	MS_1	2
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Goal	Post-intervention	3-months follow-up
GAS Score	63.7	45.4

## Patient's perspective

Grace completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 57).

Theme	Quotes
Intervention Characteristics (CIFR).	<b>Grace found the intervention very useful:</b> <i>"I found it helpful, it's been really good input from you in terms of how to manage things, how to pace yourself."</i>
Characteristics of individuals (CIFR).	Grace incorporated the support learnt at work: "I now manage my day in a way that I first call all the patients, and then I do all the administrative work at once." She also started including breaks at work to manage her fatigue: "And I have given myself 5 minutes every hour to go for a little walk. Before I used to sit for hours and just be thereso now I pace myself, you [assistant psychologist] taught me that and I do feel better with that."
Opportunity (BCW).	<b>Grace believed that VR was beneficial for her:</b> <i>"Talking it through with somebody and accepting that what you feel or what you say is valid, and I think it empowers you."</i>
Contextual factors (ICF)	Grace experienced difficulties to meet her intervention goals: "I think that [not meeting intervention goals] was the influence from work. I think they haven't taken on board what I have asked for."

Table 57	' Qualitative	findings	MS_12
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## Summary of case

Grace was experiencing high levels of work instability, anxiety, and perceived cognitive difficulties. Her line manager was not supportive at work and that caused more challenges at work. At the end of the intervention, Grace reported that she felt more confident addressing the problems with her line manager and although the

workload remained high, she was more decisive to triage patients that needed to be seen in the clinic and not addressing their queries via telephone.

# 5.6.3.13. *Case Study MS\_13 "Peter"*<sup>25</sup> Patient Information

Peter is a 31-year-old white British man, that was diagnosed with RRMS one year ago, and is currently receiving Tysabri to treat his MS. Peter presents with a low disability level (EDSS=1.5) and reported experiencing anxiety, fatigue, and word-finding difficulties as a result of his MS. Peter completed his college education and is working full-time (40 hours/week) as a Service Delivery Manager for a large private company. Peter lives with his partner and two daughters. He enjoys going gym and spending time with his family. Peter has a supportive manager at work, and there are three other people with MS in his company, which has made the senior managers be more understanding of the condition. Peter is managing relatively well at work but reports that sometimes his legs cause him difficulties when travelling to work, as he has to travel more than one hour by train. Peter also experiences difficulties concentrating at work, and word-finding difficulties when attending meetings; this made him feel anxious because it remind him of his MS challenges. Because of his young age, he reported feeling bitter about the difficulties he experiences, and anxious when thinking about his future at work.

#### **Timeline**

Peter was working from home at the beginning of the intervention and reported significant benefits from not travelling to and from work. His company had recently made redundant several workers. This meant that his workload increased, and his role changed so that he had to supervise workers from different time zones (such as people in Hong Kong), which required him to be on call at night. Even though Peter was managing his MS well, he reported being concerned about memory and thinking problems, including word-finding difficulties and fatigue at work. Peter also experienced high levels of anxiety since his MS diagnosis but had never discussed it with anyone before the intervention.

<sup>&</sup>lt;sup>25</sup> Pseudonyms used to protect the anonymity of the participants.

#### Assessment

At baseline, Peter reported that the productivity impact of his MS at work (3 out of 10) and everyday activities (2 out of 10) was low. Peter scored below clinical levels on all measures. He was experiencing low levels of perceived cognitive deficits (PDQ 28 out of 80), low levels of anxiety (HADS anxiety 7 out of 21) and depression (HADS depression 1 out of 21), work-instability (MS-WIS 10 out of 21), fatigue (MFIS-5 4 out of 20), and high levels of work self-efficacy (WSES 42 out of 50). In terms of quality of life as measured by the EQ-5D-5L, Peter obtained an index health status of 0.86 (out of 1.0), and overall health of 96 (out of 100).

Interestingly, even though he reported complaints suggestive of cognitive deficits, high levels of fatigue and anxiety, his performance on the questionnaires was within normal neuro-typical levels. At work, Peter was allowed to take more breaks and work from home (even before Covid-19).

**Intervention reasoning:** The first intervention topic aimed at understanding the impact of cognitive problems and fatigue at work and identify how he could manage them better. Peter was not familiar with reasonable accommodations, therefore, the intervention aimed at educating and identifying reasonable accommodations for him. Finally, the intervention aimed at understanding Peter's anxiety and inform him about treatments for his anxiety.

#### Intervention

The intervention is presented in Table 58.

Criteria	Description	
Why	Peter was newly diagnosed with MS and was starting to experience the impact of MS symptoms at work.	
What materials?	<ul> <li>Screening interview</li> <li>Session 1: NHS anxiety and depression; Every mind matter.</li> <li>Session 3: Memory and thinking (MS Society), Staying Smart (MS Trust).</li> <li>At the end of each session, Peter received an email with a summary of the main points discussed and the next steps.</li> </ul>	

Table 58 Intervention Description MS\_13

Criteria	Description
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Peter did not involve his line manager.</li> <li><b>Direct support:</b> Peter participated in four sessions addressing the following topics: <ul> <li>(i) <u>Emotions in MS:</u> This session address the problems that Peter was experiencing with anxiety. I informed Peter about educational resources about anxiety, and a guide to self-manage anxiety. The session also covered the relevance of sharing his fears about anxiety with a healthcare professional to improve his mental health.</li> <li>(ii) <u>Cognition in MS:</u> This session covered the impact of MS on cognition, a review of the problems he was experiencing at work, and ideas to manage those difficulties at work.</li> <li>(iii) <u>Reasonable accommodations:</u> This session reviewed the progress made implementing the techniques to manage memory and thinking problems at work and identified further difficulties. The session also identified relevant reasonable accommodations to help him manage his MS at work.</li> <li>(iv) <u>Fatigue management:</u> This session covered fatigue in MS. identified fatigue management techniques, and changes at work to help him preserve his energy levels.</li> </ul> </li> </ul>
How	The sessions were conducted using Microsoft Teams.
When and how much?	The first step involved an initial interview and goal setting (1 hour). Over the three-month intervention, Peter received 4.17 hours of direct support, spread over three sessions, and 1 hour of indirect support. In total, the intervention time plus the interview accounted for 7.33 hours of support. <b>Direct support:</b> Peter participated in four sessions lasting on average 62 minutes and ranging between 60-70 minutes. The time spent on each intervention topic was as follows: (i) Cognition in MS (90 mins), (ii) emotions in MS (60 mins), (iii) fatigue management (50 mins), (iv) reasonable accommodations (30 mins), (v) long-term career planning (10 mins), and (vi) understanding MS (10 mins).

Criteria	Description	
	<b>Indirect support:</b> The indirect support ranged between 10-20 minutes	
	per session delivered. The time included on each activity was: (i)	
	administrative tasks (30 mins), (ii) liaison with participant (20 mins),	
	and (iii) preparation of materials for sessions (10 mins).	
	All the topics agreed upon in the initial interview were discussed.	
How well?	There was an agreed end of the intervention, and Peter received an	
	email after three weeks to see if he needed further support.	

#### Follow-up and Outcomes

Table 22 presents an overview of Peter's performance on the different outcome measures included in the study.

At the post-intervention assessment, Peter remained stable in all outcome measures and experienced a small improvement on perceived cognitive deficits (PDQ from 28 to 25). The impact of MS at work and on everyday activities remained at the same level as the baseline assessment. Peter also experienced a small worsening of depression levels (HADS depression from 1 to 3) that was not clinically significant (RIC= -0.73).

At three months follow-up, Peter experienced a reduction of perceived cognitive deficits (PDQ from 28 to 23), and improvement of quality of life (EQ-5D-5L health index from 0.86 to 1). He only experienced a moderate increase in fatigue levels (MFIS-5 from 4 to 7).

At six months follow-up, Peter remained relatively stable on all measures, except for a clinically significant worsening on fatigue levels (MFIS-5 from 4 to 8).

Peter's scores on the HADS (Figure 48), PDQ (Figure 49) and MS-WIS (Figure 50) are presented in the following figures. The orange dotted line represents the start of the VR intervention.







Figure 49 MS\_13 PDQ score over 9 months.



Figure 50 MS\_13 MS-WIS score over 9 months.

**Intervention Goals:** Peter set the following goals at the beginning of the intervention:

• **Goal 1:** I find it difficult to focus at work, and if I'm in a meeting I even have problems finding my words.

**SMART Goal:** To identify at least three strategies to manage the concentration difficulties in the workplace by the end of the intervention.

- Goal 2: Since I was diagnosed with MS, I feel anxious more frequently. This also happens at work when I have a meeting with new people.
   SMART Goal: To help Peter identifying support to manage his anxiety by the end of the intervention.
- **Goal 3**: I feel fatigued quite frequently and I am not sure how to manage it. **SMART Goal**: To identify at least three fatigue management techniques for Peter by the end of the intervention.

Table 59 presents the progress made by Peter over the six months follow-up with regards to his intervention goals.

Goal	Post-intervention	3-months follow-up	6-months follow-up
1	<ul> <li>+1 Goal met more than expected.</li> <li>Peter reported benefits from reading and writing reports with his email account closed to avoid distractions.</li> </ul>	<b>0</b> Goal met. Peter was busier at work and moving homes so he was experiencing some difficulties concentrating at work.	<b>0</b> Goal met. Peter still experienced problems concentrating at work.
2	+2 Goal met much more than expected. Peter learnt about treatment options to manage his anxiety and where to seek further support.	+1 Goal met more than expected. Peter was actively managing anxiety and recognising what helped him control it.	<ul> <li>+1 Goal met more than expected.</li> <li>Peter felt more confident managing his anxiety levels.</li> </ul>
3	+1 Goal met more than expected.	+1 Goal met more than expected. Peter continued improving his ability	<ul><li>+1 Goal met more than expected.</li><li>Peter reported having problems managing</li></ul>

Table 59 Goal attainment for participant MS\_13

Goal	Post-intervention	3-months follow-up	6-months follow-up
	Peter benefited from discussing fatigue management techniques.	to manage fatigue at work.	fatigue when he is stressed at work.
GAS Score	68.3	59.1	59.1

#### Patient's perspective

Peter did not complete the follow-up interview because he was building a new home and did not have time.

#### Summary of case

Peter was diagnosed with MS one year ago and was concerned about his ability to remain at work. He reported that his MS had a moderate impact at work because he was not aware of what support was available for him. At the end of the intervention, Peter reported having benefited from learning about his MS and feeling positive about the future.

#### 5.6.3.14. Case Study MS\_14 "Emma"<sup>26</sup>

#### Patient Information

Emma is a 35-year-old black British Caribbean woman, that was diagnosed with RRMS two years ago and is currently receiving Ocrelizumab to treat her MS. Emma experiences a normal neurological state with no disability (EDSS= 0). Emma completed her bachelor's degree and is currently working full-time (37 hours/week) as a receptionist in a large public company. She has been working in the same company for 10 years but started her current post a few months before the intervention. Emma lives with her partner and has reduced her social activities as a result of the Covid-19 pandemic.

#### Timeline

During the first national lockdown, Emma was allowed to work from home as she was shielding. When she returned to work after the first national lockdown, she

<sup>&</sup>lt;sup>26</sup> Pseudonyms used to protect the anonymity of the participants.

requested her line manager to work from home two days per week. The line manager rejected the request stating that her role was not suitable for home working.

Approximately a month after, Emma had an outbreak of MS and was sick off work for three weeks. Upon her return to the office, she was referred for an OH assessment, that recommended a phased RTW, a quiet place to manage her cognitive difficulties, and allowing her to work from home at least two days per week. The line manager rejected all the recommendations.

Although Emma was newly diagnosed, she reported difficulties with memory and thinking, fatigue, and managing her workload. Her difficulties concentrating at work are exacerbated by the high levels of noise in her office.

After the first two sessions, Emma paused her participation in the intervention because of high levels of stress. During her time off the intervention, Emma found a new role and was planning to apply for it; therefore, she requested further support to address topics such as disclosure.

#### Assessment

At baseline, Emma had missed 3.45 hours at work because of her MS but reported that MS had a low impact on her work (WPAI:MS 3 out of 10) and everyday activities (WPAI:MS 2 out of 10). She scored at or above clinical levels on most measures. She was experiencing moderate to high perceived cognitive deficits (PDQ 41 out of 80), high levels of work instability (MS-WIS 14 out of 22), anxiety (HADS anxiety 10 out of 21), depression (HADS depression 11 out of 21), fatigue (MFIS-5 11 out of 20), and low of work self-efficacy (WSES 32 out of 50) suggestive of difficulties addressing problems and managing relationships with colleagues. On the contrary, she had a high level of quality of life with an associated health index of 0.85. However, on that day she reported overall health of 45 out of 100. At work, Emma was allowed to take more breaks and provided with more supervision as a result of her increased sick leave.

**Intervention reasoning:** There were several high priority topics for this intervention. The first one related to educating Emma about her legal rights and empowering her for the meeting with her line manager to negotiate the support

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recommended by OH. The second intervention topic referred to managing cognitive problems, and fatigue management at work.

# Intervention

The intervention is presented in Table 60.

Criteria	Description
Why	Emma was in a work crisis and needed VR support to help her manage her MS at work and negotiate reasonable accommodations with her line manager.
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Disability law service, citizens advice information, ACAS (The Advisory, Conciliation and Arbitration Service).</li> <li>Session 2: Disable Staff Policy, Equality Advisory &amp; Support Service (EASS).</li> <li>Session 3: Disclosure at work guide (MS Society).</li> <li>Session 6: Online fatigue management course (MS Society), booklet fatigue management.</li> <li>At the end of each session, Emma received an email with a summary of the main points discussed and the next steps.</li> </ul>
What procedures	<ul> <li>The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Emma did not include her line manager in the intervention.</li> <li><b>Direct support:</b> Emma participated in seven sessions addressing the following topics: <ul> <li>(i) Legal Rights: This session addressed Emma's problems at work, and how to negotiate the support recommended by OH with her line manager. This session also covered the Equality Act 2010.</li> <li>(ii) Legal rights (2): This session followed up the result from the meeting with her line manager. The line manager rejected all the support suggested by OH and only agreed to a phased return plan.</li> </ul> </li> <li>During the session, we agreed to contact an expert OT and lawyer for further support. After contacting both experts, it was agreed that Emma's Neurologist should write a letter of support highlighting the need for the support recommended OH. To complement the support, Emma was referred to a local OT to provide more in-depth support addressing the issue.</li> <li>(iii) Disclosure: This session covered how to disclose MS to her new line manager, information about Access to Work for her new role, and</li> </ul>

Criteria	Description
	further issues with her current line manager that requested a second OH report as she was performing below the expected level.
	(iv) <u>Cognition in MS</u> : This session explored cognitive problems at work, support to manage the cognitive problems and other reasonable accommodations at work.
	(v) <u>Capability Monitoring</u> : Because Emma was performing below the expected levels for her role, her line manager informed her that she was under capability monitoring. This session revisited some of the intervention action points discussed in the first session, the main points of the meeting, and the topics that she should address such as the failure to provide reasonable accommodations from her line manager.
	(vi) <u>Follow-up</u> : This session reviewed the feedback from the capability monitoring meeting. At this point, Emma was notified that she got a new role in a different department.
	The session finished with an introduction about fatigue management and Emma was referred to an online fatigue management course to complete at her own pace.
	(vii) <u>Fatigue management</u> : This session reviewed the progress made in understanding fatigue and completing a fatigue diary. Emma completed a fatigue diary and identified factors that increase her fatigue, such as noise and sleep issues. Finally, the session covered an overview of her situation at work, and she was provided with a list of resources for additional support in the future.
	<b>Indirect support:</b> The indirect support included the following activities: (i) liaising with participant, (ii) preparation of materials for sessions, (iii) liaison with OT, (iv) liaison with Disability Law Service, and (v) administrative tasks.
How	The sessions were conducted via telephone.
When and how much?	The first step involved an initial interview and goal setting (70 minutes). Over the three-month intervention, Emma received 7.67 hours of direct support, spread over seven sessions, and 5.5 hours of indirect support. In total, the intervention time plus the interview accounted for 14.33 hours of support.
	<b>Direct support:</b> The sessions lasted on average 65 minutes and ranged between 60-70 minutes. The time spent on each intervention topic was as follows: (i) fatigue management (100 mins), (ii)
Criteria	Description
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	<ul> <li>cognition in MS (90 mins), (iii) reasonable accommodations (60 mins), (iv) issues with employer (60 mins), (v) legal rights (40 mins), (vi) disclosure (30 mins), (vii) disciplinary meeting (30 mins), (viii) Access to Work (20 mins), (ix) long-term career planning and future steps (20 mins).</li> <li>Indirect support: The indirect support ranged between 10-130 minutes per session delivered. The time spent on each activity was: (i) requesting legal support (110 mins), (ii) liaison with participant (80 mins), (iii) liaison with healthcare professionals (60 mins), (iv) administrative tasks (60 mins), (v) preparation of materials for sessions (50 mins), and (vi) work emergency plan (10 mins).</li> </ul>
How well?	Emma completed the first two intervention sessions and stopped receiving support for a month because of high levels of stress as a result of the problems with her line manager. Once her stress levels decreased, she was highly engaged in the intervention. The intervention finished at the end of the three months.

## Follow-up and Outcomes

Table 22 presents an overview of Emma's performance on the different outcome measures included in the study.

The intervention seemed to have a positive impact on reducing the presence of perceived cognitive deficits (PDQ from 41 to 32), reducing work-instability (MS-WIS from 14 to 11), and improving work self-efficacy (WSES from 32 to 35).

At the end of the intervention Emma's experience a deterioration in fatigue levels (MFIS-5 from 11 to 13), anxiety (HADS anxiety from 10 to 16), and depression (HADS depression from 11 to 12). In terms of quality of life, there was an improvement in the health today score (EQ-5D-5L from 45 to 50), but there was no change in the health index. There was a clinically significant deterioration in the levels of anxiety (RIC= -2.25), but the change in depression (RIC= -0.36) levels was not clinically significant.

At three months follow-up, Emma experienced an improvement on all outcomes measured. The most notable improvements were a reduction in anxiety and depression; of which the improvement in anxiety levels (RIC=2.25) was clinically

significant, but the reduction in depression (RIC= 1.82) levels was not. Emma also experienced a large reduction in the presence of perceived cognitive deficits (PDQ from 41 to 25), moving below the cut-off level for risk range. Emma did not complete the six months follow-up as she was moving homes.

Emma's scores on the HADS (Figure 51), PDQ (Figure 52) and MS-WIS (Figure 53) are presented in the following figures. The orange dotted line represents the start of the VR intervention.



Figure 51 MS\_14 HADS score over 6 months.



Figure 52 MS\_14 PDQ score over 6 months.



Figure 53 MS\_14 MS-WIS score over 6 months.

**Intervention Goals:** Emma set the following goals at the beginning of the intervention:

- Goal 1: I have problems concentrating at work.
   SMART Goal: To identify the cognitive problems that Emma experiences at work and identify the strategies to manage them better.
- Goal 2: I need help managing fatigue.
   SMART Goal: To reduced Emma's fatigue levels by learning and implement fatigue management techniques in the workplace.
- **Goal 3:** I want to learn tools to help me at work and know my rights, as my employer is not supporting me at work.

**SMART Goal**: To identify relevant legal support for Emma to address the issues she is facing with her line manager by the time she finishes her phased RTW (one month).

Table 61 presents the progress made by Emma over the three months follow-up with regards to her intervention goals.

Goal	Post-intervention	3-months follow-up
1	+1 Goal met more than expected.	+1 Goal met more than expected.

Table 61	Goal	attainment	for	participant	MS_14
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Goal	Post-intervention	3-months follow-up
	Emma learnt to organise her work to maximise her physical and mental energy.	Emma was experiencing fewer cognitive difficulties at work because of the support received.
2	+2 Goal met much more than expected.	+2 Goal met much more than expected.
	Emma was using the fatigue management techniques at work and reported feeling more in control of her energy levels.	Emma reported an improved ability to manage fatigue.
3	<b>0</b> Goal met as expected.	+1 Goal met more than expected.
	Emma did not receive any further support at work from her line manager.	Emma started on a new role and her manager was open to providing her with support at work.
GAS Score	63.7	68.3

# Patient's perspective

Emma completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 62).

Table 62	Qualitative	findings	MS_14
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Theme	Quotes
Intervention Characteristics (CIFR).	Emma believes that the intervention provided her with sufficient support: "Initially, when you said between 1 to 10 hours, I remember I was thinking oh that is not that much. But in reality, with all the issues that I brought it was more than enough time." The techniques learnt to manage her memory problems at work made a positive impact on her work:
	"With the learning to manage cognition and memory at work, one thing that I routinely do now, is that if I am going to see a consultant, I go with a notepad and pen, so that whatever they tell me, I note it down. So that I am sorely reliant on my memory." However, she was still working on managing her fatigue levels:

	<i>"Understanding fatigue also helped but it is something that I am working on myself because that's a long-term work rather than a quick fix."</i>
Characteristics of individuals (CIFR).	Emma found the support informative and beneficial: "Overall it's been really good, really informative. It is good to have sort of at the time feedback but also than anything that you said you would look into, you have looked into it, and provided the information promptly."
Opportunity (BCW).	Because Emma works full-time, she benefited from receiving the support remotely: "It would have been tricky for me to have a [Microsoft] teams discussion, because every time we have spoken, I was sat in my car."
Motivation (BCW)	Emma reported on the relevance of early intervention from her personal experiences: "Before I contacted you, I already knew about the study, but at that timeI was like "oh, I don't need to talk because I am fine", so I think I left it for too late maybeif I would have contacted you sooner, I would have been in a very different situation at work."

## Summary of case

Interestingly, Emma recognised the need for early intervention from her personal experience. Emma was in a work crisis at the baseline assessment, and although she had a month off from the intervention, she requested further support once the situation normalised.

At the post-intervention interview, she reported that the intervention give her the confidence to manage her condition and address the problems at work. At three months post-intervention, she experience a clinically significant reduction of anxiety potentially caused as a result of her new role and working in a supportive environment.

# 5.6.3.15. Case Study MS\_15 "Amy"<sup>27</sup> Patient Information

<sup>&</sup>lt;sup>27</sup> Pseudonyms used to protect the anonymity of the participants.

Amy is a 62-year-old white British woman, that was diagnosed with SRMS seven years ago; however, she has experienced symptoms suggestive of MS for over 26 years. Amy was receiving Tecfidera to treat her MS and presents a moderate disability level (EDSS= 6.5). The main MS symptoms she experiences are fatigue, mobility difficulties, bladder issues, and memory difficulties. Amy's completed her college education and is a technical consultant for a large private company working full-time (37 hours/week). Amy reported to be managing well her MS at work and has a supportive manager. However, because of redundancies in the company her workload has increased significantly in the months before participating in the intervention. Amy lives with her husband who supports her in conducting household activities.

## <u>Timeline</u>

Amy was experiencing difficulties getting to and from work as she had stopped driving when she was diagnosed with MS and relies on her husband to go to work. At work, her line manager was supportive but had limited knowledge about MS and what additional support would be beneficial for Amy. Unfortunately, Amy's husband passed away a month after the intervention finished.

#### Assessment

At baseline, Amy reported that the productivity impact of her MS at work was low (WPAI:MS 2 out of 10), but it had a significant negative impact on her everyday activities (WPAI:MS 7 out of 10). Amy scored above clinical levels in all measures except for work self-efficacy where she was presented with high levels of work self-efficacy (WSES 46 out of 50). She experienced moderate perceived cognitive deficits (PDQ 45 out of 80). She also experienced moderate to high levels of anxiety (HADS anxiety 9 out of 21), depression (HADS depression 11 out of 21), work instability (MS-WIS 13 out of 22), and fatigue (MFIS-5 11 out of 20).

In terms of quality of life as measured by the EQ-5D-5L, she obtained an index health status of 0.62 (out of 1.0) and overall health of 60 (out of 100), representing some loss of quality of life. At work, Amy was allowed to take more breaks and allowed to work from home.

**Intervention reasoning:** The first intervention topic aimed at informing Amy about Access to Work and support her with the application to get taxis to work. The second intervention topic aimed at reviewing Amy's work and identifying further accommodations that might help her manage her MS.

## Intervention

The intervention is presented in Table 63.

## Table 63 Intervention Description MS\_15

Criteria	Description		
WhyAmy was interested in learning what support was available to hbecome independent when going to work.			
What materials?	<ul> <li>Screening interview</li> <li>Session 1: Access to Work booklet (UK Government).</li> <li>Session 3: Access to work application template.</li> <li>At the end of each session, Amy received an email with a summary of the main points discussed and the next steps.</li> <li>Employer: Access to Work booklet and MS and Employment, an employer's guide (MS Society).</li> </ul>		
What procedures	The first step involved an initial interview and goal setting to prioritise the intervention topics according to relevance. Amy involved her line manager in the intervention and only selected two intervention goals. <b>Direct support:</b> Amy participated in three sessions addressing the following topics: (i) <u>Access to Work:</u> This session provided Amy with information about Access to Work, with a specific focus on supporting her with the cost of taxis to and from work. (ii) <u>Reasonable accommodations:</u> This session reviewed the key aspects of Amy's role and the difficulties she was experiencing to identify any further reasonable accommodations that she could receive at work. (iii) <u>Progress made and further questions:</u> This session provided Amy with examples of Access to Work applications, and how to report the impact of her MS at work. Amy asked further questions about the application process and timelines. <b>Indirect support:</b> The indirect support included the following activities: (i) liaison with participant, (ii) administrative tasks, (iii)		

Criteria	Description
	Employer's intervention
	Amy included her line manager Jon (pseudonym) in the intervention.
	Jon completed an initial interview where he reported to have no experience managing an employee with a chronic illness and was not aware of how to best support Amy at work. He allowed her to have a flexible schedule and have broken as OH recommended. Jon completed one intervention session discussing his questions about MS, and information about reasonable accommodations for Amy.
How	The sessions were conducted via telephone.
When and how much?	The first step involved an initial interview and goal setting (40 mins). Over the three-month intervention, Amy received 1.67 hours of direct support, spread over three sessions, and 0.83 hours (50 minutes) of indirect support. In total, the intervention time plus the interview accounted for 3.17 hours of support. <b>Direct support:</b> The sessions lasted on average 33 minutes and ranged between 30-40 minutes. The time spent on each intervention topic was as follows: (i) Access to Work (60 mins), (ii) reasonable accommodations (30 mins), (iii) current issues (10 mins), and (iv) resources for the future (10 mins) <b>Indirect support:</b> The indirect support ranged between 10-20 minutes per session delivered. The time included on each activity was: (i) liaison with participant (20 mins), (ii) administrative tasks (20 mins), and (iii) preparation of materials for sessions (10 mins). <b>Employer's intervention:</b> Jon completed an initial interview (20 minutes) and one session covering topics such as (i) understanding MS (50 mins), and (ii) reasonable accommodations (10 mins). The time spent in the indirect intervention was 10 minutes to share resources about MS and work.
How well?	There was an agreed end of the intervention. Amy received an email after her final session to see if she needed further support.

# Follow-up and Outcomes

Table 22 presents an overview of Amy's performance on the different outcome measures included in the study.

The intervention did not have an impact on the outcome measures. At the end of the intervention, Amy reported an improvement in the perceived cognitive deficits (PDQ from 45 to 37), and a worsening in work self-efficacy (WSES from 46 to 41).

Amy remained relatively stable on the remaining outcomes, with a small increase of anxiety (HADS anxiety from 9 to 10), depression (HADS depression from 11 to 12), work instability (MS-WIS from 13 to 15), fatigue levels (MFIS-5 from 11 to 13), and reduction of quality of life (EQ-5D-5L health index from 0.62 to 0.52). There was no clinically significant change in the levels of anxiety (RIC= -0.38) or depression (RIC= -0.36) of the HADS.

Interestingly, the productivity impact of her MS at work had increased four points from baseline to post-intervention (WPAI:MS from 2 to 6), however, the impact of the MS in everyday activities (e.g., housework, shopping) decreased by four points (WPAI:MS from 7 to 3).

At three months follow-up, Amy returned to baseline levels to most of the outcome measures, except for a small increment of depression levels (HADS depression from 11 to 14). The change in depression levels was not clinically significant (RIC= - 1.03).

At six months follow-up, Amy reported an improvement in perceived cognitive deficits (PDQ from 45 to 40), and a worsening of quality of life (EQ-5D-5L health index from 0.62 to 0.36) and work self-efficacy (WSES from 46 to 42).

Amy's scores on the HADS (Figure 54), PDQ (Figure 55) and MS-WIS (Figure 56) are presented in the following figures. The orange dotted line represents the start of the VR intervention.







Figure 55 MS\_15 PDQ score over 9 months.



Figure 56 MS\_15 MS-WIS score over 9 months.

**Intervention Goals:** Amy set the following goals at the beginning of the intervention:

• **Goal 1:** I rely on my husband to go to work, and that is becoming challenging.

**SMART Goal:** To support Amy with the application for Access to Work before she returns to work by the end of the intervention.

Goal 2: Learn what else I can request at work to manage my MS.
 SMART Goal: To identify what reasonable accommodations could be beneficial for Amy by the end of the intervention.

Table 64 presents the progress made by Amy over the six months follow-up with regards to her intervention goals.

Goal	<b>Post-intervention</b>	3-months follow-up	6-months follow-up
1	+2 Goal met much more than expected.	+2 Goal met much more than expected.	+1 Goal met more than expected.
	Amy compiled the documents for the application for Access to Work and but had not submitted them yet because she was going to work from home for the next few months.	Amy had the application for Access to Work ready and planned to submit it after her company developed a return to the office plan.	Amy still had not applied to Access to Work as she was expected to remain working from home for the rest of the year.
2	<b>0</b> Goal met as expected. No further support needs were identified, and Amy learnt where to seek support if her needs change in the future.	+1 Goal met more than expected. Amy's employer started to proactively understand Amy's needs to provide her with further support.	+1 Goal met more than expected. Amy started having regular conversations about her needs with her line manager.
GAS Score	59.8	68.6	62.3

Table 64 Goal attainment fo	r participant MS_15
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Patient's perspective

Amy completed a telephone interview at three months follow-up explaining her experiences receiving the support (Table 65).

Theme	Quotes
Intervention	Amy believed that the intervention provided her with the right amount of support:
Characteristics	<i>"I think you gave me enough information to get my head</i>
(CIFR).	around. I do not like being bombarded with too much. So the
	information that I received was spot on."
	Amy acknowledge how important it was for her to receive
Characteristics of	this support:
individuals	<i>"I thought you were very helpful…I know now that if I need</i>
(CIFR).	support to get to work, it is feasible; it is more prominent now
	because my husband used to take me to work, and I do not have that luxury now "
	Amy recognised the impact of the Covid-19 pandemic on the intervention:
Opportunity	
(BCW).	"I would say that things have been difficult because we have
	aone this during covia-19 so things would have been different if we were in the office."
Motivation	Amy is motivated to remain at work and her line manager
(BCW)	has modified her role to support her better:
	"My role is going to change, which is good for me. I am going
	to go on the training side because I am retiring soon so I have

Table 65 Qualitative findings MS\_15

## Summary of case

In the initial interview, Amy reported that she was managing well her MS at work; but she was having difficulties travelling to work, as she relied on her husband to drive her to work. Therefore, her intervention focused on completing an Access to Work application.

At three months post-intervention, Amy reported that the intervention had a positive impact on her working life. Unfortunately, her husband passed away at the end of the intervention and she had no means to go to work. Amy was experiencing a lower mood and difficulties concentrating at work. Amy reported that she was grateful for

the intervention because she needed support to get to work, and Access to Work could provide her with taxis to and from work.

## 5.6.4. Combined quantitative data.

Table 66 presents the combined quantitative data from the participants with MS at four different time points. Data completeness was very good (100%), as all questionnaires returned were fully completed.

To test the condition of normal distribution, I plotted histograms to explore the distribution of the difference between the baseline and other time points. The distribution of the difference was normally distributed; therefore, I selected paired t-test to explore the impact of the intervention.

The distribution of the difference between baseline and the post-intervention assessment for the HADS depression was not normally distributed; therefore, I selected the Wilcoxon signed-rank for this measure. There was no significant difference on the HADS depression scores at post-intervention (*Z*=-.158, *p*< .874, r=0.04), three months (*Z*=-.224, *p*< .823, r=0.06), and at six months follow-up (*Z*=-.1.65, *p*<.098, r=.47).

There was a significant difference in goal attainment scores from baseline (M=42.57, SD=2.33) to post-intervention assessment (M=60.5; SD=8.85); t(14)=7.44, p=.0001, d=1.9. The mean paired difference of the post-intervention assessment was on average 17.94 higher than the baseline.

There was also a significant difference in goal attainment scores from baseline (M=42.61, SD=2.41) to three months follow-up (M=56.5; SD=9.79); t(13)=4.81, p=.0001, d=1.28. The mean paired difference of the three months follow-up was on average 13.93 higher than the baseline.

There was also a significant difference in goal attainment scores from baseline (M=42.9, SD=2.3) to six months follow-up (M=57.5; SD=10.66); t(11)=4.45, p=.001, d=1.28. The mean paired difference of the six months follow-up was on average 14.6 higher than the baseline.

	Descriptive Statistics				Paired t-test		
	Baseline (n=15)	Post- intervention (n=15)	3 Months follow-up (n=14)	6 Months follow-up (n=12)	Baseline vs post- Intervention	Baseline vs 3 months follow-up	Baseline vs 6 months follow-up
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean Change (SD, 95% CI), <i>p</i>	Mean Change (SD, 95% CI), p	Mean Change (SD, 95% CI), p
PDQ	40.73 (13.67)	38.12 (11.96)	37.57 (10.99)	37.42 (12.09)	-2.6 (8.74, -7.44 to 2.24), <i>p</i> = .269	-2.07 (8.53, -6.99 to 2.85), <i>p</i> = .380	83 (9.08, -6.6 to 4.93), <i>p</i> =.757
HADS anxiety	9.6 (5.19)	9.8 (4.32)	8.21 (4.11)	8.58 (3.37)	-20 (3.66, -1.83 to 2.23) <i>p</i> = .836	57 (3.47, -2.58 to 1.43), <i>p</i> = .550	.58 (2.52, -1.02 to 2.19), <i>p</i> =.443
MS-WIS	14.8 (3.32)	14.46 (3.74)	14.29 (3.12)	15.17 (2.95)	33 (2.49, -1.71 to 1.04), <i>p</i> =.613	21 (3.35, -2,15 to 1.72), <i>p</i> =.815	.91 (2.99,98 to 2.82), <i>p</i> =.312
MIFS-5	12 (3.76)	11.6 (3.45)	12.07 (3.02)	10.54 (4.63)	40 (3.18, -2.16 to 1.36), <i>p</i> =.634	.64 (2.76,95 to 2.23), <i>p</i> =.400	.16 (3.92, -2,32 to 2.66), <i>p</i> =.886
EQ-5D-5L*	.64 (.19)	.62 (.17)	.66 (.19)	.63 (.18)	01 (.11,08 to .04), p=.600	01 (.09,07 to .03) p=.550	03 (.12,11 to .44), <i>p</i> =.354
GAS*	42.57 (2.33)	60.5 (8.85)	56.55 (9.79)	57.51 (10.66)	17.94 (9.33, 12.77 to 23.10), <b><i>p</i>=.0001</b> *	13.93 (10.82, 7.68 to 20.18), <b><i>p</i>=.0001</b> *	14.6 (11.35, 7.39 to 21.82), <b><i>p</i>=.001</b> *
WSES*	38.6 (4.86)	38.86 (4.77)	40.5 (3.95)	38.75 (5.53)	.26 (3.01, -1.4 to 1.93), <i>p</i> =.737	1.71 (4.35,80 to 4.23), <i>p</i> =.165	91 (2.93, -2.78 to .95), <i>p</i> =.303

Table 66 Paired t-test for quantitative measures.

PDQ: Perceived deficit questionnaire, HADS: Hospital Anxiety and Depression Scale, MS-WIS: Multiple Sclerosis Work Instability Scale, MFIS-5: Modified Fatigue Impact Scale -5 items, EQ-5D-5L: EuroQol 5-dimensions, 5 levels, WSES= Work Self-efficacy Scale, GAS: Goal attainment scale, SD: Standard Deviation. \*: Measures where a higher score represents a positive outcome. \*: statistically significant change.

## 5.6.4.1. HADS Anxiety.

Figure 57 presents the fluctuation in the HADS anxiety scores across all participants with MS.



#### Figure 57 Group HADS anxiety score over 9 months.

The participants as a group were experiencing high levels of anxiety at baseline. At the post-intervention assessment, the HADS anxiety scores increased for seven participants decreased for six participants, and one remained stable. Of the participants experiencing an increase in anxiety levels, one increased to the "possible" anxiety level, and two to "probable" anxiety by the end of the intervention. Two participants experienced clinically significant improvement in anxiety levels (MS\_06 and MS\_07), and one experienced a clinically significant deterioration (MS\_14).

At three months follow-up, three participants (MS\_03, MS\_12, and MS\_14) experienced a clinically significant change in anxiety levels. At six months follow-up one participant experienced a clinically significant deterioration (MS\_04).

## 5.6.4.2. Depression.

Figure 58 presents the fluctuation in the HADS depression scores for all participants with MS.



Figure 58 Group HADS depression score over 9 months.

Similar to their anxiety levels, the participants with MS also scored high on feelings of depression. The average HADS depression score decreased for six participants at the post-intervention assessment. Only one (MS\_06) experienced a clinically significant improvement in depression. Eight participants experienced a worsening in depression levels at the end of the intervention, of whom two increased above the possible depression cut-off. Only one participant (MS\_08) reported the same anxiety levels at the post-intervention assessment.

At three months follow-up, one participant experienced a clinically significant improvement in depression levels (MS\_12). At six months follow-up, seven participants experienced a worsening in depression levels, none of which was clinically significant.

## 5.6.4.3. Cognitive deficits.

Figure 59 presents the fluctuation in the PDQ score for all participants with MS.



Figure 59 Group PDQ score over 9 months.

At baseline, eight participants scored above the risk range (<40) of perceived cognitive deficits. At the post-intervention assessment, ten participants experienced a reduction in perceived cognitive deficits, of whom four scored below the cut-off point of risk range. Five participants worsened on this measure, of whom three scored above the risk range.

At three months follow-up, four participants worsened; of whom one scored above the risk range (<40). Eight participants experienced a reduction in this outcome, of whom two moved below the risk range.

At six months follow-up, four participants worsened, and eight participants reported fewer cognitive difficulties in this outcome.

## 5.6.4.4. Work instability.

Figure 60 presents the fluctuation in the MS-WIS scores for all participants with MS.



Figure 60 Group MS-WIS score over 9 months.

The levels of work instability were relatively high from baseline and remained high at the post-intervention assessment. Eight participants' work instability scores decreased following the intervention, but work instability remained high. One participant (MS\_07) decreased from high to moderate work instability.

At three months follow-up, seven participants' work instability increased, and one became high risk. Six participants experienced a reduction in work instability; of whom two (MS\_07 and MS\_12) moved below high risk and two (MS\_10 and MS\_14) below low risk. One participant experienced no change.

At six months follow-up, seven participants reported increased work instability; of whom two (MS\_02 and MS\_03) moved at or above high risk and two moved above low risk (MS\_05 and MS\_11). Four participants reported decreased work instability, but only one moved below the high-risk level (MS\_07). One participant (MS\_09) work instability scores remained at baseline levels.

## 5.6.4.5. Fatigue.

Figure 61 presents the fluctuation in the MFIS-5 scores for all participants with MS.



Figure 61 Group MFIS-5 score over 9 months.

The participants were experiencing high levels of fatigue, in fact, fatigue management was a goal for 10 participants. Three participants reported a  $\geq$  four-point reduction in fatigue post-intervention. Four remained stable, and one participant experienced a worsening of four points. There was no change for the remainder of the participants.

At three months, two (MS\_01 and MS\_04) participants self-reported fatigue levels worsened when compared to the baseline assessment.

At six months follow-up, three (MS\_01, MS\_03 and MS\_13) participants got significantly worse, and two (MS\_07 and MS\_08) reported a significant improvement in fatigue levels.

## 5.6.4.6. Quality of life.

Figure 62 presents the fluctuation in the EQ-5D-5L health index scores for all participants with MS.



Figure 62 Group EQ-5D-5L score over 9 months.

The participants were a heterogeneous group in terms of quality of life, and several reported poor quality of life as a result of the limitations caused by MS. The participants remained relatively stable across the four data collection points. At the post-intervention assessment, five participants reported an improvement in quality of life, six participants a worsening, and four remained stable. At three months follow-up, five participants reported an improvement in quality of life, seven participants a worsening, and two remained stable. At six months follow-up, five participants reported an improvement in quality of life, seven participants reported an improvement in quality of life, seven participants reported an improvement in quality of life, seven participants reported an improvement in quality of life, six participants a worsening, and two remained stable. At six months follow-up, five participants reported an improvement in quality of life, six participants a worsening, and one remained stable.

## 5.6.4.7. Work self-efficacy.

Figure 63 presents the fluctuation in the WSES scores for all participants with MS.



Figure 63 Group WSES score over 9 months.

Work self-efficacy was the variable where participants presented the most homogeneous performance. At the post-intervention assessment, ten participants experienced an improvement in levels of work self-efficacy, four participants experienced a decline, and one experienced no change. At three months, eight participants experienced an improvement in work self-efficacy, five experienced a deterioration, and one remained stable. At six months follow-up, five participants experienced an improvement in work self-efficacy, five reported deterioration and two remained stable.

## 5.6.4.8. Goal attainment.

Figure 64 presents the fluctuation in goal attainment for all participants with MS.



#### Figure 64 Group GAS score over 9 months.

This was the only measure where the participants improved, (see Table 66). At the post-intervention assessment, all participants except one met their intervention goals.

At three months follow-up, three participants (MS\_04, MS\_09, and MS\_12) did not meet their intervention goals; and one participant (MS\_09) did not meet the goals at six months follow-up.

## 5.6.5. Combined qualitative data.

The themes identified in the post-intervention interviews were categorised as barriers and facilitators to explore the acceptability of the intervention.

I have previously presented the qualitative findings for each case study separately in their respective case study. This section reports the combined qualitative findings for all participants to explore their experiences, and acceptability of the intervention. Four main themes were drawn from the interviews: (1) context, (2) the employer, (3) empowerment, and (4) intervention components and attributes. Theme 4 includes 3 sub-themes referring to (4.1) intervention components, (4.2) tailoring, and (4.3) therapist attributes.

The findings from these interviews were used to refine further the intervention following the PBA. A table of changes is presented in appendix K, based on the participant's experiences of the participants.

## 5.6.5.1. Context

The impact of context on rehabilitation has been extensively researched. The context was coded in the interviews following the ICF (Figure 65).



Figure 65 Intervention context following the ICF.

Only one participant had previously received support with employment. They were aware of information available about work and MS. However, they did not always understand the information, or it was not relevant for them:

"One of the main things was talking to you [PhD researcher], talking to a professional that is offering me explanations and talked me through the process. Because yes, I have access to the internet, but sometimes if you have somebody like yourself to put it in lay terms to understand...I just thought that it [the intervention] was very enlightening and empowering." (MS\_05)

Unfortunately, the Covid-19 pandemic interfered with the intervention:

"Interviewer: Was there anything that did not work well with you?

Participant: Covid-19...haha that is all I can say Covid-19 got in the way. I mean because it stopped the participation of the intervention with the school; the only thing I can say that got in the way, nothing else did. Environmental surroundings did." (MS\_04)

Because of Covid-19, the support was delivered remotely, and the participants reported high acceptability of this delivery mode. In fact, some participants felt that receiving the support in person could have been a barrier to participating in the intervention:

"I think with Covid-19 and having to use Microsoft teams for everything with my work, I found it very beneficial and a very good way. I have enjoyed it because I had it in the comfort of my space, I didn't have to travel anywhere, or get ready, you know all the things that affect your MS." (MS\_05)

Only one participant felt the need to have meetings in person:

*"If you are struggling emotionally, it would be good to have that human contact." (MS\_09)* 

The participants reported improved management of their MS and relationships at

work, which they felt could be difficult to capture with standardised tools:

"I think it's [the intervention] been very interesting and a comprehensive programme, I mean although from my questionnaires it might not seem like much has happened; it has helped me focusing." (MS\_09)

The participants started incorporating the techniques learnt within their working schedule to manage better their MS:

"Before I used to sit for hours and just be there...so now I pace myself, you taught me that and I do feel better with that." (MS\_12)

Overall, the participants felt that this type of support should be provided to everyone

with MS who is at work to ensure they are supported in such an important area of

their lives:

"I said to you [PhD researcher] very early in the programme, I consider myself very capable, but without your support, things would have been completely different, I think. So for others with MS or without MS that need support with other issues, I think this is an excellent, excellent programme that should be on offer nationally." (MS\_14)

Unfortunately, these services are not commonly offered in the NHS, and employment status is not usually recorded:

"I mean, it could be a very good clinical question: Has your MS affected you at work over the last 12 months? And there it is where they find "no, I don't work" or "well yes, but it's been alright" so then they can refer the person to you [PhD researcher]...otherwise the NHS doesn't know whether you work or not." (MS\_08)

Healthcare professionals believe this support is relevant, however, MS clinics are usually too busy to address all relevant topics. Furthermore, healthcare professionals lack knowledge in this area, and are not always confident to provide advice with employment in the clinic:

"As doctors, I think it would be very tricky for us to also have that expertise, and be confident enough to deliver those interventions, when it is outside our area of expertise." (HCP\_03)

Regarding the barriers to participating in this type of support, the main barrier

identified was working full time:

"I mean I don't work full-time so that made it [participate in the intervention] easier. It might be a little bit more difficult for somebody who works 5-9 Monday to Friday." (MS\_08)

The second barrier reported was "not experiencing problems at work". The participant reflected that if a person is managing well at work, they might not be interested in understanding their rights at work; and therefore reject VR support. To address this, the participants believed that having information about VR soon after diagnosis would be beneficial even for those who do not have problems at work, because if a crisis appears they will have the means to manage the problems.

## 5.6.5.2. The employer

The most common issues at work usually arose from difficulties managing relationships with the employer. There were mixed views about whether to include the employer in the intervention:

"I was a bit concerned in the early stages about including my employer. Because I feel like I have a supportive employer anyway, I kind of felt that it might be a little bit of a slur on them, that I wanted them included on it." (MS\_10)

The main idea shared was that the employer should not be aware of all the aspects of

MS affecting the person with MS at work, because that can lead to further

discrimination at work:

"At the start [of the intervention] it needs to be only the person [with MS] and the person [therapist] doing the intervention so that you get to know the person and issues before the employer pops in." (MS\_08)

At the beginning of the intervention, the participants with MS feared disclosing their needs at work, because of the repercussion of their requests. However, the

intervention helped them change that mentality to be able to express their needs to

their line manager:

"With doing the study [intervention] with you [PhD researcher] and having an understanding, I have been more open, and I feel more confident, and I have sort of explained the areas where I am not doing very well...and she [line manager] has been supportive and again I feel empowered, I feel productive, and I feel a valuable member of the team." (MS\_05)

In general, the employers reported not know much about MS, and they had only

heard about it through what their employees told them. Therefore, the employees

reported that the intervention helped them understand better the needs of their

employees with MS:

"I think it's been very insightful. I think that the explanation that you [assistant psychologist] gave me about the condition and background of what is involved in the condition and by extension things to be aware of, as an employer was very useful." (EMP\_03)

The employers also recognised that the intervention empowered the person with MS

to start addressing the problems they were experiencing:

"I think it has been useful because as you know, [name] has issues of coming to terms with her condition, and I think this has helped her face up to it and therefore has been more open to all of us at work." (EMP\_01)

For those with a supportive manager, the managers recognised an improvement in

the way the person with MS was working after the intervention:

"I had my yearly review from my manager, and he said since November or December last year he has seen that my output has improved, and I am doing more, I have more energy to give or put into my work, so yes, it is all flying colours from every direction." (MS\_11)

On the contrary, those line managers who were not as supportive had no interest in learning more about MS. Several participants with MS were keen to request their employers to work from home at least two days per week because working from home during the Covid-19 pandemic improved their productivity. Unfortunately, the employers of two participants with MS rejected the option to work from home as a reasonable adjustment. They only remained working from home because of Covid-19 regulations:

"Without COVID-19 I would be in the office. Their [HR] answer on that is, well we have already given you reasonable adjustments we can't give them to you forever. (MS\_08)"

These types of issues with the line managers made a couple of participants with MS seek alternative employment because they found the situation overwhelming. A participant reflected the following:

"I left my job. I was talking with my original manager on my last day: she apologised because of the first day that I was sick, and she rang me... and I said you know that I was crying on the phone, but she wanted to continue having the conversation. So she apologised for that." (MS\_14)

Fortunately, things can improve with the right management, and this participant found a new role where she felt supported and motivated to work:

"It's [the new role] a completely different atmosphere. From meeting the higher managers it seems like they care to help for how they were communicating, making me feel at ease." (MS\_14)

## 5.6.5.3. Empowerment

Empowerment was a recurring topic throughout the interviews. The participants reflected how the knowledge gained throughout the intervention gave them the means to address complex conversations with their line managers:

"Interviewer: And compared to before the programme, has your confidence to deal with employment issues changed?

Participant: oh yes! Quite radically actually. I think because I knew what my legal standing was, that in return gave me more confidence when I have been speaking to managers and helping me to challenge things at work as well. (MS\_03)"

In particular, understanding their condition was seen as beneficial to request further

support:

"I feel empowered and capable. I have had some conversations with my new line manager, and she is very supportive. Whenever I need it, I would be able to speak up for myself. Because I think a lot of the things with the understanding the MS, now I feel in a better position because I understand how it affects me in work, I can ask for relevant things." (MS\_05)

The intervention also included participants who were not experiencing problems at

work, because early intervention is considered important in VR. It was clear from the

feedback, that even those participants who were managing well at work still had

worries about the future:

"Before we started talking, the cognitive side worried me, it scared me, because that is the side of me that I use all the time at work, that's the side that pays my wages, keeps food on the table." (MS\_01) The intervention helped them to have a more positive view about their future at

work:

"It feels as if in my head there was a roadblock on my career somewhere in the distance. I don't know where, and I don't know how far away it is. But it feels now as if that roadblock might still be there somewhere, but I feel that I have got more of an idea and information about how to delay that roadblock. (MS\_01)"

The participants discussed how before the intervention they tried to hide their

symptoms or felt defeated when they appeared at work because they were unsure as

to how to manage them. However, the intervention helped them understand that they

could do things to manage them:

"I think a lot of the time you can think oh, I am just being lazy or that I don't have the energy to do what somebody else asked me to do. And I think accepting that it is a basic function [MS symptoms], it is fantastic." (MS\_05)

The intervention also helped them regain control over their working lives and face

the problems they had been experiencing at work for some time:

"I think it [the intervention] helped moving things forward at work, I think my supervisor found it helpful as well because she had only talked about it [MS] with me, and that [the intervention] would have perhaps answered questions." (MS\_09)

The intervention helped the participants with MS realise that they were still capable of working regardless of their MS:

"You don't realise that you still have value until somebody tells you "Just because you can't do it the same way you have always done it, it doesn't mean that you are not a valuable member of the staff"; and I think that was a great thing, especially for somebody who is newly diagnosed." (MS\_07)

Overall, the participants were grateful for having had the opportunity to receive this

support:

"I want to say thank you very much [PhD researcher], because honestly if the support you provided wasn't there, I think the situation would have been very different so I cannot thank you enough, the study has been amazing, and I do hope that it gets rolled out nationally because it is invaluable for the huge difference that it can make in not that much time." (MS\_14)

## 5.6.5.4. Intervention components and attributes

Three main sub-themes were drawn from the interviews referring to the intervention components, tailoring of the intervention, and the therapist's attributes.

1. <u>Intervention components</u>

The participants with MS highlighted the importance of conducting a detailed assessment of needs at work for the intervention. The participants felt that it was important to have discussions about their responsibilities at work, the problems they were experiencing, and how to tackle the problems:

"I think it was the practical tips really, and talking through them with somebody, it is nice when somebody understands what is going on or says that these things happen, and they are real. It is Ok to feel like that." (MS\_12)

The participants also discussed how the intervention provided support in a wide range of issues that were relevant for them. The participants believed that it was important to complement the discussions from the sessions with further information (e.g., booklets), to help them have further resources to help them stay at work.

Because the intervention addressed multiple intervention components, a feature that was seen as important providing summaries of the sessions to help participants with MS remember the content:

"You [PhD researcher] used to send us an email summarizing what we covered [in the session] and any information with it. And obviously, you gave us the information about what we will be covering in the next session. You would always then re-cover what we did in the previous session, so it jogged our memory of what we had covered and what we were going to cover today. (MS\_04)

Finally, some participants discussed that it might have been interesting to have joint meetings between employer, employee, and the assistant psychologist:

"I suppose instead of discussions between both of us, it could be good to include the employee in a conversation as well. Perhaps you could act as a facilitator for an open discussion between us. That would be quite interesting."  $(EMP_03)$ 

However, there were mixed views about this, because it might not allow for an open honest conversation for fear of the consequences of their comments in the meetings. The intervention was seen as having a positive impact on the working lives of the participants, and they felt grateful because of their passion for work.

2. Intervention Tailoring

The participants with MS valued the fact that the intervention was tailored to their circumstances:

"I think because it [the intervention] was based around me and my outcomes, I felt it was all valuable because it was all specific to what I was saying." (MS\_05)

Including personalised goals was also seen as positive, because the intervention focused on what is important for the person with MS:

"I think it is really good that the patients...they can decide themselves the goals that they want to set and then the information that is given to achieve the goals." (*MS\_04*)

Regarding the amount of support received, five participants with MS required more than the 10 hours of support initially offered. When discussing the reasons for needing extra hours of support, the participants expressed that at work different situations change or evolve, which leads to needing more support. Overall, the participants with MS and employers suggested the possibility of restructuring the intervention length for those participants whose intervention involves applying for different types of support that take more than three months to complete:

"With some things like 'Access to Work', the sort of length of time for the study might need to be more flexible so that you start and if things like that that have to go back to Government or HR, you can have a sort of number of hours in one month, and then come back to it... unfortunately with Covid-19 everything has slowed down." (MS\_08)

The participants with MS reported that to improve the intervention in the future, it would be necessary to provide follow-up sessions after the intervention to address new issues:

"I think...it is I suppose is to look at it [the intervention] from a long-term perspective. Right now I feel good, I feel empowered, but then in another three months another problem might arise that is different from what we had, and it is being able to tap into support as new issues arise." (MS\_05)

3. Therapist's attributes

When discussing relevant attributes of the intervention, the participants agreed that having a therapist offering suggestions about work was beneficial for them:

"I think sometimes you just get involve in living your life and there isn't anybody there, a different perspective...so it is nice that you [PhD researcher] can come with suggestions rather than "here is a piece of paper, just do it" because that is never going to happen. But it is nice that there is somebody there who is accountable. (MS\_11)

A participant highlighted that it is important that the therapist has extensive knowledge about MS and work, but also, for the therapist to collaborate with other professionals to deliver a comprehensive intervention: "The person that is leading it [the intervention], is quite important as well. Like you [PhD Researcher], or if it is not you, another person, because you have done a lot of research that you have a really good natural knowledge on the topics that I wanted advice about, but then also, you supplemented your natural knowledge with seeking advice from other professionals that would be more knowledgeable in a particular knowledge as well." (MS 14)

Overall, the participants felt that the therapist was open-minded and easy to talk to, and gave them the confidence to take control of their working lives and address their fears and difficulties in a safe space:

"I think it was you [PhD Researcher]...you made me feel more confident. It is all of that, I think the whole thing has been very beneficial and you have been lovely." (MS\_12)

## **5.6.6.** Convergence matrix

The combined findings from both methodologies and level of agreement are presented in Table 67.

Overall, the quantitative findings were not sensitive enough to measure the change caused by the intervention; and these changes were mostly identified by the qualitative findings. Therefore, there was a disagreement between the quantitative and qualitative data in several of the themes identified.

Two themes presented in the convergence matrix (relationship with line manager and empowerment) were extracted only from the qualitative findings because these themes were not covered in the quantitative measures used. They have been included in the convergence matrix because of their relevance to understanding the impact of the intervention on managing relationships and problems at work.

There were complementary data from the anxiety, depression, and goal attainment themes. The qualitative data complemented the quantitative findings to help us understand the context that caused or prevented a change in these variables. For example, the qualitative data provided insight into the reasons why two participants did not meet the intervention goals.

Finally, there was convergence on only one theme (fatigue). The intervention helped three participants to reduce their fatigue levels; however, most participants experienced a change in their fatigue levels by the end of the intervention. During the interviews, the participants reported that although the fatigue management

component of the intervention was useful, other personal variables (e.g., family issues, increased workload) and the overall impact of MS made it difficult for them to manage better their fatigue.

Theme	Quantitative finding	Qualitative finding	Convergence matrix coding
Cognition	The participants did not experience a change in their perceived cognitive deficits.	The participants with MS reported an improved ability to manage their cognition at work by using the techniques from the intervention.	Disagreement: The participants reported an improvement, but this was not captured on the quantitative data.
Anxiety	At three months follow-up three participants experienced a reduction in anxiety scores. At six months follow-up one participant experienced significant deterioration.	Participants reported a fluctuation in anxiety levels as a result of the Covid-19 pandemic and family issues.	Complementary: The intervention had a limited impact on the participants' anxiety levels
Depression	At three months follow-up one participant experienced a reduction in depression scores. No change at six months follow-up	Participants reported increased feelings of isolation and depression as a result of the pandemic and personal circumstances	Complementary: The intervention had a limited impact on depression levels.
Work self- efficacy	Participants remained relatively stable on this measure over time.	Participants with MS reported improved self- efficacy at work, managing relationships and symptoms.	Disagreement: Improvements in work self-efficacy were not observed in the quantitative data.
Fatigue	The fatigue levels of the participants with MS did not	Participants with MS reported that they were	Convergence: The intervention did not help the participants to

#### Table 67 Convergence matrix case study.

Theme	Quantitative finding	Qualitative finding	Convergence matrix coding
	improve over time.	still learning to manage their fatigue levels.	manage their fatigue better at work.
Work Instability (WI)	The intervention did not help the participants with MS to reduce WI levels.	The participants with MS overall reported that they felt more confident about their workability. The employers reported that their employees had become more proactive in managing their MS at work and that had a positive impact at work.	Disagreement: While the participants reported an improvement in their ability to work, the data from the WI questionnaire did not capture any change.
Goal attainment	Three participants did not meet their goals at three months follow-up and one at six months follow- up.	Participants reported in the interviews that environmental factors such as Covid-19 regulations stopped them from achieving some goals.	Complementary: Both datasets agree that the intervention helped the participants with MS to achieve their intervention goals.
Relationship with line manager	No measure recorded this.	The employer was an interview theme. The participants reported the need for employer engagement to improve workplace relationships.	Silence: Only the qualitative data reported on the relevance of the relationship with the line manager.
Empowerment	No questionnaire measured this.	All participants with MS reported feeling empowered as a result of the intervention. This was also observed by employers and healthcare professionals.	Silence: Only the qualitative data reported on empowerment.

# 5.7. Discussion

The case study presented in this chapter has provided evidence about the feasibility of delivering a job retention VR intervention for employed people with MS. This

study also provided valuable data about the acceptability of the intervention and experiences of receiving the support.

To reach the recruitment target of 15 people with MS I required more time (+2 months) than originally planned. The delay was potentially due to the increased number of caring responsibilities that arose as a result of the multiple national lockdowns to manage the Covid-19 pandemic. Furthermore, the recruitment from the NHS started two months after the ethical approval was granted, because the NHS was overwhelmed with Covid-19 patients. I expect future studies would reach the recruitment targets once healthcare services return to normal.

The recruitment target of line managers and healthcare professionals was not met. For the participants with MS who were not interested in including their employer, common reasons were having a poor relationship with the employer, the employer being busy with Covid-19 regulations, or not wanting to bother the employer. The main reason for not wanting to include a healthcare professional was because the NHS was overwhelmed.

All the participants with MS that started the intervention completed it. This finding is surprising because VR interventions for people with MS are characterised by high rates of early dropout (148). Common reasons for dropping out include disability levels, high workload or stress at work (148). These reasons align with the reason given by one of the participants with MS who stopped the intervention temporarily because of stress at work.

## 5.7.1. Outcome measures selected

The intervention had no significant impact on the outcome measures selected (except for goal attainment). The intervention goals were tailored to the specific needs and circumstances of the person with MS, and all except for one participant met their goals by the end of the intervention.

On the contrary, performance on the questionnaires fluctuated over time according to the person's situation. Several participants completed the questionnaires while they were sick, or on furlough, and this may have affected their results because they reported lower levels of quality of life and higher levels of depression than at baseline.

The participants experienced high levels of anxiety and depression from the outset of the study. Their performance on these measures is likely to have been influenced by the unpredictability of the Covid-19 pandemic and the three national lockdowns as of July 2021. Furthermore, the participants experienced complex personal circumstances throughout the study such as losing a family member as a result of Covid-19, family issues, and low mood as a result of social isolation. The change in the levels of anxiety and depression were assessed using the reliable index change (233); however, considering that MS is a progressive and unpredictable condition, it was not expected for the participants to return to neuro-typical levels on this measure.

The participants with MS also experienced high levels of perceived cognitive deficits. The VR intervention did not aim to improve the underlying cognitive deficits experienced by the participants. The intervention aimed to provide the person with MS with strategies to manage memory and attentional problems that might have an impact on their work performance. This was included because a higher score on the PDQ is associated with a higher probability of unemployment (240).

On the contrary, not all the benefits of the intervention can be captured with a questionnaire. For example, one participant was in a work crisis because a new PIP assessment meant she no longer qualified for PIP and she lost her mobility car, which was essential for her to get to work. The line manager did not allow her to work from home; therefore, the intervention supported her to prepare for the PIP tribunal and apply for 'Access to Work', which are both lengthy processes that took longer than the intervention duration to resolve. Hence, there was no pre-and post-intervention change for this participant in terms of support received. However, thanks to the intervention she reported feeling prepared to go through the PIP tribunal and to complete the Access to Work application.

The aforementioned example shows that in VR, clinicians, and researchers should not rely only on standardised questionnaires, because they lack sensitivity to identifying the specific issues that each person experiences. Therefore, they do not capture the full extent of the impact of research. This data should be complemented with other qualitative data (such as interviews) to contextualise the quantitative findings.

#### 5.7.2. Post-intervention interviews

The post-intervention interviews conducted provided valuable information about the impact of the intervention. The participants with MS reported increased levels of confidence managing problems at work and improved ability to request support at work as a result of increased knowledge about their MS and symptoms. This feedback aligns with that from previous VR interventions for people with MS that report improved workability (130,151). This finding also aligns with recent research from the MS Society that reports that almost three quarters (74%) of people with MS keep their diagnosis secret at work because of fears of not knowing how to explain their condition to others (190).

The participants reported the most important characteristics of the intervention being the quality of the information received, the therapist's knowledge (of MS and the law) and behaviour (e.g., being open-minded and easy to talk to).

One of the most important design objectives of the intervention was around the flexibility of the sessions (Chapter 4). The intervention was developed to provide flexible support in terms of topics and schedule. However, the post-intervention interviews of this study reflected the next level in terms of flexibility that refers to the length of the intervention. The participants (MS and employers) believed that the intervention length should be tailored to the needs of the person receiving the intervention.

There was good acceptability of receiving the intervention remotely either via telephone or Microsoft Teams, with most participants reporting a preference for remote support. There is evidence about the acceptability of providing remote support to increase work participation (e.g., RTW) for people with musculoskeletal and mental health problems (241). There is robust evidence that providing telephone interventions in the aforementioned conditions can reduce intervention cost, speed up the RTW process, and that it is an acceptable approach for the patients (241).

Remote interventions or telerehabilitation (rehabilitation delivered via communication technologies) have also been implemented with people with MS (242). Telerehabilitation has been used to support people with MS to find employment by providing them with emails with information (127,129).

Telerehabilitation can also be beneficial for those experiencing mobility difficulties, fatigue or living in remote areas (242).

## 5.7.3. Strengths and limitations

This study provides valuable information about the personal and professional challenges that people with MS and their employers experience at work. The findings provide detailed examples of common problems that people with MS experience at work, and what support is beneficial for them.

Furthermore, the mixed-methods approach has been beneficial to contextualise the quantitative data (i.e., questionnaires) by complementing it with the post-intervention interviews. Although the intervention was only effective at improving goal attainment, the participants reported benefits from participating in the intervention.

The disagreement between the quantitative and qualitative data may have been caused by the lack of sensitivity of the measures used, and because the intervention targeted specific problems discussed by the participants who may not be covered in the items of the included questionnaires.

There are several limitations to this study. The first limitation refers to the characteristics of the participants included, because there were no self-employed participants, and most of them had an office-based job. Therefore, the support provided in this intervention may not be generalisable to all employed people with MS. Nevertheless, there were two participants with a physical job that found the intervention beneficial.

Another limitation relates to the severity of participants' MS. Only one participant was in the "severe disability" group according to their EDSS, and most participants were classified as having "moderate disability". There is mounting evidence that higher levels of disability can lead to more complex problems at work (83,84,92,93,243) and these may not have been fully captured in the intervention.

The participants with MS as a group were relatively newly diagnosed; however, they had been experiencing symptoms suggestive of MS for several years before the formal diagnosis. This time gap between symptoms and diagnosis could have a significant impact on work, because their performance may have deteriorated even before the diagnosis (244,245). Apart from the productivity loss associated with the
symptoms, they can also experience higher rates of sick leave, work instability, and deterioration of the relationship with line managers before the formal MS diagnosis (244,245).

Finally, only three participants involved their line managers in the intervention. Several other line managers were interested in the study, but they didn't have time to participate in the study. Interestingly, even though including the employer in the intervention can be beneficial for the person with MS, only one-third of people with MS agree to include their employer in these interventions (6,125,246). People with MS might consider it risky including the employer in the intervention, because of the sensitivity of the topics discussed, and because some employers may have a negative perception of disability.

## 5.8. Conclusion

The findings of this case study show that it is acceptable and feasible to deliver a job retention VR intervention for people with MS. The participants with MS reported improved confidence and empowerment to manage relationships, symptoms, and problems at work. The intervention improved goal attainment but did not have an impact on other relevant outcomes measured. VR is a complex intervention, and as such, it can be challenging to measure the impact of the intervention. Therefore, combining quantitative and qualitative methods can be beneficial to assess the impact of these interventions.

Although two-thirds of people with MS in the UK experience problems at work, there is a lack of specialist VR services for people with MS in the UK (54,161). This service gap hampers effective MS management (161). This study shows that VR interventions should be delivered in a hybrid mode including remote and in-person sessions. This approach can make the intervention accessible to a larger number of people that need it because those with complex cognitive, auditory, or physical needs might benefit from receiving support in person. This approach can also help include people who have poor (or no access to) internet connection.

Finally, future VR interventions should provide further flexibility in the intervention timeline and provide follow-up sessions when and if required.

## **Chapter 6: Job retention VR intervention**

## 6.1. Introduction

Chapter 5 presented the intervention description and content of the case studies at an individual level. The VR intervention that each participant received was selected from a menu of intervention components and tailored to their needs. To date, there is limited evidence about the main VR intervention components and support required by people with MS and their employers. Therefore, this chapter presents an overview of what VR for people with MS entails by combining the data from the participants that completed the intervention in Chapter 5. Because both employers and people with MS completed the intervention, the data are presented separately to reflect the support needs of each participant group.

This chapter also presents the final intervention description refined based on the experience of delivering the intervention, as recommended by the Person-Based Approach (PBA).

## 6.2. Aims and objectives.

This chapter aims to describe and identify the core intervention components and underlying mechanisms of the intervention. The information extracted about the intervention will help to refine the intervention logic model. To achieve the proposed aims I assessed:

- The number of sessions and hours of support received.
- Intervention delivery mode.
- Resources used to deliver the intervention and organisations involved.
- Intervention topics discussed.

## 6.3. Methods

## 6.3.1. Participants

Participants with MS (n=15) and employers (n=3) who received the job retention VR intervention as part of the case study (Chapter 5).

#### 6.3.2. Data collection

Data regarding the intervention content and characteristics were collected during the mixed-methods single case study (Chapter 5). Data were collected using multiple tools to address the following TIDieR sections (Table 68).

TID: D	Intervention Description Objectives			
Hooding		Tool / Data		
meaung	Research Question	source	Method(s)	
Brief Name and Why?	Presented in Chapter 4			
What materials	Intervention resources and organisations involved	Proforma	Quantitative	
What procedures?	What is the intervention content? Which topics were address?	Proforma Records from sessions	Quantitative and qualitative	
Who provided?	Presented in Chapter 5			
How? / Where?	What delivery modes were used?	Proforma	Quantitative	
When and how much?	How many hours of support were required per participant?	Proforma Records from sessions	Quantitative and qualitative	

Table 68 Data collection tools for intervention content and characteristics.

#### 6.3.2.1. Intervention content

To address the objectives of the intervention content, I completed a proforma for every intervention session with each participant (MS and employer). This captured information about the dose, intensity and content of the intervention and is described in more detail in Chapter 4.

I recorded what was discussed during the sessions (direct contact) and additional activities conducted outside of the sessions (indirect contact). I used a notebook during the sessions to record timings and topics and used this to complete the proforma immediately following the session to increase the accuracy of the content. Travel time was not recorded because the intervention was only delivered remotely due to the Covid-19 restrictions.

The proforma captured direct and indirect intervention separately to accurately reflect the content of the sessions, and activities conducted outside of the sessions (e.g., liaison with other professionals). Therefore, this chapter presents the direct and indirect intervention time for the participants with MS as two separate sections.

The employer's intervention was recorded following the same procedure. However, because of the reduced amount of data available, both direct and indirect interventions are reported together.

#### 6.3.2.2. Intervention Logic Model

The intervention logic model was updated following my experience of delivering the intervention, data from the proformas from the sessions, and discussions in the post-intervention interviews (Chapter 5). I present the changes to the logic model as a narrative.

#### 6.3.3. Data analysis

The data recorded in the proformas were extracted into Excel to measure the time spent per session per participant for any given topic. A list of all the topics discussed in the sessions was recorded and mapped to the preliminary intervention components. Those that did not fit with the preliminary components (see Chapter 4) were coded under "other", which allowed for incorporating new components in the intervention. The topics were reviewed through an iterative process to merge repetitive categories and create broader intervention topics.

The indirect time was recorded following a list of common activities conducted before or after the intervention session, such as preparation of materials for the session, sending reminders or liaising with other healthcare professionals to address intervention topics.

#### 6.4. **Results**

This section will present first the intervention description following TIDieR, followed by an updated intervention logic model. A summary of the TIDieR checklist for the final intervention is presented in Appendix L.

#### 6.4.1. What materials?

A comprehensive list of resources used during the delivery of the intervention is presented in Appendix G.

#### 6.4.2. What procedures?

This section presents first the intervention procedures for the participants with MS followed by the employer's intervention.

# Intervention for Participant's with MS

## Initial interview

The aim of the initial interview (Chapter 5) for participants with MS was to collect demographic information, MS characteristics (e.g., main MS symptoms that were causing them difficulties at work), and to understand the role and support received at work. The initial interview also focused on the work aspirations or ambitions of the person (e.g., find a new role, change working hours), and main challenges to remain at work.

To help identify the main challenges to remaining at work, the participant and interviewer reflected on the difficulties experienced by the participants completing certain activities that enable a person to engage in work, such as difficulties accessing the workplace or maintaining good energy levels throughout the day.

At the end of the interview, participants were asked to select three intervention goals that were used to tailor the intervention content and estimate the hours of support required per participant.

#### Intervention sessions

The number of sessions was determined according to the importance of the topic discussed. The participants with MS completed on average 4.9 (SD=1.7) sessions (Figure 66) over the three months intervention.



Figure 66 Intervention sessions per participant

#### Intervention content

The topics addressed during the intervention were divided into direct and indirect interventions.

## **Direct** intervention

Thirty-seven topics were covered during the sessions, the topics and time spent on each topic for all the participants with MS as a group are presented in Figure 67. These topics were combined into larger thematic groups according to the intervention components identified in the preliminary logic model (Chapter 4).



Figure 67 Direct intervention content per hour

Twelve main intervention components were identified (Figure 68). Six intervention components account for 75% of the intervention time. The topics included in each component can be seen in Table 69.

Component	Intervention topics			
	Cognition in MS			
	Memory problems at work			
Managing Cognition	Cognitive problems at work			
in MS	Using a diary			
	Word finding difficulties			
	Attention and concentration			
	Fatigue in MS			
Estima Managamant	Impact of fatigue at work			
Faligue Management	Fatigue diary			
	Tips to manage fatigue			
	Education about reasonable accommodations			
Reasonable	Identify needs at work			
Accommodations	Identifying beneficial support at work			
	How to request support			
	Benefits (universal credit, Patient Independent			
Accessing Benefits	Payment)			
and support	Access to Work			
	Blue badge			
	Legal support			
Understanding Legal	Disciplinary meeting			
Rights	Disclosure			
	Equality Act			
Current Issues	Problems with employer			
Current Issues	Current issues			
Work & Covid-19	RTW plan			
WOIK & COVID-17	Working during Covid-19			
	Understanding MS			
Education about MS	MS Symptoms and its progression			
	Explaining MS to others			
Mood in MS	Anxiety, depression & MS			
Vocational	Vocational exploration			
exploration	Long-term career planning			
	Mobility and exercising with MS			
Mobility & MS	Falls			
	Pain at work			
	Review progress made			
Miscellaneous	Refine goals			
	Resources for the future			

Table 69 Merge	of intervention	topics into	intervention	components



Figure 68 Intervention Content per component

The main intervention components included the following:

- Managing Cognition in MS accounted for 20% of the time and was the largest intervention component. Three main topics covered were: discussing memory problems at work (32%), coping strategies to manage the impact of cognitive problems at work (30%), education about what is cognition, and what factors affect or exacerbate cognitive difficulties (23%). Other topics also covered within this component were learning to use a diary to better manage better the workload (8%), discussing word-finding difficulties (6%) and how to manage attention and concentration problems (1%). One participant was referred to a clinical neuropsychologist for further cognitive assessment as he was experiencing complex needs that required further support.
- Fatigue management accounted for 19% of the intervention. This included education about MS-related fatigue and factors that exacerbate fatigue (30%), identify how fatigue affects the person at work (30%) and tips to manage the fatigue (28%). For those participants who had more problems managing the fatigue, and/or who were unsure as to what caused the fatigue, they were asked to complete a fatigue diary (12%), and this was reviewed in the sessions to identify what strategies could be more beneficial according to their experiences. For those participants who had more urgent topics to address in the intervention, or less time available to participate in further

sessions, they were referred to an online fatigue management course from the MS Society that allowed them to learn and complement their knowledge about MS-related fatigue on their own time.

- Reasonable accommodations accounted for 12% of the intervention. This included discussing barriers in the workplace (36%), identification of reasonable accommodations (28%), education about what can be considered a reasonable accommodation (21%), and guidance and practice on how to request support at work (15%). This component was highly inter-related with the component of understanding legal rights, as none of the participants was familiar with the Equality Act 2010. To identify reasonable accommodations, the sessions included discussing the essential job functions of the person and the main difficulties experienced at work.
- Accessing benefits and support accounted for 9% of the intervention time. This was included in the intervention because it was a key component to support the participants to remain at work. Participants with MS needed support accessing benefits, such as Universal Credit and PIP. This involved supporting people to identify the benefits they were eligible for, based on Government guidelines. Participants were supported to understand the application process and documents required (54%). A couple of participants were assisted to apply for 'Access to Work' either by informing them about the service and reviewing their applications (33%). One received help applying for a blue badge (13%).
- Understanding legal rights accounted for 8% of the intervention. This component included discussing legal rights and supporting the participant in obtaining legal support (39%), providing support with disciplinary meetings (24%), education about the Equality Act 2010 (18%), and support with disclosure (18%). When discussing these topics with the participants, it was particularly important to support them before and following their meetings with the employer and to establish an action plan to follow up on what was discussed in each meeting.
- Current issues: This component accounted for 7% of the intervention and

focused predominantly on issues with the employer or at work (64%), family issues or questions about available treatments (36%). It included both work and non-work-related topics that impacted the participants' lives, such as arguments with their partners or disagreements with work colleagues.

- Work & Covid-19 accounted for 6% of the intervention. This included information about the Covid-19 regulations of the workplace (67%), and support to RTW (33%) for both the participants on furlough and the participants who had been working from home and were returning to their offices. To RTW, participants needed support to return to the office (e.g., safety concerns about Covid-19) and have realistic expectations about their workload and productivity in the first few weeks. This was particularly important because some participants had spent over six months working from home.
- Education about MS accounted for 6%. This included discussing how to explain MS to co-workers (42%), understanding MS (29%), and its symptoms and progression (29%). Some participants were frustrated because their colleagues did not understand how MS symptoms fluctuated according to the time of day or environmental factors (e.g., heat). Therefore, this component focused on developing strategies to help the person with MS to explain the impact of their MS to their manager or colleagues; and understand how MS can affect their work.
- Mood in MS accounted for 4% of the intervention. This component focused on understanding feelings of anxiety and depression. Several participants were experiencing anxiety and depression associated with the pandemic. The social isolation resulting from home working, and the impact of the progression of MS symptoms at work. Two participants were referred for further psychological support to address this.
- Vocational Exploration accounted for 4% of the intervention. This involved vocational exploration (59%) aiming at identifying employment alternatives for participants who were thinking about moving to a new role, and long-term career planning (41%) for those who were starting to think about their

ongoing ability to continue in their current role. This was essential for participants to make informed decisions about their careers.

- Miscellaneous accounted for 4% of the intervention. This included providing information about further resources to complement the knowledge gained (70%), refine the intervention goals (18%), and review progress made or further questions (12%). As the intervention progressed, participants experienced new difficulties and changes in their employment status, therefore, these changes had to be captured in the intervention goals, and resources shared with them.
- Mobility in MS accounted for 1% of the intervention. This included discussing pain at work (50%), how to manage the risk of falling (33%), and ideas for increasing the number of exercises participants took (17%).

## **Indirect Intervention Content**

The indirect intervention included all activities conducted outside the intervention sessions to follow up on actions from the sessions or seek further support. Figure 69 presents the activities included under 'indirect intervention'.



Figure 69 Indirect intervention content per hours

The indirect intervention included the following components:

• Liaison with the participant: This component includes all the contact with the participant (via email) outside the sessions to track progress, agree on action plans, and update them on further information to address the

employment issues they were experiencing.

- **Preparation of materials:** This included the time spent collating relevant documents and materials for the session.
- Administrative tasks: This included activities such as reminding participants about sessions and sending a summary of the session.
- Liaison: This included time spent contacting employers (47%) and having conversations with healthcare professionals, such as OTs (53%) to address the most complex issues of the intervention, such as participants with MS experiencing discrimination in the workplace, disciplinary meetings, and employers refusing to provide reasonable accommodations to the employee with MS. The assistant psychologist liaised with other professionals to guide her through the process and to define a plan of action to best support the person with MS.
- Session follow-up: This included developing action plans for work emergencies (50%), review and identification of reasonable accommodations outside the sessions (30%), and support with workplace regulations during Covid-19 (20%).
- **Benefits and support:** This included providing support and guidance with the application for benefits or a blue badge (50%), review and provide feedback for Access to Work applications (40%), and support in obtaining financial advice (10%).
- Legal support: This included the time spent contacting the Disability Law Service, Citizens Advice and ACAS (Advisory, Conciliation and Arbitration Service) for further information about legal rights and employer's responsibilities.

#### **Employers' Intervention**

Only three employers took part in the intervention. Three other participants were willing to include their employer, however, two of the employers were on sick leave for the duration of the intervention after one employer broke her foot and another had a car accident.

#### Initial Interview Employers

The interview for the employers focused on their role as a line manager, and their understanding of MS and the support that they provide to the person with MS at work. Furthermore, it was an opportunity to explore their concerns about MS and how it affected their employee at work.

The three employers (line managers) included in the study received on average 1.94 (0.38) hours of support. All completed the initial interview and one intervention session. The intervention content for the employers is presented in Figure 70.



Figure 70 Employer's intervention content per hour

The employers were interested to know what reasonable accommodations they could provide the person with MS at work to improve their work performance and were interested in understanding more about the condition. The employers had two main concerns: (i) the impact of MS symptoms such as memory problems at work, and (ii) how to manage productivity deficits and their impact on the working team. Overall, they were concerned about how much they should expect from an employee with MS who is experiencing difficulties at work, and the impact that reduced productivity can have on colleagues when working in a team.

#### 6.4.3. How and where?

All sessions were delivered individually and remotely. The participants with MS as a group received a total of 73 sessions. Eight participants selected Microsoft Teams as their preferred modality, and seven via telephone. There was a close preference

between the two modalities, with 37 (51%) sessions delivered using Microsoft Teams, and 36 (49%) sessions via telephone. Two participants had a combined delivery mode because of technological issues.

Because most participants (n=9) were working part-time, they selected to have the sessions at a time when they were not working. Those participants with MS working full-time (n=6), selected to have the sessions during working hours and had the permission of their line managers to do so.

All employers selected as their preferred time to have the sessions during working hours even though they were working full-time.

#### 6.4.4. When and how much?

The intervention was delivered between June 2020-January 2021. On average, the intervention time, including the initial interview, was 8.36 hours (SD=4.48) per participant with MS. The initial interview lasted on average 60 minutes (SD=16.9), and they received on average 4.74 hours (SD=2.33) of direct support and 2.61 hours (SD=2.2) of indirect support.

Figure 71 presents the number of hours of support received by each participant with MS over the three months intervention.



Figure 71 Total intervention time (in hours) across participants with MS

Most of the intervention time (56.8%) was spent providing direct contact, and 12% of the total intervention time was spent conducting the initial interview. Because the intervention was delivered remotely, no time was spent travelling. The remainder of the intervention (31.3%) was spent on indirect contact (Figure 69).

Five participants with MS (33.3%) received more than the initially agreed 10 hours of support when counting both the direct and indirect support. This was because they were experiencing complex problems at work both in managing their condition and relationships with co-workers; and required lengthier discussions addressing a wider range of topics. Interestingly, one of these participants (MS\_08) who only received four sessions, received more indirect support than direct support. This was because her intervention involved greater liaison with other professionals and support reviewing materials for benefit applications (such as Access to Work), which required more time outside the sessions.

Seven participants with MS (46.67%) required between 5 to 8.5 hours of support (equivalent to 4 to 5 sessions) to address their employment concerns. These participants reported being worried about their employment situation and needed support to manage their MS symptoms at work (e.g., managing cognitive difficulties at work), and to manage relationships at work. In particular, this group lacked confidence in understanding their MS and how to request support at work from their line manager.

The three participants with MS (20%) who required the least support (up to 5 hours) addressed their employment concerns in three sessions. The interventions for these participants was characterised by signposting them to relevant organisations and ensuring they had resources at their disposal should they need them.

#### 6.4.5. Intervention Logic Model

The refined logic model is presented in Figure 72. The *resources* section of the logic model was refined to include the need for a mentor for the assistant psychologist to address complex problems, such as participants being discriminated against at work, or in need of specialist VR support. The participants also reported as a key resource for the intervention the email/letter summarising the content of the session, so that they could revisit the content learnt and actions for the next session.

Detailed information about the activities and content of the intervention is presented here and in Chapter 5 and this chapter. The *activities* undertaken during the intervention varied according to the needs of the person with MS and whether they included their employer in the intervention. Few people with MS were keen on involving their employer in the interventions for fears of further discrimination at work. However, the participants still believed that it was important to include their line managers to educate them because they could provide reasonable accommodations and support at work.

Regarding the *mechanisms* of the logic model, after delivering the intervention three mechanisms were highlighted by participants who received the intervention. Rehabilitation should be understood as a process (105), and the intervention needs to be tailored to the individual's goals and needs concerning job retention. The participants believed that monitoring the progress made by the employer or person with MS at work was necessary to address new problems and refine the support according to new barriers found at work. This mechanism was closely related to another new mechanism included that refers to "prompt support"; if the person delivering the intervention is monitoring progress, new issues can be identified and addressed as soon as they appear and the person with MS is better supported at work.

Resources	Activities		
Assistant Psychologist (AP)	Refer person with MS to intervention		
Employed person with Multiple Sclerosis (MS)	Person with MS contacts AP about intervention and is screened for eligibility		
Employer and colleagues willing to participate in intervention	AP assess current work situation, needs at work, and impact of MS at work		
Mentor to support AP	Goal setting and selection of intervention content		
Charity leaders willing to share	Person with MS referred to relevant professionals (if needed)		
information about the intervention	Information for the person with MS about working MS, legal rights, disclosure, and cognitive impairment		
Summary of session letter	Information about fatigue management		
List of services to refer the person with MS Sign posting leaflets Relevant stakeholders willing to	Support identifying and requesting reasonable accommodations		
	AP provides education to the employer/colleagues about MS, invisible symptoms, and how to support the person with MS		
get involved End of intervention package with	AP signposts participant to relevant organisations and local and national resources		
further support	AP supports and guides the person with MS to implement knowledge gained during the intervention		
	Advice about how to prioritise work and career paths		
	Participants receive a summary letter after each session with topics and actions for next meeting		
	Final session: Review progress made and if required referral to other services		

Mechanisms	Outcomes		
Trust between AP and employed person with MS	Job retention		
Early intervention	Improved workplace-relationships		
Responsive service	Person with MS meets intervention goals		
Timely support	Improved emotional well-being		
Managing expectations of patient and employer	Improved quality of life		
	Reduced fatigue		
Collaboration between parties/ Coordinated effort	Employer better informed about how to support the person with MS		
Employer engagement	Person with MS able to manage		
Awareness about resources available	workplace difficulties (self-efficacy)		
Detailed individual assessment	Increased productivity		
Re-accessible support	Person with MS aware of support available and how to access it Person with MS understands impact of MS at work and coping strategies		
Individually tailored support			
Flexible content and structure			
Monitor progress and new issues/challenges implementing support	Person with MS understand what to look for in the future		
learned	Reasonable adjustments		
Constant communication throughout the intervention to solve queries and track	Improved work-ability		
progress	Person with MS feels supported at the end of the intervention		
	Support travelling to and from work		

Finally, another mechanism included in the revised logic model refers to "coordinated effort". Some participants who did not meet the intervention goals reported that the lack of involvement of their line manager in the intervention led to outstanding issues at work. Identifying the most effective ways to involve relevant parties such as line managers, HR professionals or OH might be necessary to ensure there is a coordinated effort to support the person with MS.

The *outcomes* of the logic model did not vary from the previous logic model, because the preliminary logic model included extensive detail about relevant outcomes for people with MS. Overall, people with MS were keen on receiving personalised support matching their needs and were interested in improving their workplace relationships, being capable of explaining their MS to others and managing symptoms at work.

### 6.5. Discussion

This chapter presented the content and structure of a VR intervention for employed people with MS and their employers, following the TIDieR guidelines (142).

The intervention included an initial interview and up to 10 hours of support tailored to the needs of the person with MS. The most common intervention topics addressed were support managing cognitive problems at work, fatigue management, and reasonable accommodations.

The participants with MS presented different clinical, employment, and demographic characteristics. They received between 3 to 18 hours of VR support. Five participants with MS required more than 10 hours of support because they either had multiple issues to address in the intervention or were experiencing complex problems at work, such as employers being unwilling to provide reasonable accommodations or having disciplinary meetings because of extensive sick leave. Those participants working for companies where there was poor communication between employer and employee or that did not allow flexibility in the working arrangements, led to people experiencing more complex issues at work, and by extension required more hours of support. This finding aligns with the literature that identifies problems with colleagues and line managers can be a barrier to remain and RTW (80,247).

The employers only completed one session each to further understand the impact of MS at work and identify reasonable accommodations for their employees with MS.

#### 6.5.1. Intervention components

The final intervention included 12 main components. Not all participants needed each component because the intervention was tailored to their needs.

The BSRM VR recommendations indicate that newly diagnosed people with MS usually need support seeking information (60). However, after delivering the intervention it was clear that even those newly diagnosed can experience a work crisis if they have been out of work for a while. On the contrary, those with a supportive employer might benefit from receiving relevant information for the future even if they were diagnosed several years ago. The employer has a major impact on the needs of the person with MS at work; therefore, it can be challenging to create a stratified intervention that accounts for the multiple interfering factors that influence the support needs of the person receiving the intervention.

During the intervention development phase (Chapter 4), I believed that sign-posting to information and resources would be sufficient for those experiencing basic problems at work. However, the presence of cognitive difficulties, lack of time, and challenges understanding the information provided meant participants needed to discuss this with the assistant psychologist to fully understand the information shared. Previous research has found that information provision alone was ineffective to support a person to RTW (128).

The participants with MS reported cognitive difficulties; thus, managing cognition at work was the most common intervention component. Although there are challenges associated with measuring cognitive deficits in MS; previous studies have shown that those who experience higher levels of cognitive impairment are less likely to be employed than those without cognitive impairment (248,249).

Fatigue management was the second most common intervention component addressed. Previous studies have identified variables such as fatigue, anxiety, and depression as factors that contribute towards leaving the workforce prematurely (250). Increased fatigue is one of the main factors that predict unemployment for people with MS (243). Support identifying and requesting reasonable accommodations at work was the third most common intervention component. The participants with MS were not aware of the support they needed at work or how to request it. Some had disagreements with their employers in the past because they refused to provide them with additional support.

Employers commonly rejected the option to work from home to help the person with MS to manage fatigue. However, during the Covid-19 pandemic, the vast majority of people were forced to work from home. When it was time to plan the RTW, the participants with MS were keen to request working from home at least two days per week to manage their workload better. However, several line managers rejected the request.

Negative attitudes from colleagues, as well as having an unsupportive workplace are factors that have been associated with increased odds of job loss and reduction of working hours (251,252). Those participants with MS experiencing poorer relationships with their line managers were considering finding alternative employment or reducing their working hours.

Support with legal rights was closely related to reasonable accommodations because the participants (employers and MS) were not aware of the Equality Act 2010 and the legal responsibility of the employer to provide reasonable accommodations at work.

Finally, support accessing benefits were included in the intervention even though it was not identified in the initial development of the intervention (Chapter 4). This component was incorporated because several participants with MS had economic difficulties that were interfering with their work.

#### 6.5.2. Underlying mechanisms

During the intervention development phase, mechanisms such as tailored support, flexibility delivering the intervention and re-accessible support were highlighted. The participants also reported the relevance of these mechanisms in the post-intervention interviews (Chapter 5).

Delivering the intervention provided further insight into the underlying mechanisms of the intervention. Participants highlighted the relevance of *monitoring progress* 

throughout the intervention, as their work situation changed as new MS symptoms or issues with their employer appeared. VR should be able to monitor these issues and provide support promptly (*early intervention*) to reduce work instability. To achieve this, participants highlighted *constant communication* with the therapist to be able to ask their doubts as they appeared.

Finally, collaborating and *coordinating efforts* was identified as a necessary mechanism to achieve the intervention goals and reduce work instability. Those instances where the employer was not keen on learning or work with the person with MS to identify reasonable accommodations worsen their relationships in the workplace.

#### 6.5.3. Strengths and limitations

One of the main strengths of this study refers to the diversity of methods used to collect the data about the intervention delivered. Data from a proforma, and notes were taken by the therapist during the intervention were combined to measure the intervention content and timing. This combination of methods provided rich data to understand what should be included in VR interventions for people with MS.

Regarding the limitations of this study, is that the intervention was not delivered by a multidisciplinary team. Ideally, VR should be delivered by a multidisciplinary team to provide more comprehensive support. The need for multidisciplinary teams has been recognised in the literature (146). To compensate for this, the assistant psychologist delivering the intervention was mentored by an experienced OT to address complex issues.

Finally, only three employers completed the intervention, therefore this study has not been able to provide detailed information about their needs. This finding aligns with previous research in VR for people with LTNC (178). Employers are a key factor to achieve work stability. Unfortunately, many participants with MS were not comfortable involving their employers because they had a poor relationship with their managers. To compensate for the lack of employer engagement, the intervention empowered the participants with MS to request additional support from their line managers and how to inform them about the impact of their MS at work.

## 6.5.4. Conclusion

The present intervention is multi-faceted, including components addressing both MS symptoms and environmental barriers. These types of intervention are highly individualised and need to be able to cross boundaries between sectors, such as the workplace and healthcare system, to ensure they provide comprehensive support to the person with MS.

Further research is needed to evaluate the effectiveness and cost-effectiveness of the intervention, and longitudinal studies are needed to understand the support needs of people with MS over a longer period. Future studies should also consider the needs of employers and potentially include other relevant stakeholders, such as the General Practitioner (GP) Human Resources (HR) or Occupational Health (OH), to improve the support the person with MS receives at work.

# **Chapter 7: Discussion**

#### 7.1. Chapter overview

This chapter presents an overview of the overall findings from the different studies presented in this thesis. The findings from the individual studies have been discussed in their respective chapters; therefore, this chapter aims to merge the findings and situate them within the extant literature. This chapter concludes with clinical implications and future research recommendations.

#### 7.2. Summary of study aims

This thesis aimed to develop, implement and evaluate a job retention VR intervention for employed people with MS. To develop the intervention, I followed the MRC framework for developing and evaluating complex interventions and the personbased approach (PBA). The first two studies were a systematic review (Chapter 2) and an interview study (Chapter 3). These studies aimed to identify the VR interventions previously implemented to support people with MS to remain, return or find new employment; and to understand the experiences of people with MS at work and the need for VR support, respectively.

The findings from these studies informed the development of a VR intervention (Chapter 4), that was subsequently tested using a mixed-methods case study design (Chapter 5) on 15 people with MS. These case studies aimed to assess the feasibility of delivering the intervention and explore its acceptability. The intervention was further refined (Chapter 6) with the findings from the case studies.

### 7.3. Summary of key findings

The systematic review (Chapter 2) identified 13 VR interventions aiming at job retention (six), RTW (five), and generic VR services (two). There was considerable variability among the interventions in terms of content and attributes. But the full description of the intervention was only available for three interventions.

The interventions adopted a holistic approach targeting both disease-related and environmental barriers and stressed the need for detailed vocational assessment and employer involvement (or prospective employer). The most common underlying mechanisms identified were early intervention, tailored support, and empowerment of the person with MS (6,77,126,131,148,160).

To address the knowledge gaps identified from the systematic review in terms of intervention content, dosage, and outcomes, I conducted an interview study (Chapter 3). The interview study acknowledged the fact that VR support is required for both people with MS and their employers. This study identified some of the most important needs for people with MS at work, such as support managing symptoms, relationships (with employers and co-workers), and identifying workplace accommodations. Complementing the systematic review's findings, this study identified the need to involve and educate the employer on their legal responsibilities and how to implement reasonable accommodations. The participants reported early intervention (e.g., from diagnosis) and tailored support as key mechanisms of VR. Providing timely support (e.g., as soon as a problem appears) was also identified as relevant due to the progressive character of the condition.

The intervention development phase (Chapter 4) combined the findings from the systematic review and interview study to develop a preliminary intervention. The intervention theory and logic model were developed at this stage and refined with feedback from relevant stakeholders. This intervention was then tested using a case study design.

The case study (Chapter 5) provided valuable information about the feasibility and acceptability of delivering the VR intervention. Furthermore, using interviews, I identified barriers and enablers to delivering this intervention. Delivering the intervention helped me identify key intervention components such as support managing cognition and fatigue, support with reasonable accommodations, legal rights, and support accessing benefits, among others. The intervention was acceptable, and the participants highlighted the importance of the context of the intervention, the need for employer involvement, and therapist attributes (e.g., knowledgeable, open-minded). Participants also reported that receiving support tailored to their situations was one of the most important attributes of the VR intervention.

## 7.4. Discussion of findings

The VR interventions identified in the systematic review did not report sufficient information on the processes and materials used to deliver the intervention. Therefore, I conducted an interviews study (Chapter 3) to further understand what

VR for people with MS should include. Using reporting guidelines such as TIDieR allows researchers to build on the evidence from previous interventions (142).

Another issue identified in the systematic review was the heterogeneity of outcomes measured, poor reporting of outcomes, and variability of intervention aims. This heterogeneity hampers the progress in the understanding of the effectiveness of VR interventions. VR is a complex intervention; therefore, measuring its impact is challenging due to the multiple variables affecting the outcome. This challenge was reflected when assessing the impact of the intervention (Chapter 5). The standardised measures did not capture the impact of the intervention; however, the postintervention interviews provided insight into the changes the participants experienced. This discrepancy in the data may have been caused because the intervention was highly individualised and the outcomes could not assess all the issues addressed.

Regarding the main underlying mechanisms of VR for people with MS, the need for early intervention is widely reported (60,77,107,160), and its relevance was also highlighted by the participants with MS in the intervention (Chapter 5). They had been diagnosed with MS for an average of 5.38 (SD=4.83) years and experienced symptoms suggestive of MS for an average of 14.87 (SD=10.42) years. This gap in time between symptoms emerging and diagnosis means that they had experienced problems at work (e.g., high sick leave rates) even before their diagnosis. There is evidence that people with MS miss working days even before diagnosis (244). For this reason, VR should be provided soon after diagnosis to inform them about their legal rights and support available.

Unfortunately, to date, there are limited VR services for people with MS in the UK (54,161). The interviews conducted with healthcare professionals (Chapter 3 and 5) highlighted that they do not routinely address employment issues in the MS clinic because they lack time, knowledge, and confidence to discuss these issues. This has been previously reported in the literature (91). Therefore, healthcare professionals should be supported to have a conversation about work, or at least be aware of services available to refer the person with MS.

The importance of employer engagement is also emphasised in the literature (6,131), clinical guidelines (60,107), and was a key theme throughout the thesis. Employers lack knowledge about MS, and issues with employers are widely reported in the literature (253). Open communication between employer and employee is key to support the person with MS at work (119). Unfortunately, not all people with MS have a good relationship with their employer. This thesis provides examples of indirect employer involvement to empower the employee with MS to have conversations with their employer about their MS and needs at work. In fact, the participants with MS reported improved confidence in managing issues at work in the post-intervention interviews.

Employers are also fundamental to provide reasonable accommodations. Support identifying reasonable accommodations was one of the most common intervention components delivered in the intervention (Chapter 6). The "visibility" of the symptoms play a key role in the provision of support at work. Employers tend to be more accommodating in providing support for those symptoms that are visible (e.g., walking difficulties), rather than the invisible ones (e.g., fatigue, anxiety). This is a source of conflict because people with disabilities do not always receive the necessary accommodations to work effectively (121). In fact, the employers of some participants with MS in the intervention rejected reasonable accommodations to their employees with MS, even though the accommodations identified require no extra cost for the employer (e.g., working from home, flexible schedule). Similar findings have been reported in the literature about VR and MS (131,180).

The challenges people with MS experience requesting reasonable accommodations might explain why they do not feel supported at work. In fact, previous research has found that discrimination at work is one of the most common causes to leave the workforce prematurely for people with MS (254,255). Thus, the intervention developed as part of this thesis includes support for the employer (e.g., education about MS, reasonable accommodations) and the person with MS (e.g., support requesting reasonable accommodations) to improve the support they currently receive at work. Although the intervention was mainly focused on improving the work experience of people with MS, employers would also benefit from this type of

intervention. In fact, there is evidence that it is more beneficial for employers to retain an experienced employee than recruiting and training a new employee (256).

The intervention components identified as important for VR for people with MS share similarities with VR interventions to support people with other long term conditions (60), such as TBI (149), and mental health conditions (257). For example, VR for people with spinal cord injury focuses on supporting the person to RTW after the injury, vocational training to regain skills or assistive technology to compensate for the difficulties (258–260). For people with epilepsy, "training and placement" programmes have been found successful to support the person to RTW, although they require careful monitoring for those with complex problems managing seizures (261). These programmes focus on upskilling the person with the injury and then placing them in a work setting to use the skills (262).

In people with mental health problems, Individual Placement Support is a type of supported employment that merges employment and mental health services. It has proved to be beneficial to support them to remain at work (263). Finally, people with TBI need support facilitating the RTW process. To achieve this, adapting the environment and the job to accommodate the injury are key aspects of VR, which are driven by a detailed assessment of the impact of the injury and job duties (203,219).

The experience gained delivering the intervention developed as part of this thesis, shows that VR for people with MS should follow a biopsychosocial approach that understands the impact of a disability taking into consideration the biological, psychological, and social factors.

The main difference between VR for people with MS and the aforementioned conditions is that MS is a chronic progressive condition, that fluctuates over time; therefore, people will need further support as the condition worsens or new symptoms appear. Furthermore, people with MS need support to remain at work, rather than RTW. This can make it difficult to identify those in need of VR support at the right time.

#### 7.4.1. Theoretical frameworks

The MRC framework for developing and evaluating complex interventions provided conceptual guidance to inform the development of the VR intervention. In fact, the process of identifying barriers and facilitators to change was informed by this framework. This framework highlights the need to identify those factors that lead to a successful implementation. Therefore, the MRC framework, along with the BCW and the ICF informed the questions to identify the factors that would facilitate or hamper the participation in the VR intervention (Chapter 3).

The MRC framework for developing and evaluating complex interventions also recognises the need to understand previous evidence and model the intervention processes and outcomes as part of the development of the intervention's underpinning theory (133). Therefore, a logic model was developed to understand how the intervention brings about its effect. This is a novel approach to understand VR for people with MS.

The ICF helped understand the symptoms that people with MS experience and how environmental factors, such as the work environment, workplace relationship, and the employers' knowledge about reasonable adjustments and the Equality Act 2010 create further barriers to job retention. This framework was beneficial to develop the research tools and engage stakeholders in the research studies, as it provides a common language to explain the impact of MS at work. Unfortunately, the environmental factors on the ICF are not well defined (264). Therefore, I benefited from combining the ICF with other frameworks such as the BCW.

The BCW supported the understanding of barriers and facilitators identified in the interviews study (Chapter 3) and implementation of the intervention (Chapter 5). The BCW has allowed me to understand what conditions related to the person with MS, and their context (e.g., family, job responsibilities) need to be in place to facilitate their participation in the intervention and improve its acceptability. This framework has been previously used to identify the barriers and enablers of delivering complex interventions for other populations such as acquired brain injury (265). Interestingly, similar barriers were identified in the aforementioned study compared to the intervention presented in Chapter 5, such as lack of awareness about the need for

support, and lack of time and/or motivation to participate in the intervention. Identifying these barriers early in the intervention development process was beneficial to address them before implementation.

Finally, the CIFR framework provided evidence about the factors that led to the successful implementation of the intervention such as remote support, collaboration between parties, and review of progress made. The case studies were implemented in a community setting; thus, the factors identified are not sufficient to understand how the intervention could be implemented in a different setting (e.g., NHS).

#### 7.4.2. The PBA for intervention development

At the inception of this project, I did not have an intervention that I could test, therefore, following the MRC framework for developing and evaluating complex interventions, I first reviewed the literature to understand what previous research was available. The poor reporting of the interventions and heterogeneity of intervention aims made it clear that it was necessary to develop a new intervention.

The PBA allowed me to incorporate the evidence found from the systematic review and complement it with feedback from potential end-users. I incorporated as stakeholders people with MS, healthcare professionals (OTs and neurologists), and employers of people with MS. The views and experiences of the stakeholders influenced the development of the intervention; therefore, it would have been beneficial to have more diversity in the stakeholders recruited. Unfortunately, most participants with MS included had an office-based job, were relatively newly diagnosed, and there was no ethnic diversity. The group of healthcare professionals would have also benefited from including the views of MS nurses, GPs, and OH because they also play an important role in the care of people with MS. Including views from stakeholders with diverse characteristics would have been beneficial to develop a more comprehensive intervention, because they might have reflected on issues that were not captured with the stakeholders included.

Finally, the PBA was beneficial to develop the intervention through an iterative process based on the experience of delivering the intervention.

#### 7.4.3. Job retention intervention for people with MS

The intervention developed as part of this thesis was feasible and acceptable to the participants who received it (Chapter 5). The findings from the case studies provided insight into the support that people with MS need at work, including detailed examples of problems that people with MS experience at work such as difficulties managing MS and lack of support from employers.

The participants (MS, employers, and healthcare professionals) believed that employment status should be systematically recorded in the MS clinic to provide VR support as part of MS care. The intervention described in Chapter 6 is a remote intervention delivered outside of the MS usual care that people receive in the NHS. The flexibility that the intervention provides in terms of content and delivery mode (e.g., remote support, sessions booked as required) could be beneficial for employed people with MS who have limited time. This was one of the main attributes discussed when developing the intervention (Chapter 4). Unfortunately, MS Clinics cannot provide this level of flexibility because they lack resources (e.g., time, office space). Furthermore, this intervention was delivered by an assistant psychologist and MS Clinics do not always have psychologists available or a member of the team with knowledge about VR. To compensate for this lack of capability, VR support could be provided outside of the MS Clinics, but working in close collaboration with them. This aligns with findings from the interviews study (Chapter 3), where participants with MS believed that healthcare professionals should inform people with MS about VR services, but the support should be provided outside of a hospital, because of the negative connotations that hospitals have for people.

As previously described, a multidisciplinary biopsychosocial intervention is needed to support people with MS at work. The MS clinic already provides support with symptom management, which is important to improve the wellbeing of the person. The VR intervention could complement symptom management with education about legal rights, exploring employment alternatives, and identifying reasonable accommodations. This approach could lead to sustainable job retention and fits within the ICF model selected to underpin the development of the intervention.

To achieve this synchronisation between the healthcare system and the VR intervention, there is a need to better understand the training needs of MS clinics to support symptom management with a focus on employment.

The findings of this thesis also reported on the need for companies to develop better policies and greater disability awareness to address the unconscious bias that employers may have towards people with disabilities. To address this issue, there is a need for interventions at multiple levels, from the organizational level (e.g., the employer) to the national level (e.g., Government) to improve the support that people with disabilities receive at work.

Finally, one issue identified during the evaluation of the intervention was the outcomes selected to assess the impact of the intervention. The only outcome that reflected a change (improvement) at the end of the intervention was goal attainment. The other outcomes may not have reflected a change because of the short-term of the intervention. It may also not be possible to detect a change in mood (e.g., anxiety, depression) or quality of life in people with a chronic and progressive condition in such a short time (6 months follow-up). Furthermore, the participants completed the outcome measures during the Covid-19 pandemic; therefore, the uncertainty of the pandemic may have caused further challenges in their lives. Thus, VR interventions should include goal setting as an outcome measure, as these interventions are highly individualised, and setting goals can reflect a change that is meaningful to the person receiving the intervention.

#### 7.4.4. Clinical implications

- People with MS are diagnosed in MS services; therefore, informing them about VR support at diagnosis can facilitate the provision of early intervention.
- Employment status should be systematically recorded in the clinical notes to gather data about employment rates and identify issues promptly.
- People with low disability levels should be encouraged to receive VR even if they do not experience work problems because it can provide them with valuable information for their future at work.

- VR services should be easily accessible (e.g., via telephone, videoconference or email) to address queries promptly without the need to travel to further appointments.
- Healthcare professionals reported a lack of confidence in addressing employment issues with people with MS. Therefore, they should receive education about antidiscrimination laws and be aware of services to refer people with MS who are experiencing problems at work.

#### 7.5. Conclusion

In conclusion, it was feasible to develop the intervention following the MRC framework for developing and evaluating complex interventions and the PBA. Furthermore, based on the findings from the case studies it was feasible and acceptable to deliver the intervention to employed people with MS and their employers.

People with MS need support managing conversations with employers, selfmanaging symptoms, identifying reasonable accommodations, and understanding their legal rights. Information provision only was not sufficient to meet their vocational needs; therefore, providing education and monitoring progress made at work appeared to be fundamental to support them at work.

The findings from this thesis show that employer engagement is fundamental to address workplace issues; however, it is common for people with MS to experience problems with their employers. Therefore, it is important to empower the person with MS to manage conversations with their employer.

#### 7.5.1. Future research

This thesis has provided information about the vocational needs of people with MS. However, there is a need to further understand what type of support is beneficial for whom according to their personal, environmental and MS characteristics. This research question could be addressed using a realist approach that understands the mechanisms that act at an individual and organisational level, by which these interventions produce the intended outcome. Therefore, future research should involve conducting a realist review to explore theory-driven representations of how VR interventions might work for each individual.

Unfortunately, it was not feasible to assess the effect of the intervention with the outcomes selected, as they could not capture the range of issues covered with the intervention. Therefore, there is a need to develop better outcomes to measure the impact of VR interventions. VR interventions should also include outcomes to measure the impact on society, and healthcare service utilisation.

Future research should also explore in more detail the VR needs of people with MS from lower socioeconomic positions or who have a physical job, as this would provide further evidence to refine the intervention developed as part of this thesis. There is also a need to understand how to include employers, HR managers and/or OH in VR interventions and explore relevant components for them. In particular, there is a need for interventions designed for employers to improve their disability awareness. These interventions could provide general disability awareness so that the knowledge gained could be generalised to multiple conditions.

Finally, future research should also address the effectiveness and cost-effectiveness of VR interventions for people with MS. These issues could be explored in larger research studies such as RCTs. However, before embarking on this route, further research should focus on developing an implementation and adaptation plan to incorporate this intervention within existing healthcare services. This preliminary step will help to understand the barriers and facilitators to deliver these interventions in a healthcare setting and develop a blueprint of the intervention and training manual that clinicians can use across the UK to deliver the intervention.

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# Appendix

# **Appendix A: Systematic Review Searches.**

## PubMed search strategy.

(((((("Multiple Sclerosis"[mh]) OR ("Myelitis, Transverse"[mh:noexp]) OR ("Demyelinating Diseases"[mh:noexp]) OR ("Encephalomyelitis, Acute Disseminated"[mh:noexp]) OR ("Optic Neuritis"[mh])) OR ((("multiple sclerosis") OR ("neuromyelitis optica") OR ("transverse myelitis") OR (encephalomyelitis) OR (devic) OR ("optic neuritis")) OR ("demyelinating disease\*") OR ("acute disseminated encephalomyelitis"))))) AND (((((((((("Rehabilitation, Vocational" [Mesh]) OR "Employment"[Mesh]) OR "Employment, Supported" [Mesh]) OR "Work capacity evaluation" [Mesh]) OR "Work" [Mesh])) OR ((work retention) OR job retention)) OR (((vocational assessment) OR vocational education) OR vocational guidance)) OR work adjustment) OR sheltered workshop) OR career mobility)

## **OVID (MEDLINE & EMBASE)**

- #1 Exp Multiple Sclerosis/
- #2 Myelitis, Transverse/
- #3 Demyelinating Diseases/
- #4 Encephalomyelitis, Acute Disseminated/
- #5 exp Optic Neuritis/
- #6 neuromyelitis optica/
- #7 encephalomyelitis/
- #8 1 or 2 or 3 or 4 or 5 or 6 or 7
- #9 exp Rehabilitation, Vocational/
- #10 exp Employment/
- #11 exp Employment, Supported/
- #12 exp Work Capacity Evaluation/
- #13 exp Work/
- #14 work retention/
- #15 job retention/
- #16 vocational assessment/
- #17 vocational education/
- #18 vocational guidance/

- #19 sheltered workshop/
- #20 career mobility/
- #21 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20

#22 8 and 21

### Web of Science

- #1 Multiple Sclerosis
- #2 Myelitis, Transverse
- #3 Demyelinating Diseases
- #4 Encephalomyelitis Acute Disseminated
- #5 "Optic Neuritis"
- #6 neuromyelitis optica
- #7 encephalomyelitis
- #8 1 or 2 or 3 or 4 or 5 or 6 or 7
- #9 Vocational Rehabilitation
- #10 Employment
- #11 Supported employment
- #12 Work Capacity Evaluation
- #13 work retention/
- #14 job retention/
- #15 vocational assessment/
- #16 vocational education/
- #17 vocational guidance/
- #18 sheltered workshop/
- #19 career mobility/
- #20 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
- #21 8 and 20

# **PsycInfo**

- #1 Exp Multiple Sclerosis/
- #2 Myelitis, Transverse/

- #3 Demyelinating Diseases/
- #4 Encephalomyelitis, Acute Disseminated/
- #5 exp Optic Neuritis/
- #6 neuromyelitis optica/
- #7 exp encephalomyelitis/
- #8 1 or 2 or 3 or 4 or 5 or 6 or 7
- #9 exp Rehabilitation, Vocational/
- #10 exp Employment/
- #11 work retention/
- #12 job retention/
- #13 vocational assessment/
- #14 vocational education/
- #15 vocational guidance/
- #16 sheltered workshop/
- #17 career mobility/
- #18 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
- #19 8 and 18

## CINAHL

((((MH multiple sclerosis) OR (MH Myelitis, Transverse) OR (MH optic neuritis) OR (MH Encephalomyelitis, Acute Disseminated) OR (MM "neuromyelitis optica") OR (MM "myelitis transverse") OR (MH "Demyelinating Diseases+"))) OR ((((MM "encephalomyelitis") AND (MH "Rehabilitation, Vocational") OR (MH "Work+") OR (MH "Employment+") OR (MH "Employment, Supported+") OR (MH "Work Capacity Evaluation+") OR (work retention OR job retention) OR (vocational assessment OR MM "vocational education" OR vocational guidance) OR (MM "sheltered workshop") OR (MM

# **Appendix B: Vocational treatment components**

The definitions of the following intervention's components were extracted from Hart et al. (2006) and Chiu et al. (2013).

#### Table 70 Vocational rehabilitation Components

Vocational treatment components extracted from Hart et al. 2006

Treatment components focused on vocational content

**Vocational counselling/education**: providing work knowledge and education; practical problem-solving; setting or adjusting vocational goals

**Job development/job-seeking** planning and managing job search; preparing resumes/applications: interviewing skills; other activities leading to job placement.

**Specific vocational skills training:** training in transferable skills such as computer or clerical skills.

**Case management/advocacy:** interventions on behalf of client (whether client present or not) intended to improve clients work-related situation including referrals; transportation, housing, and logistics; negotiations with employers

**Work trials:** temporary practice jobs (usually unpaid), part or full-time, clinic or community-based.

Treatments and Services following job placement

**Job coaching:** treatment involving staff member accompanying client to jobsite or working with client/employer off-site the job training; troubleshooting; and development of strategies and job performance and job maintenance; includes employer/co-worker education and job modifications

**Developing natural jobsite supports** formal or systematic procedures for enlisting and mentoring a co-worker or supervisor to act as a coach or support the client at the workplace

**Job follow along:** ongoing contact with client and/or employer and/or family for monitoring and troubleshooting; implies formal coaching has ended EITHER Scheduled, OR PRN

Vocational treatment components extracted from State Vocational Rehabilitation services not included in Hart et al. 2006

**Vocational assessment:** including assessment of skills, abilities, preferences. Services provided and activities performed to determine an individual's eligibility for VR services, to assign an individual to a priority category of a state VR agency that operates under an order of selection, and/or to determine the nature and scope of VR services to be included in the individual plan for employment.

**On-the-job training:** Training in specific job skills by a prospective employer; generally the individual is paid during this training and will remain in the same or a similar job upon successful completion; this category also includes apprenticeship training programs conducted or sponsored by an employer.

**Maintenance:** Monetary support provided for those expenses such as food, shelter, and clothing that are excess of the normal expenses of the individual and that are necessitated by the individual's participation in an assessment for determining eligibility and vocational rehabilitation services.

**Rehabilitation Technology:** The systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation.

**College or university training:** Full-time or part-time academic training above the high school level that leads to a degree (associate, baccalaureate, graduate, or professional), a certificate, or other recognized educational credential.

**Basic academic remedial or literacy training:** Literacy training or training provided to remediate basic academic skills needed to function on the job in the competitive labour mark

**Miscellaneous training:** Any training not recorded in one of the other categories listed, including GED or high school training leading to a diploma

Job readiness training: Training to prepare an individual for the world of work.

**Disability-related augmentative skills training:** Including orientation and mobility, rehabilitation teaching, training in the use of low vision aids, Braille, speech reading, sign language, and cognitive training/retraining.

**Other Vocational Components Not Detailed Above** 

Assessment of work requirements e.g., Job analysis

Assessment of work performance

# Appendix C: Summary of findings systematic review

Table 71 Summary of findings from systematic review.

Study	Program & Country	Type of intervention	Inclusion Criteria	Components	Outcomes	Staffing	Intervention length & study design	Study Design	VR Approach
LaRocca et al. (77)	Job Retention Intervention (USA)	Job retention	-Diagnosis of MS -Employment (at least part-time) -Risk for employment problems -Living close to research centre	-Vocational counselling -Case management -Job follow along -Assessment of work requirements -Cognitive remediation	Employment status (employed or not)	Psychologist and Employment Specialist	Up to 12 months 1-year follow- up Face-to-face and telephone	RCT	Specialist MS vocational rehabilitation services
Rumrill et al. (128)	Career Possibilities Project (USA)	Return to work	-Diagnosis of MS -Unemployed	-Vocational counselling -Job develop./seeking -Job coaching -Vocational assessment -Rehabilitation Technology -Job readiness training -Accommodation Planning Team	Accommodations self-efficacy measure. Employability maturity interview Job-seeking activity. Employment status	Vocational Rehabilitation Counsellor and Rehabilitation Counsellor	16 weeks Face-to-face and telephone	ССТ	Specialist MS vocational rehabilitation services
Sweetland (131)	Working yet Worried (UK)	Job retention	-Diagnosis of MS -Employed -Within one year of diagnosis	-Vocational counselling -Case management -Job coaching -Job follow along -Employer engagement -Vocational Assessment -Assessment of work requirements	MSIS-29 IWQ MS-WIS BI GSES EuroQol EQ-5D	Occupational Therapist	12 months Face-to-face and telephone	RCT	Specialist MS vocational rehabilitation services
Dorstyn et al. (127)	Work and MS (Australia)	Return to work/Find new job	-Adults (≥18 years) -Diagnosis of MS -Looking for employment	-Job development/seeking	My vocational situation scale. Job-procurement self-efficacy	Self-help	4 weeks Email	RCT	Specialist MS vocational rehabilitation services

Study	Program & Country	Type of intervention	Inclusion Criteria	Components	Outcomes	Staffing	Intervention length & study design	Study Design	VR Approach
Dorstyn et al. (129)			-English Fluency - Internet access		MSWDQ Life orientation test- revised. PHQ-9			Pilot RCT	
1 Rumrill et al. (89)	MS back to Work (1) (USA)	Return to work	-Adults (+18) -Unemployed	<ul> <li>Job development/seeking</li> <li>Job placement</li> <li>Employer engagement</li> </ul>	-	Rehabilitation professional/ counsellor	Length not available. Face-to-face (Group)	1 Expert opinion	Specialist MS vocational rehabilitation services
2	Return to Work (1) (USA)	Return to work	-Adults (+18) -Unemployed	<ul> <li>Vocational assessment</li> <li>Vocational counselling</li> <li>Job development/seeking</li> <li>Goal setting.</li> </ul>	-	Rehabilitation professional	25 hours Follow-up: 1 year Face-to-face (Group)	1 Expert opinion	Statutory pan- disability vocational rehabilitation services
Rumrill et al. (6)	Job Raising Program (1) (USA)	Return to work/Find new job	-Unemployed -Employed and looking for work	-Job development/seeking -Job readiness training -Job club	-	Community experts	10 weeks Follow-up: 8 years Face-to-face (Group)	2 Expert opinion	Statutory pan- disability vocational rehabilitation services
3 Rumrill et al. (156)	Project Alliance (1,2) (USA)	Job retention	-Employed -Diagnosis of MS	-Case management -Employer engagement. -Job coaching -Job follow along -Assessment of work requirements	-	Rehabilitation professional, employer, co- worker, and job analyst	Not available Face-to-face (Group)		Statutory pan- disability vocational rehabilitation services
	Career Crossroads: Employmen t and MS (2) (USA)	Job retention	-Diagnosis of MS -Employed	-Vocational counselling -Job coaching	-	Not available	Several weeks Group/ Self-help DVD	3	Specialist MS vocational rehabilitation services

Study	Program & Country	Type of intervention	Inclusion Criteria	Components	Outcomes	Staffing	Intervention length & study design	Study Design	VR Approach
	MS Employmen t Assistance Service (2,3) (USA)	Job retention	-Diagnosis of MS	-Vocational counselling -Return to work assessment -Vocational assessment -Job development/seeking -On the job accommodation planning.	-	Rehabilitation counsellor	Intervention length according to client's needs Telephone and email	Mix methods	Specialist MS vocational rehabilitation services
Tansey et al. (152) Chiu et al. (153)	State VR Program	Return to work/ Job retention/	-People with MS either employed or	- Vocational counselling -Vocational assessment -Job coaching	-	Not available	Intervention length according to	Secondary data analysis	Statutory pan- disability vocational
Chiu et al. (67)	(USA)	job	unemployed	-Renabilitation technology			Not available	Survey	services
Fraser et al. (148)	Neurologica l Vocational	Return to work/ Job		<ul> <li>Vocational Assessment</li> <li>Job development/ job seeking</li> </ul>		Rehabilitation	Approximately 215 hours per job experienced.	Quantitati ve study	Statutory pan- disability
Fraser et al. (147)	Service Unit (USA)	Find new job		-Specific vocational skills training	-	Counsellor	Follow-up ranged from 6- 24 months. Face to face	Quantitati ve study	vocational rehabilitation services
Stimmel et al. (130)	Neuropsych ologically- based vocational intervention. (USA)	Job Retention	-Diagnosis of MS -Female sex. -Aged 18 to 64. -Employed ≥20 hours/week.	-Neuropsychological assessment -Tailored recommendations such as cognitive remediation, psychotherapy, fatigue management, occupational/ physical therapy	PHQ-9 SDMT FSS	Clinical Psychologist	Follow-up at 1 to 6 months post-assessment Face to face	Pilot RCT	General rehabilitation program
MS: multiple Instability Sca Severity Scale	sclerosis; VR: vo ale; BI: Barthel in e.	cational rehabilita dex; GSES: Gene	tion; RCT: randomised contralised self-efficacy scale; M	rolled trial; CCT: clinical controll ISWDQ: MS Work Difficulties Q	ed trial; MSIS-29: MS Imj uestionnaire; PHQ-9: Patio	pact Scale; IWQ: MS ent Health Question	S Impact on Work Que naire; SDMT: Symbol	stionnaire: MS digit modalities	WIS: MS Work test; FSS: Fatigue

# **Appendix D: TIDieR Checklist VR interventions**

*Note:* The references provided in the TIDieR checklists are first from the primary paper of the intervention. The references provided in the "Other" column are from resources such as other published papers about the intervention and materials obtained from the authors (142).

TIDieR item	Item description	Page in
		manuscript
		where item
		is reported
1 Brief name	Job Retention Intervention	p-41 (77)
2 Why	Most persons with MS have at least limited contact with health care providers. However, the	p-38-39 (77)
	average health care provider has neither the	<b>、</b> /
	time nor the expertise to deal with employment	
	problems.	
	-	
3 What-	No details	
Materials		
4 What-	Medical/Counselling component: The	p-40-41
Procedures	psychologist asked about the person's current	(77)
	overall functioning at home and work.	
	MS symptomatology	
	Interpersonal issues	
	Emotional Issues	
	Employment services component: During the	
	initial interview, an Employment Profile was	
	filled out by the employment specialist detailing	
	medical information, education, employment	
	history, family situation including marital and	
	financial status, disclosure status, and current	
	employment stresses and problems.	
5 Who	Psychologist and Employment specialist	p-40 (77)
provided		
6 How	Face-to-face and via telephone	p-40-41
		(77)
7 Where	Research and Training Centre for MS.	p-39 (77)
8 When and	12-month with 1-hour interview with	p-40-41
how much	Psychologist; 1-hour interview with	(77)
	Employment Specialist, followed by calls every	
	1 or 2 weeks; contact number to call	
	protessionals at any point; follow-up at the end of the study	
0 Tailoring	No details	

Table 72 TIDieR "Job Retention Intervention"

10	No details	
Modifications		
11 How well	All participants completed the interviews, but	p-39 (77)
	only a few participants followed the	
	recommendations.	
	Drop out/ completion rate: 2/21	

Table 73	TIDieR	"Career	Possibilities	Project"
10000 10	11Dicit	Curcer	1 000000000000	110,000

TID:0P_PHD	Itom description	Page in
itom	item description	r age m
Item		
		where item
		is reported
1 Brief name	Career Possibilities Project	p-243 (128)
2 Why	The purpose of this study was to demonstrate	p-243 (128)
	and evaluate the effects of a career re-entry	
	project for people with MS. Implementing two	
	"least intervention" strategies focused on	
	assessment, self-directed job-seeking, and	
	resource utilization.	
3 What-	No details	
Materials		
4 What-	<b>Intervention group 1:</b> Telephone call by	p-245-246
Procedures	rehabilitation professional to schedule a career-	(120)
	counselling interview. Structured interview to	(128)
	identify vocational profile, followed by	
	Accommodations Planning Team (APT).	
	<b>Intervention Group2:</b> Traditional job-seeking	
	skills intervention consisting of two telephone	
	contacts and a packet of information.	
5 Who	Rehabilitation professional, employer, and VR	p-245 (128)
provided	counsellor	1 , ,
6 How	Telephone and face-to-face	p-245-246
		(128)
7 Where	No details	
8 When and	No details	
how much		
9 Tailoring	No details	
10	No details	
Modifications		
11 How well	No details	

Table 74 TIDieR "Working yet Worried".

TIDieR item	Item description	Page in
		manuscript
		where item
		is reported

1 Brief name	Working yet Worried	p-120 (131)
2 Why	Early intervention to reduce or remove job- related barriers before they undermine job satisfaction and, eventually, threaten job retention. Although input may be brief the progressive nature of the disease means that people with MS need to be able to re-access services as and when required, consequently services should be open access and could benefit from empowering the person to take control of their situation	p-86 (131)
3 What- Materials	Interview guide (presented on thesis), COT Fatigue Management	p-133 (131)
4 What- Procedures	Interview to explore needs at work, and provision of advice and support about disclosure, the DDA, workplace accommodations, and Access to Work scheme. After each session, an action plan was developed for both OT and participant. Each participant had access to as many treatment sessions as necessary to complete the plan, where appropriate referrals were made to other rehabilitation professionals.	p-125 (131)
5 Who provided	Occupational therapist.	p-94 (131)
6 How	Face to face, telephone, and email.	p-132-135 (131)
7 Where	National Hospital for Neurology and Neurosurgery (NHNN) and the Institute of Neurology (ION)	p-94 (131)
8 When and how much	One year intervention. Participants would have up to six sessions on consecutive weeks lasting 1.5 hours per session.	p-143 (131)
9 Tailoring	Participants with complex work situations could receive additional support until the end of the study.	p-136 (131)
10 Modifications	Not applicable	
11 How well	Of the 27 recruited four people withdrew; two due to severe relapses requiring hospital admission, one due to death in the, and one withdrew but gave no reason.	p-133 (131)

Table 75 TIDieR "Work and MS"

TIDieR item	Description	Page in
		manuscript
		where item
		is reported

1 Brief name	Work and MS	Abstract
		(129)
2 Why	A consumer-based job information resource,	p-273 (129)
	Work and MS, was developed to strengthen the	
	Australian vocational care for people with <s< th=""><th></th></s<>	
3 What-	The modules focus on requisite job skills sets,	p-274 (129)
Materials	namely the job-seeking process (3 modules), job-	
	interviewing skills (2 modules), and career	
	development (1 module). Each module presented	
	as a PowerPoint presentation including the	
	following key components: (1) objectives, (2) key	
	points (eg, online activity worksheets that can be	
	completed and e-mailed for feedback), (3)	
	downloadable education materials, and (4) a	
	summary of content.	
4 What-	Intervention participants were e-mailed the first 3	p-273 (129)
Procedures	Work and MS modules to review at their own	
	pace. A follow-up email with the remaining 4	
	modules was sent 1 week later. At 4 weeks post-	
	enrolment (time 2), all participants received a link	
	to a follow up online survey.	
5 Who	Not applicable, remote intervention.	
provided		
6 How	Email	p-273 (129)
7 Where	Remote intervention	p-273 (129)
8 When and	Participants were e-mailed the modules to review	p-274 (129)
how much	at their own pace.	
	The modules were designed to be brief, with pilot	
	testing suggesting that each requires up to 20	
	minutes to complete online (excluding activity	
	worksheets).	
9 Tailoring	Not applicable	
10	Not applicable	
Modifications		
11 How well-	Adherence to Work and MS was acceptable; 69%	p-273 (129)
Planned	indicated having accessed the material.	

#### Table 76 TIDieR "MS back to work: Operation job match"

TIDieR item	Item description	Page in
		manuscript
		where item
		is reported

1 Brief name	The project, MS Back to-Work (subsequently re-	p-168 (89)
	named Operation Job Match),	
2 Why	It combined the best elements of the person-	p-168 (89)
	environment reciprocation that serves as the	
	conceptual basis for most conventional job	
	placement programs. It placed dual emphasis on	
	increasing individual participants' job-seeking	
	proficiency and enlisting assistance from the	
	employment community in generating a wide	
	range of career options for people with MS.	
3 What-	No details	
Materials		
4 What-	The project was imbued with both job-seeking	p-168 (89)
Procedures	skills training and selective placement	
	techniques. The job-seeking skills component	
	included such topics as interviewing tips,	
	etiquette and coping with on-the-job stress.	
	Selective placement activities included matching	
	participants with jobs through a job bank.	
5 Who	Rehabilitation counsellor/ Rehabilitation	p-168 (89)
provided	professional.	
6 How	A job bank formed by a network of corporate and	p-168 (89)
	small business sponsors who identified private-	
	industry employment opportunities for people	
	with MS.	
7 Where	No details	
8 When and	No details	
how much		
9 Tailoring	No details	
10	No details	
Modifications		
11 How well	No details	

Table 77 TIDieR	"Return to	o Work	program"
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TIDieR item	Item description	Page in manuscript where item is reported
1 Brief name	Return-to-Work program (RTW)	p- 169 (89)
2 Why	The fact that most people with MS have successful employment histories but leave their jobs within a few years of initial signs of the disease means that placement interventions to assist unemployed people with the illness should be framed in a RTW context.	p- 169 (89)
3 What-	No details	
Materials		

4 What-	Module 1: Coping with disability and related life	p- 169-171
Procedures	changes; Module 2: Life and benefits planning;	(89)
	Module 3: Return to work	
5 Who	Rehabilitation professional	p- 170 (89)
provided		-
6 How	In 6-10 person groups that spend approximately	p- 170 (89)
	25 h in direct contact, RTW participants begin the	
	process with orientation and group cohesion	
	exercises.	
7 Where	No details	
8 When and	In 6-10 person groups that spend approximately	p- 170 (89)
how much	25 h in direct contact.	-
9 Tailoring	No details	
10	No details	
Modifications		
11 How well	No details	

#### Table 78 TIDieR "Job Raising Program".

TID: D Home	Itom description	Do go in
I IDIEK item	Item description	Page in
		manuscript
		where item
		is reported
1 Brief name	Job Raising Program	p-169 (89)
2 3 3 3 4 1		
2 why	Placement and retention model for people with	p-169 (89)
	adult-onset, chronic disabilities. The Job Raising	
	Program was conceived with the lofty aspiration of	
	'greatly exceeding the success of any of the other	
	existing rehabilitation-related programs, public or	
	private.	
3 What-	No details	
Materials		
4 What-	Sharing the goal of obtaining and/or maintaining	p-169 (89)
Procedures	employment, participants received information and	
	direction from community experts on such matters	
	as (a) assertiveness (b) interviewing skills (c)	
	resume writing and (d) the job market	
5 Who	No details	
	No details	
provided	~	1.60.(0.0)
6 How	Group	p-169 (89)
7 Where	No details	
8 When and	These services were delivered in a 10-week, small	p-169 (89)
how much	group (10-12 participants) format in which	
	participants met for 3 h once a week	
9 Tailoring	No details	

10	No details	
Modifications		
11 How well	No details	

#### Table 79 TIDieR "Project Alliance"

TIDieR item	Item description	Page in manuscript	Other*
		where item is reported	
1 Brief name	Project Alliance	p-132 (6)	
2 Why	Comprehensive job retention program that combines needs assessment principles and self-advocacy training with employer consultation and community resources. It emphasized early accommodation and collaborative problem solving between the employee and the employer rather than the more traditional job seeking skills training and placement assistance.	p-132 (6)	p-86 (156)
3 What-	No details		
Materials			
4 What-	On-site job analysis, Input from follow-	p-132 (6)	
Procedures	implementation and monitoring of reasonable accommodations and other job retention strategies.		
5 Who provided	VR professionals, the employee, the employer, and co-workers.	p-132 (6)	
6 How	A trained rehabilitation specialist met with the employer and employee with MS to encourage open communication and to strategize job accommodations as a means of facilitating stability before resignation or termination of the worker's job occurred.		p-86 (156)
7 Where	No details		
8 When and how much	No details		
9 Tailoring	No details		
10 Modifications	No details		
11 How well	No details		

TIDieR item	Item description	Page in manuscript where item is reported
1 Brief name	Career Crossroads: Employment and MS	p-132 (6)
2 Why	This program was developed for individuals who are currently working and hope to retain employment.	p-132 (6)
3 What- Materials	This program consists of a video, an accompanying manual, and a leader manual.	p-132 (6)
4 What- Procedures	Topics covered include the importance of work to one's physical and emotional well-being, the impact work has on MS and the impact MS has on work, legal protections afforded under disability and healthcare legislation, the advantages and disadvantages of disability disclosure, practical strategies for managing disability in the workplace, requesting and implementing accommodations, work-life balance, proactive planning, tax incentives for hiring people with disabilities, and resources for workers with MS.	p-133 (6)
5 Who provided	Self-help intervention (DVD)	p-132 (6)
6 How	Small-group setting.	p-132-133 (6)
7 Where	N/A	
8 When and how much 9 Tailoring	The program is designed to be implemented in a small-group setting over several weeks. No details	p-132 (6)
10 Modifications	N/A	
II HUW WEII	INU UCIAIIS	

Table 80 TIDieR "Career Crossroads: Employment and MS"

#### Table 81 TIDieR "MS Employment Assistance Service"

TIDieR item	Item description	Page in manuscript where item is reported	Other*
1 Brief name	Kent State Employment Assistance	p-86 (156)	
	Centre		
2 Why	Job retention resource that can be		p-132
	utilised by employed individuals with		(6)
	MS to proactively address specific job		

	retention questions and concerns before		
	they become crises.		
3 What-	No details		
Materials			
4 What-	Services may include career		p-132
Procedures	counselling, return to work assessment		(6)
	and consultation, vocational interest		
	assessments, transferable skills analysis,		
	job-seeking skills training, and on the		
	job accommodation planning.		
5 Who	Nationally Certified Rehabilitation		p-132
provided	Counsellors		(6)
6 How	No details.		
7 Where	Remotely (Telephone and Internet)	p-86 (156)	
8 When and	Varies according to needs.		p-132
how much			(6)
9 Tailoring	Services are individually tailored to the		p-132
	unique needs of each caller.		(6)
10	No details		
Modifications			
11 How well	No details		

Table 82 TIDieR"State Vocational Rehabilitation Program"

TIDieR item	Item description	Page in manuscript where item is reported	Other*
1 Brief name	State VR Program	p-110 (153)	p-111 (152)
2 Why	The program provides a range of services to people whose disabilities have impeded their ability to obtain or maintain competitive employment.	p-110 (153)	
3 What-	No details		
Materials			
4 What-	VR counselling and guidance, college or	p-110 (153)	
Procedures	university training, assistive technology/job accommodations, job search assistance, and job training and placement.		
5 Who provided	No details		
6 How	No details		
7 Where	No details		
8 When and how much	No details		

9 Tailoring	No details	
10 Modifications	No details	
11 How well	No details	

Table 83	TIDieR	" Neurological	Vocational	Service"
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TIDieR item	Item description	Page in	Other*
		manuscript	
		is reported	
1 Brief name	University of Washington Neurological	$p_{-129}(147)$	
1 Ditei name	Vocational Service	p=12)(1+7)	
2 Why	No details		
3 What-	All subjects participated in initial intake	p-130-131	
Materials	interviews in which they obtained	(147)	
	detailed information about the		
	vocational services program. They		
	completed a detailed vocational intake		
	questionnaire, several measures related		
	to physical and psychosocial		
	functioning, and an abbreviated		
	neuropsychological battery.		
4 What-	Vocational Exploration (5 hours per),	p-130 (147)	
Procedures	vocational Assessment (90 hours per),		
	and vocational training (120 hours per)		
5 Who	Trained rehabilitation counsellor		p-71
provided			(148)
6 How	No details		
7 Where	No details		
8 When and	No details		
how much			
9 Tailoring	No details		
10	No details		
Modifications			
11 How well	No details		

Table 84 TIDieR "Neuropsychologically-based vocational intervention".

TIDieR item	Item description	Page in manuscript where item is reported
1 Brief name	Neuropsychologically-based vocational intervention.	p. 1292 (130)
2 Why	Cognitive impairment, fatigue, and depression are	p. 1293
--	--	----------
	all highly correlated with work instability in MS.	(130)
	As such, neuropsychological assessment, which	
	can identify and address these common problems,	
	is a potentially useful vocational intervention.	
3 What-	Minimal Assessment of Cognitive Function in	p. 1293
Materials	Multiple Sclerosis (MACFIMS).	(130)
4 What-	Following the evaluation, participants were	p. 1294-
Procedures	provided with a detailed report highlighting	1295
	cognitive strengths and weaknesses, and	(130)
	individualized recommendations targeting those	
	problems affecting employment (e.g., cognitive	
	remediation, psychotherapy, fatigue management,	
	occupational/ physical therapy). Experimental	
	participants received follow-up contact from a	
	care-coordinator nurse at approximately one and	
	six months after feedback.	
5 Who	Testing was completed by graduate-level trainees	p. 1294
provided	under the supervision of a clinical psychologist	
	with expertise in neuropsychological testing of	
	individuals with MS.	
6 How	In-person, or via telephone.	p. 1294
7 Where	7 Where Tertiary-care multiple sclerosis centre.	
	(1	
8 When and	When and         Not provided.	
how much	h	
9 Tailoring	Not applicable	
10	Not applicable.	
Modifications		
11 How well	The dropout rate was high (39%), and almost	p. 1297
	exclusively occurred before neuropsychological	(130)
testing, attrition was similar between groups.		

## Appendix E: Semi-structured interview topic guide

## Semi-Structured Interview Guide for People with MS

#### Current services available

- 1. Before you read the information about this study, had you ever heard of the term vocational rehabilitation? [ICF- Personal Factors]
- 2. In your experiences, what support is available to help people with MS in employment? [ICF- Environmental Factors]
- 3. Have you received vocational rehabilitation? [ICF- Environmental Factors]
- 4. Can you tell me about your own experiences being at work with MS?] [ICF-Part 1: Body functions and structures and impairments & Activities and participation] [BCW- Barriers and Facilitators]
- 5. Have you made any changes in your work routine or environment to overcome the difficulties to work with MS? [ICF- Activities and participation]

## Preferences of people with MS for VR support

- 6. What kind of support do you think people with MS might need at work? [ICF- Contextual Factors] [Research objectives]
- 7. What support do you think that organisations and their employees might benefit from to enable people with MS to function effectively at work? [ICF-Contextual Factors] [Research objectives]

## **Identification of barriers to implementation**

- 8. Do you think there may be any negative consequences for people with MS in participating in or receiving support for employment? [ICF- Personal Factors] [BCW- Barriers and Facilitators]
- 9. If this support existed, what would stop people with MS from participating? [ICF- Activities and participation] [BCW- Barriers and Facilitators]

## Semi-Structured Interview Guide for Service Providers

#### **Opening question**

1. Can you tell me about your working experience with people with MS? [ICF-Activities and participation]

#### Management of employment issues/ Current services available

- What sorts of issues do people with MS bring to you regarding their employment? [ICF- Part 1: Body functions and structures and impairments & Activities and participation]
- 3. What services or support are currently available to help people with MS to make decisions about employment? [ICF- Contextual Factors]
- 4. In your knowledge or understanding which are the difficulties of accessing employment services for people with MS? [BCW- Barriers and Facilitators]
- In your knowledge what are the gaps in these services? [BCW- Barriers and Facilitators]
- 6. Have you provided vocational rehabilitation support or referred people with MS to vocational rehabilitation services? [ICF- Activities and participation]

#### Characteristics of VR for people with MS

- 7. How do you think vocational rehabilitation support should be designed for people with MS? [ICF- Contextual Factors] [Research objectives]
- 8. What are the most important treatment components or features of MS VR service? [ICF- Contextual Factors] [Research objectives]

## **Barriers to implementation**

- 9. Do you think there may be any negative consequences in implementing this help with employment issues? [ICF- Personal Factors] [BCW- Barriers and Facilitators]
- 10. How would we know that the vocational rehabilitation intervention was working?[ICF-Contextual Factors] [BCW- Barriers and Facilitators]

# **Appendix F: Intervention Overview**

Table 85 presents an overview of the intervention following the TIDieR checklist.

Criteria	Description		
CITCOIN			
Brief Name	Preventing Job Loss for People with MS		
	The problem:		
	<ul> <li>The average age of diagnosis of MS is between 20-40 years of age. These are the prime working years of an adult.</li> <li>After 10 years with the condition, less than 50% of people with MS remain at work.</li> <li>There is inconclusive evidence of the effectiveness of VR to support people with MS to remain at work.</li> </ul>		
	Theory:		
	Biopsychosocial approach.		
Why	• VR recommendations for people with long-term neurological conditions.		
	• Work disability prevention (Loisel Framework)		
	• UK Equality Act 2010.		
	Key components and mechanisms:		
	• Intervention tailored to characteristics of the person with MS and workplace.		
	• Employer engagement.		
	Identification of workplace barriers and reasonable		
	<ul> <li>Engagement/Collaboration with other professionals</li> </ul>		
	Screening interview.		
What	<ul> <li>List of services to refer the person with MS.</li> <li>Informational and advantional recourses</li> </ul>		
materials?	<ul> <li>Informational and educational resources.</li> <li>Summary letter after each appointment.</li> </ul>		
	<ul> <li>End of intervention package with top tips.</li> </ul>		
	• First, the person with MS will complete an interview to		
What	goals		
procedures	<ul> <li>Between 1 to 10 hours of individually tailored support over</li> </ul>		
	three months distributed according to the needs and		
	preference of the participant.		

Table 85 Intervention overview following TIDieR Checklist

Criteria	Description
	<ul> <li>Those people with MS who agree to involve their employer, their employer will participate in an initial interview (up to 1 hour) and receive up to 3 hours of support.</li> <li>At the end of the intervention, the person with MS will discuss progress made, evaluate goals and future steps.</li> </ul>
Who provided?	An assistant psychologist with experience working with people with MS will deliver the intervention. The assistant psychologist will be mentored by an OT with extensive experience delivering VR for people with MS and other conditions.
How	<ul> <li>The intervention will be delivered individually.</li> <li>The interview and sessions of the intervention can be conducted <i>face-to-face</i> and/or via <i>telephone</i> or <i>Skype</i> according to the preference of the participant.</li> </ul>
Where	<ul><li>People with MS will have the flexibility to decide where they would like to receive the intervention.</li><li>The sessions can be delivered <i>face-to-face</i> in a quiet venue, or <i>remotely</i> via telephone or Skype.</li></ul>
When and how much?	<ul> <li>Person with MS:</li> <li>Initial interview (1 hour)</li> <li>Up to 10 hours of VR over three months. Not all people with MS will require 10 hours, as this will depend on the complexity of their needs.</li> <li>Employer:</li> <li>Initial interview (1 hour)</li> <li>Up to 3 hours of support distributed over three months. Not all employers will require all the hours of support, as this will depend on their needs.</li> </ul>

Criteria	Description		
Tailoring	<ul> <li>Delivery: Each person can select the date and delivery mode of the sessions.</li> <li>Content: The content of the intervention will be tailored from a menu of intervention components.</li> <li>Employer involvement: Not all people with MS will agree to involve their employer and this only optional for the intervention.</li> <li>Length of sessions: It is estimated that the sessions will last between 30-60 minutes according to the topic and the relevance of the topic for the person with MS.</li> <li>The intervention will be tailored to increase its acceptability and facilitate the incorporation in their schedules.</li> </ul>		
Modifications	Not applicable yet		
How well?	<ul> <li>A proforma for each intervention session will be completed to record the length and content of the session.</li> <li>Information about the number of people with MS involving their employers in the intervention will be recorded.</li> </ul>		

## **Appendix G: Resources for Intervention**

The following list includes some of the resources that will be used as part of the intervention distributed according to the topic they cover. However, the intervention is not limited to these resources:

## Access to Work

- <u>https://www.gov.uk/access-to-work</u>
- Factsheet for costumers
- Eligibility and process information
- Quick guide Access to Work (2019- UNISON Disability)

#### Disclosure

- Disclosure and accommodations
- Telling your employer decision sheet
- Videos MS Society about Disclosure
- Disclosure (Shift.ms and MS Society)
- Disclosure in the Workplace (National MS Society)

#### Discrimination

- Disability discrimination, key points for the workplace
- Top 10 myths about disability in the workplace
- Disability discrimination, obligation for employers (ACAS)
- <u>https://www.acas.org.uk/</u>

## MS at work

- MS in the Workplace, an employer's guide (MS Society)
- Work and MS, an employee's guide (MS Society)
- Why and how should HCP talk to people with MS about work?
- Working with MS: Employment Resources for People with MS
- Working and studying with MS (MS Trust)
- Strengths and weaknesses at work decision sheet
- Understanding your work situation decision sheet

## **Equality Act**

- Check if you are disabled under the Equality Act.
- MS Trust- The Equality Act.
- Disability Equality at Work (Unite Negotiators Guide).

## Fatigue (management)

- Fatigue: What you should know? (National MS Society)
- Fatigue (MS Society)
- Living with fatigue: fatigue management for people with MS (MS Trust)
- Living well with MS, managing fatigue (MS Society Canada-Book)
- MS Fatigue (Canada MS Society-short document)
- Managing fatigue in the workplace (National MS Society)

## Interviews

- Employment and Multiple Sclerosis: A guide to vocational exploration for OTs (MS Society Ireland- January 2018 and September 2018)
- Working with MS: Living well with MS (National MS Society)- Information and exercises

## Legal Advice

- Disability Law Service for MS: Free and confidential legal advice (https://dls.org.uk/)
- Get help with discrimination at work (Citizens Advice) (https://www.citizensadvice.org.uk/)
- <u>https://www.disabilityrightsuk.org/getting-advice</u>

## MS Symptoms

- Visible and Invisible symptoms in MS (MS Society)
- Memory and thinking (what is cognition, and what to expect)
- Living with the effects of MS booklet
- Tremor (what causes tremors and how to manage)
- Muscle spasms and stiffness
- Managing cognitive challenges in the workplace (National MS Society)

## Mood:

- Stress: What is stress, effects of stress and ways to manage stress.
- Anxiety: What is anxiety, coping with anxiety, Thinking errors.
- MS and your emotions: understanding and dealing with your feelings.
- Anger, laughter, and tears: understanding emotional outbursts in MS.

## **Reasonable Accommodations**

• Asking your employer for reasonable accommodations (Citizens Advice)

- Flexible working/ discrimination (Citizens Advice)
- Reasonable adjustments in the workplace, advice, and guidance (ACAS)
- Workplace adjustment agreement (MS Society & Business Disability Forum)
- Assistive Technology in the workplace (National MS Society)
- Let's be reasonable, disability equality in the workplace (UNISON Disability)
- Disability leave: Bargaining guide and model policy

## **Understanding MS**

- Explaining MS to others
- Living with the effects of MS
- Just diagnosed (MS Society)

## **Appendix H: Initial interview**

## **Initial Interview Participant with MS**

## **Demographic Information**

Gender:	Year of birth:		
Relationship Status:	Education:		
Job Title :	Weekly hours:		
Type of employment:	Ethnicity:		
Full-time / Part-time			
Type of employer:	Sizes of company:		
Voluntary/ private/ public			
	• Small (10-49 employees)		
	• medium (50-249 employees)		
	• large (>250 employees)		
Previous employment history:	Did you leave your previous job because		
	of MS?		
	yes/no		
	-		

## **MS** Characteristics

Years with MS:	Type MS:
Years with symptoms:	Medication for MS:
Other conditions:	

Of the following list of common MS symptoms, can you indicate which, if any, may cause or are currently causing difficulties for you at work?

Fatigue	Pain	Ш
Difficulty walking/ standing/ bending/ moving around	Urinary or bowel problems	
Weakness	Difficulties with vision	
Difficulty with memory, everyday thinking and concentration	Depression/ anxiety or other mood problems	
General MS worsening	controlling movement	
Difficulty with using your hands	Speech difficulties	

## **Work Characteristics**

What does your job entail?
Have you told your employer that you have MS?
Have you received any work modifications in your schedule or work
environment?

I wish to stay in my current work role	
I wish to explore alternative employment options	
I wish to change my working hours	
I am not currently considering work and/or educational options but may wish to do so in the future.	
None of the above	

## What do you see as your main challenges to remain at work?

# Understanding the barriers to job retention

Do you think any of the following will be a barrier to engaging in work?	yes	no	If yes, do you have any proposed solutions or supports already in place?
Performing independent activities of daily living:			
Having consistent energy levels and a sleep routine			

Do you think any of the following will be a barrier to engaging in work?	yes	no	If yes, do you have any proposed solutions or supports already in place?
Accessing work (e.g., driving, using public transport).			
Access within work e.g., being able to access the following:			
<ul> <li>The workplace building</li> <li>Your workspace within the building</li> <li>Accessing and using workplace equipment (e.g., computers)</li> <li>Toilets</li> <li>Communal areas (e.g., staff room, canteen).</li> </ul>			
Maintaining activities outside of work – (e.g., socialising, hobbies, family life, household skills).			
Other relevant activities:			

## GOALS

Set three SMART GOALS to achieve during the intervention:

GUIDE FOR SMART GOALS
Specific: Avoid vague statements, make the goals clear
Measurable (e.g., once a week, every day)
Achievable, be careful setting goals that are too ambitious
<b>Realistic:</b> It should be important for you and <b>relevant</b> for your
work
Timed: Timeframe for the goal

## Initial interview employer

Gender:	Ethnicity:
Education:	Job Title:
Type of employment:	Type of employer:
Full-time / Part-time	Voluntary/ private/ public
Years working with the person with	Sizes of the company:
MS:	<ul> <li>Small (10-49 employees)</li> <li>medium (50-249 employees)</li> <li>large (&gt;250 employees)</li> </ul>
Relationship with the tperson with MS	3:

- 1) Are you aware of what Multiple Sclerosis is, and the most common symptoms that the condition causes?
- 2) Do you have any experience supporting people with Multiple Sclerosis (MS) or other types of serious health conditions at work?

## Initial interview healthcare professional

Gender:	Ethnicity:
Education:	Job Title:
Type of employment:	Type of employer:
Full-time / Part-time	Voluntary/ private/ public
Years working with the person with MS:	<ul> <li>Sizes of the company:</li> <li>Small (10-49 employees)</li> <li>medium (50-249 employees)</li> <li>large (&gt;250 employees)</li> </ul>
Describe the relationship with the person v	L vith MS:

## **Appendix I: Post-intervention interviews**

## Post-Intervention Interview Guide for People with MS

## Experience during the programme

- 1. Can you tell me about your own experiences in participating in the programme?
- 2. Did the programme help you or not achieve the goals you set at the beginning?
- 3. Compared to before the programme, what has changed in your work environment or relationships?
- 4. Compared to before the programme, has your confidence in managing your MS symptoms at work changed?
- 5. Compared to before the programme, has your confidence to deal with employment issues changed?

## **Future Implementation**

- 6. We are planning to make this programme available for all people with MS and their employers. Before we do this, we need to refine the programme with the feedback of people with MS and employers. What can we do to improve it?
- 7. What would you consider the most important characteristics of this support to help people with MS?
- 8. If we were to roll out this programme, what other aspects should we take into consideration?

## **Post-Intervention Interview Guide for employers**

#### **Experience during the programme**

- 1. Can you tell me about your own experiences in participating in the programme?
- 2. Has the programme helped you identify or address the needs of your employee?
- 3. What did you find most useful/ least useful about the programme?

#### **Future Implementation**

- 4. We are planning to make this programme available for all people with MS and their employers. Before we do this, we may need to refine the programme with feedback from people with MS and their employers. In your view, what do we need to do to improve it?
- 5. What would you consider the most important characteristics of this support for employers?
- 6. If we were to roll out this programme, what should be considered forward?

## Post-Intervention Interview Guide for healthcare professionals

#### Experience with the programme

- 1. Can you tell me why you agreed to participate in this study?
- 2. What impact did the programme have on the person with MS at improving their work experience?

## **Future Implementation**

We are planning to make this programme available for all people with MS and their employers. Before we do this, we need to refine the programme with the feedback of other stakeholders. If we were to roll out this programme:

- 3. How should this type of support be available for people with MS?
- 4. What would you consider the most important characteristics of this support for people with MS?
- 5. From your experience, what might prevent this type of programme from working?

# Appendix J: Coding Matrix Case Study

Table 86 Coding matrix mapped to theoretical frameworks.

Nodes	Definition	Framework / Rationale
Intervention imple	mentation	
Intervention Characteristics	<ul> <li>Adaptability: Degree to which an intervention can be adapted.</li> <li>Evidence strength and quality: Stakeholders perception of the quality and validity of evidence supporting intervention.</li> <li>Complexity: Perceived difficulty of implementation.</li> </ul>	
Characteristics of individuals	<ul> <li>Knowledge and beliefs about the intervention: Individuals' attitudes toward and value placed on the intervention.</li> <li>Self-efficacy: Individual belief in their capabilities to execute courses of action to achieve implementation goals.</li> <li>Individual identification with organisation: A broad construct related to how individuals perceive the organization and their relationship and degree of commitment to that organization.</li> <li>Other personal attributes: Includes other personal traits such as tolerance of ambiguity, intellectual ability, motivation, competency.</li> </ul>	
Outer setting	<ul> <li>Patient needs and resources: The extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known by the organisation.</li> <li>Cosmopolitanism: The degree to which an organization is networked with other external organizations.</li> <li>External policies and incentives: Broad constructs that encompass external strategies to spread interventions, including policy and regulations.</li> </ul>	CIFR
Inner setting	<ul> <li>Networks and communications: The nature and quality of webs of social networks and formal and informal communications within an organization.</li> <li>Implementation climate: The absorptive capacity for change, shared receptivity of involved individuals to an intervention.</li> </ul>	
Process	<ul> <li>Planning: The degree to which a scheme or method of behaviour and tasks for implementing an intervention are developed in advance and the quality of those schemes or methods.</li> <li>Engaging: Attracting and involving appropriate individuals in the implementation and use of the intervention.</li> </ul>	

Nodes	Definition	Framework / Rationale
<ul> <li>Executing: Carrying out or accomplishing the implementation according to plan.</li> <li>Reflecting and evaluating: Quantitative and qualitative feedback about the progress and quality of implementation.</li> </ul>		
<ul> <li>Activities and Participation</li> <li>Mobility</li> <li>General tasks and demands.</li> <li>Relationships</li> <li>Work and Employment</li> <li>Transport to</li> </ul>	<ul> <li>Activity is the execution of a task or action and participation is involvement in a life situation.</li> <li>Mobility: Changing body position or transferring from one place to another.</li> <li>General tasks and demands: Carrying out tasks, organising routines and handling stress.</li> <li>Interpersonal interactions and relationships: Carrying out actions and tasks required for interacting with people.</li> <li>Work and employment: Engaging in all aspects of work (e.g. performing required tasks, attending work)</li> </ul>	ICF
work Body Functions	<ul> <li>work (e.g., performing required tasks, attending work on time, supervising others or being supervised)</li> <li>Transport to work: Using transportation to and from work.</li> <li>Body functions are the physiological functions of a body and body structures are anatomical parts of the body (e.g., organs).</li> </ul>	
<ul> <li>Energy and drive</li> <li>Memory</li> <li>Attention</li> <li>Emotions</li> <li>Pain</li> <li>Sleep</li> </ul>	<ul> <li>Energy and drive: Physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs.</li> <li>Memory: Specific mental functions of registering and storing information and retrieving it as needed.</li> <li>Attention: Specific mental functions of focusing on an external stimulus or internal experience for the required period.</li> <li>Emotions: Mental functions related to the feeling (e.g., fear, anxiety, joy).</li> <li>Pain: Unpleasant feelings indicating potential or actual damage to body structure.</li> <li>Sleep: Amount of sleep, sleep cycle, etc.</li> </ul>	ICF
Environmental Factors Products and technology Relationships Attitudes	<ul> <li>Physical, social, and attitudinal environment in which people live and conduct their lives.</li> <li>Products and technology: Equipment and technology in an individual's immediate environment (e.g., assistive technology for employment)</li> <li>Relationship with colleagues: Relationships with individuals at work who share demographic features.</li> </ul>	ICF

Nodes	Definition	Framework / Rationale
<ul> <li>Services, systems, and policies</li> <li>Personal Factors</li> <li>Acceptance</li> </ul>	<ul> <li>Relationship with employer: Relationship with individuals in a position of authority who have decision- making responsibility for others.</li> <li>Attitudes: Observable consequences of ideologies that influence the behaviour and relationships between individuals.</li> <li>Services, systems, and policies: Services, systems and policies designed according to established governments that meet individual's needs.</li> <li>Particular background of an individual's life and living and including the features of the individual that are not part of a health condition.</li> </ul>	
<ul><li>Profession</li><li>Experience</li></ul>	<ul> <li>Acceptance: Relates to the acceptance of the diagnosis and implications of having a chronic progressive condition.</li> <li>Profession: Characteristics of the job (e.g., office base, organisation's culture)</li> <li>Experience: Past experiences at work that influence behaviours and ideologies of an individual.</li> </ul>	ICF
Behaviour Compo	nents	
Opportunity	All the factors that lie outside the individual that make the behaviour possible or prompt it	
Capability	The individual's psychological and physical capacity to engage in the activity concerned. It includes having knowledge and skills.	
Motivation	Brain processes that energize and direct behaviour. It includes habitual processes, emotional responding, and analytical decision-making.	

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# Appendix K: Table of changes PBA

Table 87 Table of changes PBA

Table of changes PBA					
Negative Comments	Positive Comments	Possible Change	Reason for change	Agreed change	MoScoW*
3 months might not be sufficient for all people with MS		Add a follow-up session for those who need it at the end of the three months.	Improve support provided- Reported by several participants	Yes	Must have
	Including other professionals is beneficial to provide comprehensive support.				
Employers should not be involved at the beginning of the intervention, according to the relationship with the person with MS.		The initial interview should cover the relationship with employer to understand the best approach towards employer engagement	Avoid further issues with employer at work	Yes	Should have
	Monitoring progress through the sessions is beneficial to discuss what support did not work or how to progress.				
Some participants had difficulties thinking about goals in the initial interview; but they believe they are highly relevant for the intervention.		Flexibility setting intervention goals or modifying them according to progress made.	Supporting the person with MS to select intervention goals that match their needs and preferences	Yes	Must have

# Appendix L: Final intervention TIDieR

Table 88 presents the job retention VR intervention following TIDieR guidelines, refined with the knowledge gained from the case study.

Criteria	Description
Brief Name	Preventing Job Loss for People with MS
Why	<ul> <li>Rationale:</li> <li>People are in the prime working years of an adult when they are diagnosed with MS</li> <li>After 10 years with the condition, fewer than 50% of people with MS remain at work</li> <li>Approximately 90% of people with MS have work experience, however, they leave the workplace prematurely and need support to remain at work</li> <li>Theory:</li> <li>Biopsychosocial approach</li> <li>VR recommendations for people with long-term neurological conditions.</li> <li>Work disability prevention (Loisel Framework)</li> <li>Equality Act 2010</li> </ul>
What materials?	<ul> <li>Initial interview</li> <li>MS services</li> <li>Informational and educational resources</li> <li>Session summary letter/email after each appointment</li> <li>End of intervention package with top tips</li> </ul>
What procedures	<ul> <li>The process:</li> <li>Employed people with MS referred to intervention</li> <li>The first step involves a detailed assessment of the employment, MS characteristics and goal setting. The person with MS can involve their employer (HR or Occupational Health) in the intervention</li> <li>The person with MS can book sessions regularly according to their availability and needs during the three-month intervention</li> <li>The therapist sends a reminder the day before the session</li> <li>At the end of each session, the person with MS receives a summary email with topics discussed, next steps, and signposting to resources</li> </ul>

#### Table 88 TIDieR Final Intervention

Criteria	Description		
	• Goals can be refined as the intervention progresses, and there should be a frequent review of progress made		
	Person with MS:		
	<ul> <li>Initial interview</li> <li>Initial interview</li> <li>Three-month VR intervention with a menu of intervention components, such as cognition in MS, fatigue management, reasonable accommodations, understanding legal rights, education about MS, vocational exploration, the mood in MS, support with benefits and other work-related issues relevant to the person with MS</li> <li>Follow-up sessions for people with complex issues, if and when needed</li> <li>End of intervention package with relevant resources</li> <li>Employer:</li> <li>Initial interview to understand their knowledge and questions</li> </ul>		
	<ul> <li>about MS</li> <li>Three-month intervention addressing topics such as understanding MS, reasonable accommodations, and their legal responsibilities</li> </ul>		
Who provided?	<ul> <li>Psychologist and OT</li> <li>Extensive knowledge about MS, its symptoms, progression, and management of the condition</li> <li>Knowledge about employment law</li> <li>Knowledge about reasonable accommodations and management of workplace issues</li> </ul>		
How	<ul> <li>The sessions should be provided individually to ensure the content is tailored to the needs of the person</li> <li>Possibility of including line manager or HR in relevant sessions with the person with MS and therapist</li> </ul>		
Where	The intervention could be delivered face-to-face or remotely (e.g., telephone or teleconference) according to the preferences of the person.		
When and how much?	<ul> <li>Person with MS: The first step involves an initial interview         <ul> <li>(approximately 1 hour). According to the situation of the person with MS, they will need a different number of hours of support, ranging between 2-6 for newly diagnosed, up to 11 for those working yet worried, and up to 20 hours for those in a work crisis. The intervention time includes direct and indirect support.</li> </ul> </li> <li>Employer: The employer can complete an initial interview         <ul> <li>(approximately 30 minutes) and could receive up to 4 hours of support.</li> </ul> </li> </ul>		

Criteria	Description
Tailoring	The number, length, frequency, and content of the sessions will vary
Tanoring	according to the needs of the person with MS.
Modifications	There were no modifications to the intervention
Wioumcations	There were no mourications to the intervention.
How well?	The intervention content, sessions offered and received, and the
	number of people that complete the intervention can be assessed with
	a proforma to measure the intervention delivery.