Fatigue Management Training Evaluation

Prepared for the MS Society by ICF

March 2024

Contents

Acronyms and abbreviations

MS	Multiple Sclerosis
FACETS	Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle
Facilitators	Health professionals who have received FACETS training from MS Society
FACETS training	The training health professionals have received from MS Society
FACETS programme	The programme health professionals have delivered to patients with MS
OT	Occupational Therapist
CBT	Cognitive Behavioural Therapy

Background and methodology

Background

The MS Society provides facilitator training courses for health care professionals (HCPs) to equip them with the knowledge and skills to deliver the FACETS (Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to lifeStyle) programme. FACETS is a group-based fatigue management programme for people with multiple sclerosis (MS) to support them to self-manage fatigue.

- Prior to the Covid-19 pandemic, the FACETS facilitator training course was delivered to health professionals (hereafter referred to as ‘facilitators’) in-person. The training was moved online after the pandemic (from 2021 onwards).
- The FACETS facilitator training course has always been primarily funded by National Health Services Trusts professional development budgets, and when this hasn’t been possible, local groups (consisting of volunteers that provide support services for people with MS) have funded the training for facilitators.

ICF were commissioned to evaluate the FACETS facilitators’ training course provided by the MS Society. The evaluation aimed to investigate the following research questions:

1. Is the delivery of the FACETS facilitator training course suitable and effective for facilitators supporting people with MS?
2. How, and to what extent, are facilitators undertaking the FACETS facilitator training course disseminating the learning to people with MS?
3. What is the impact of the FACETS facilitator training course on facilitators supporting people with MS, and people with MS?
    - How does the training impact the confidence and ability of facilitators to provide advice to people with MS on fatigue management?
    - How does the training impact the ability of people with MS to self-manage their fatigue?

The FACETS facilitator training course

- The FACETS facilitator training course intends to equip facilitators with the knowledge and skills to deliver the FACETS programme to support their patients with MS to self-manage their fatigue.
- According to the FACETS Fatigue management programme Facilitator manual*, FACETS programmes are designed for in-person delivery to people with MS through six sessions, covering topics relating to fatigue management:
  - Session 1: What MS-related fatigue is: Provides a general introduction to the programme, noting expectations, and includes an icebreaker. An introduction to MS-related fatigue is given, including the types of fatigue, contributing factors and a conceptual map/model of fatigue in MS.
  - Session 2: Opening an energy account: Covers functions, barriers and techniques for using available energy effectively. Includes relaxation types and techniques, a breathing exercise and sleep hygiene principles.
  - Session 3: Budgeting energy: Considers types of activity and how to balance activity and rest. It considers how to manage fatigue using a toolbox approach, which involves delegating, prioritising, pacing, grading (i.e. considering how to reduce the impact of an activity) and organisation and planning ahead. It also considers lifestyle factors and how to set realistic goals.
  - Session 4: Stress and the cognitive behavioural model: Covers the stress response (fight-or-flight), ways of coping with stress, and introduces the cognitive behavioural model.
  - Session 5: Putting unhelpful thoughts on trial: Provides information on unhelpful thought patterns and how to challenge unhelpful thoughts.
  - Session 6: Taking the programme forward: The concluding session introduces the ‘force field’ (i.e. things that help or hinder fatigue management). It provides an opportunity to revisit programme themes, and introduces a ‘keeping on track’ planner to help patients implement their learning beyond the programme.

*MS Society (n.d.) FACETS Fatigue management programme Facilitator Manual.

Methodology

The evaluation comprised of a review of the FACETS training manual, two surveys and two qualitative interviews carried out between November 2023 and February 2024.

Qualitative interviews

- Undertaken with two facilitators who had completed the FACETS facilitator training course.
- Focused on gathering detailed information about their experience of FACETS facilitator training course delivery, their own delivery of FACETS programmes to people with MS, and outcomes for themselves and their patients.
- Additionally, one interviewee provided reflections from colleagues who had also completed the FACETS facilitator training course since June 2021. They were asked to distinguish between her own views and the views of her colleagues during the interview.

Interviewee characteristics

- Interviewees had different roles in different locations: one was an allied health professional working for the NHS in England, one was a Community Worker for a charitable organisation in Ireland.
- However, they both worked with people with MS on a daily basis, providing one-to-one support either in their workplace, online, or at the homes of patients.

Surveys

Surveys were disseminated to facilitators, who were asked to disseminate the survey for people with MS to their patients that had attended a FACETS programme.

Facilitators survey

- Targeting facilitators who had completed the FACETS training course between June 2021 & October 2023.
- Gathered information on motivations for undertaking the training, perceptions of the training, and outcomes for themselves and their patients.
- In total, 14 facilitators responded to the survey, with a 14% response rate.

Survey for people with MS

- Targeting the patients of facilitators who had completed a FACETS programme.
- Aimed to gather information on their experience of the programme and its impact on their ability to manage fatigue.
- However, there were no responses to this survey. This is discussed further under limitations.

Survey respondent characteristics

Job roles: There were a mix of job roles among the respondents: 5 were MS Specialist Nurses, 5 were Community workers/ Case workers, 3 were Occupational Therapists (OTs) and 1 was a Physiotherapist.

Location: Most were from England (8 of 14) or Ireland (5 of 14), with one respondent based in Wales.

Organisation: Most (9 of 14) worked in national health services, while 5 (all Community workers/Case workers) were employed in the voluntary sector, e.g. MS therapy centre.

Experience of supporting MS patients with fatigue (prior to FACETS facilitator training course):

- While the majority had provided some level of fatigue management support, only 2 of the survey respondents had previously delivered fatigue management training and 3 had specifically arranged one-to-one sessions on fatigue management.
- Other types of support that were more frequently provided by facilitators included ad-hoc fatigue management support during appointments (9 of 14), the provision of information leaflets on fatigue and fatigue management (7 of 14) and referrals to colleagues (4 of 14).

Completion of FACETS facilitator training course:

- There were respondents from:
  - 2021: 5 of 14 respondents from the June cohort, and 2 from the December cohort.
  - 2022: 1 respondent from the July cohort, and 5 from the December cohort.
  - 2023: 1 respondent from the October cohort.

Limitations of the evaluation

There were two key limitations to the research carried out to inform the evaluation.

- Low survey response:
  - No responses were received to the survey for people with MS & the response rate for the facilitators survey was low.
  - Possible explanations were difficulties for facilitators in obtaining consent to disseminate the survey from the data protection teams of their NHS Trusts, the fieldwork timeframes (which ran over the festive period) and the period between facilitators completing the FACETS facilitator training course and subsequently being asked to take part in the survey on their experience (as cohorts since 2021 were invited).
  - As a result, this report can only provide indications about the impact of FACETS for patients with MS based on the perceptions of facilitators.
  - Likewise, findings should not be assumed to be representative of all FACETS facilitators.

- Time between completing the FACETS facilitator training course and taking part in the research:
  - Both interviewees and nearly all (13 of 14) survey respondents completed the FACETS facilitator training course at least 11 months prior to engaging in the evaluation.
  - As such, some research participants may have struggled to recollect specific aspects of the FACETS facilitator training course.
  - This was seen during the interviews, where participants' reflections on the delivery of the FACETS facilitator training course were sometimes limited as they struggled to recall it in its entirety.

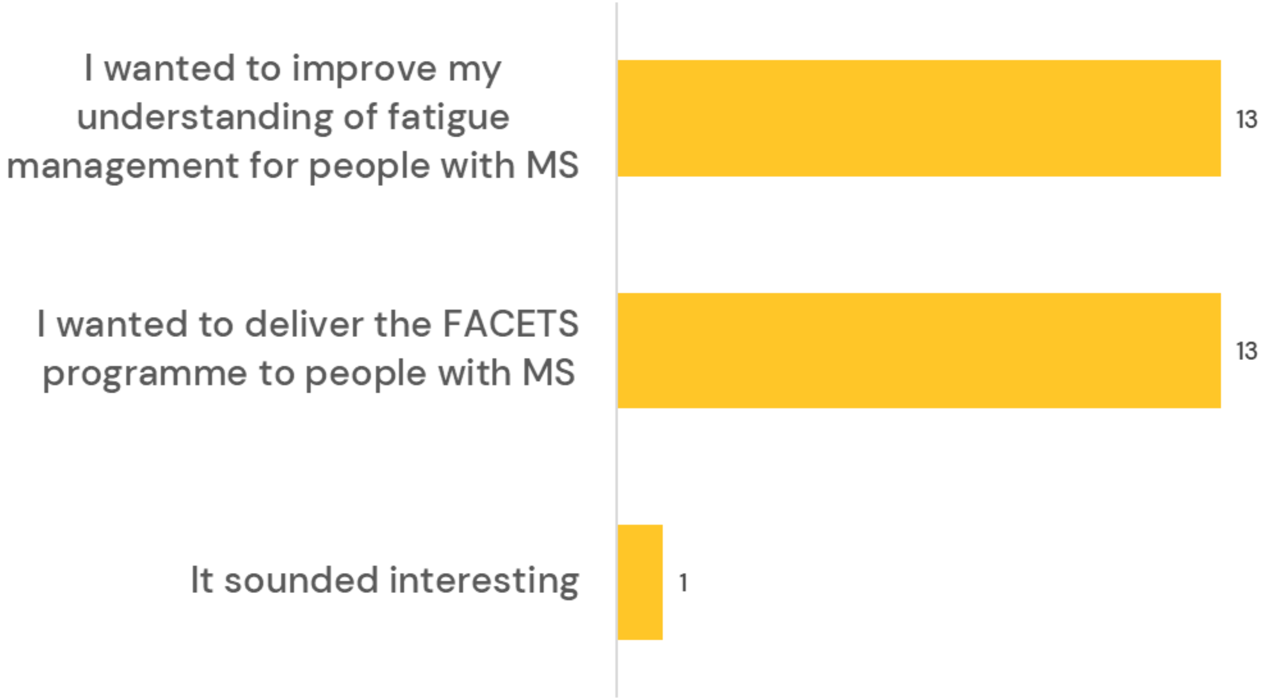
Findings: Training delivery

Motivations for participating in the FACETS facilitator training course

The two main reasons facilitators took part in the FACETS facilitator training course were:

- To improve their understanding of fatigue management for people with MS; and,
- To deliver the FACETS programme to people with MS.

What are the main reasons* you decided to undertake the MS Society training to become a FACETS facilitator? *(n)*



Source: Facilitators survey (n=14)

**Respondents were asked to pick up to two of the main reasons for undertaking the training.*

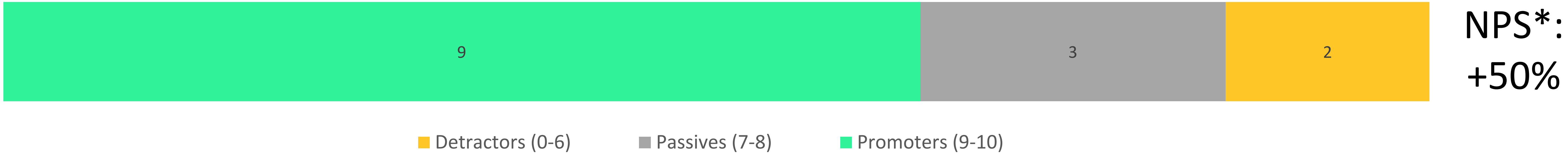
Interviewees described an interest in gaining the knowledge required to deliver FACETS programmes to people with MS. They also commented on the pressures experienced by national health services supporting people with MS:

- After repeating similar fatigue management advice to patients with MS in one-to-one sessions, an interviewee felt inclined to complete the FACETS facilitator training course in order to provide fatigue management support in a group setting.
- Another interviewee reflected on the limited capacity of OTs, with MS patients waiting around three months to be seen, and only one fatigue management programme being offered by local OTs annually. It was felt more local, structured programmes were necessary.

The training was well-received by facilitators overall

Overall, facilitators were happy with the FACETS facilitator training course received. Most survey respondents (9 of 14) were highly likely to recommend the FACETS training to other health professionals rating it between 9-10. The overall NPS* score was positive, at +50%.

On a scale of 0 to 10, where 0 is not at all and 10 is very likely, how likely are you to recommend the FACETS facilitator training to other health professionals supporting people with MS? *(n)*



Source: Facilitators survey (n=14)

Interviewees similarly received the programme well, noting that the FACETS facilitator training course met their expectations.

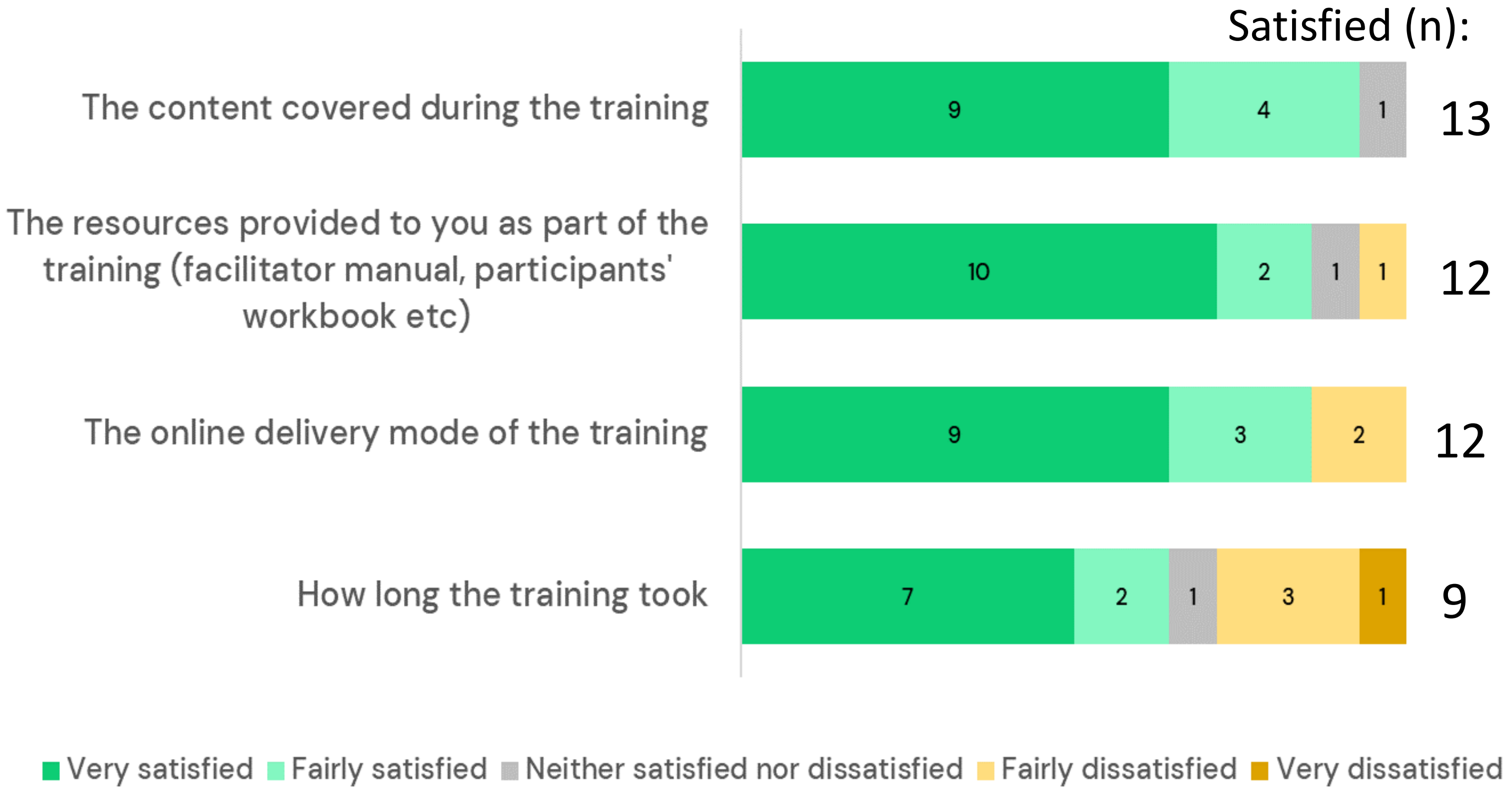
- One interviewee was happy with the training received, although noted that she would have liked to receive resources ahead of the training (see Slide 16).
- However, the other interviewee stated that the fast pace of the training day left their colleagues feeling less enthusiastic about the training overall (see Slide 16).

NPS (Net Promoter Score) provides a metric to gauge overall satisfaction and brand engagement. It can range from -100 to +100. It is calculated by subtracting the proportion of **detractors (those providing an answer of 6 or below) from the proportion of **promotors** (those providing an answer of 9 or 10). Nevertheless, caution should be taken in interpreting these results due to the very small base size.*

Facilitator satisfaction with training components was high

Most facilitators were satisfied with the FACETS facilitator training content, the resources provided, the online delivery mode and the length of the training.

To what extent were you satisfied or dissatisfied with the following aspects of the delivery of the FACETS facilitator training? *(n)*



Source: Facilitators survey (n=14)

Interviews helped to explain the high levels of satisfaction with most training components:

- The content exposed facilitators to new information: one interviewee learnt about the nuances between primary and secondary fatigue, and the other had not considered Cognitive Behavioural Therapy (CBT) in the context of fatigue management before.
- The resources were detailed and useful for recapping the training content before delivering a FACETS programme.
- The online delivery mode was accessible and convenient - attending in-person training was thought to be impractical due to the expense and additional travel time required. The online breakout room function also gave facilitators the opportunity to discuss how they planned to deliver the training.

Satisfaction with the length of the training was slightly lower (4 of 14 were dissatisfied). Some felt the pace of the training was too fast, and the training should be spread across more than one day (see Slide 16).

Interviewed facilitators also praised other areas of FACETS facilitator training course delivery

Trainers were knowledgeable and engaging, providing expertise on how to adapt the training for online delivery. Facilitators felt comfortable asking questions and enjoyed having the opportunity to discuss potential scenarios with trainers.

The programme content being specific to MS fatigue was deemed to be important, given that fatigue can look considerably different for someone with MS compared to other neurological conditions, due to it being a life-long condition.

The evidence-base for the training was felt to be useful; facilitators were able to share the publicly available evidence that supports the FACETS content with patients, enhancing the programme's credibility.

“[The trainers] were very knowledgeable and understood the content, and it was very clear from the training I attended that they were experienced in delivering the programme themselves and they were able to answer questions around ‘what if this happened’ and ‘what if that happened’.”

(Interviewee)

“I think having the evidence base behind it is a massive bonus, and [the programme] being MS-specific – [attendees] feel someone actually took the time [to create a programme suited to them], which is important.”

(Interviewee)

Several areas for improvement in FACETS facilitator training course delivery were identified

Suggestions were made by both interviewees and survey respondents:

- Ensuring messaging around the FACTETS facilitator training course is very explicit in detailing who can attend the training, as there was some confusion around whether professionals in the voluntary sector who were not OTs could participate.
- Explicitly encouraging facilitators to adapt the FACETS programme to their patients' specific needs.
- Only accepting people on to the training that will receive the resources in good time, so everyone can follow along with the materials during the training to consolidate their learning.
- Ensuring all materials are quality-checked before they are disseminated to facilitators, to avoid some elements (such as the activities and homework) being missing.
- Delivering the training in shorter sessions across 2-3 days, as some research participants felt a considerable amount of content was covered in one day, which was hard to engage with online (which can feel more taxing than in-person training).
- Enabling facilitators to see the impact of FACETS programmes by providing them with outcomes measures, and tools they can disseminate to programme attendees to gauge impact (such as questionnaires). This would provide a standardised approach to measuring programme effectiveness, and MS Society could request this feedback to also have a better understanding of the impact FACETS programme delivery is having on patients.

“We also did not get the material in time before [the] course started so I wasn't able to follow along.”
(Survey respondent – Community worker/ Case worker)

“There was an awful lot crammed into one day, and that was particularly challenging because you're at a computer and I suppose so that was my recollection. And when [I talked with my colleagues] about that, everyone kind of compared with that, that really was probably too much in one day… It would be better if there was less in one day, and maybe over two days or like two shorter sessions, because really a full day's training at a desk looking at a screen probably isn’t [the best way to deliver all the content].”
(Interviewee)

“It was a very intense day, with lots of information. If it was spread over two days it might be easier to retain all of the information and go over things again.”
(Survey respondent – MS Specialist Nurse)

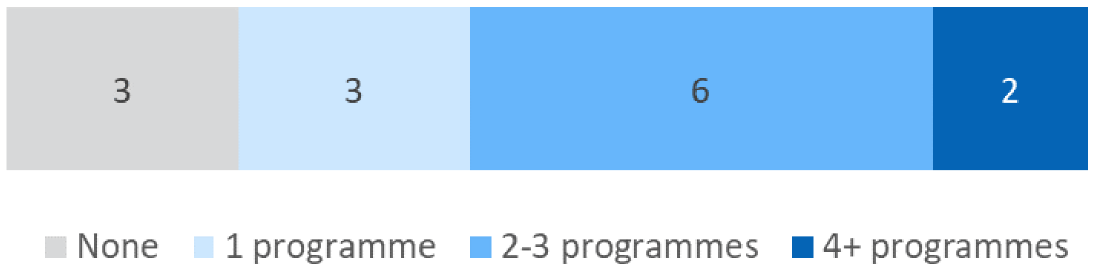
Findings: Outcomes and impacts

Most facilitators had delivered FACETS programmes to people with MS since completing the training

Almost everyone participating in the evaluation (both interviewees, and the large majority (11 of 14) survey respondents) reported having delivered at least one FACETS programme to people with MS.

- The number of sessions they had delivered varied - from just one programme, up to a total of six programmes. Among survey respondents, an average of 2-3 programmes had been delivered by each facilitator.

Since completing the training, how many FACETS programmes have you run for people with MS? *(n)*



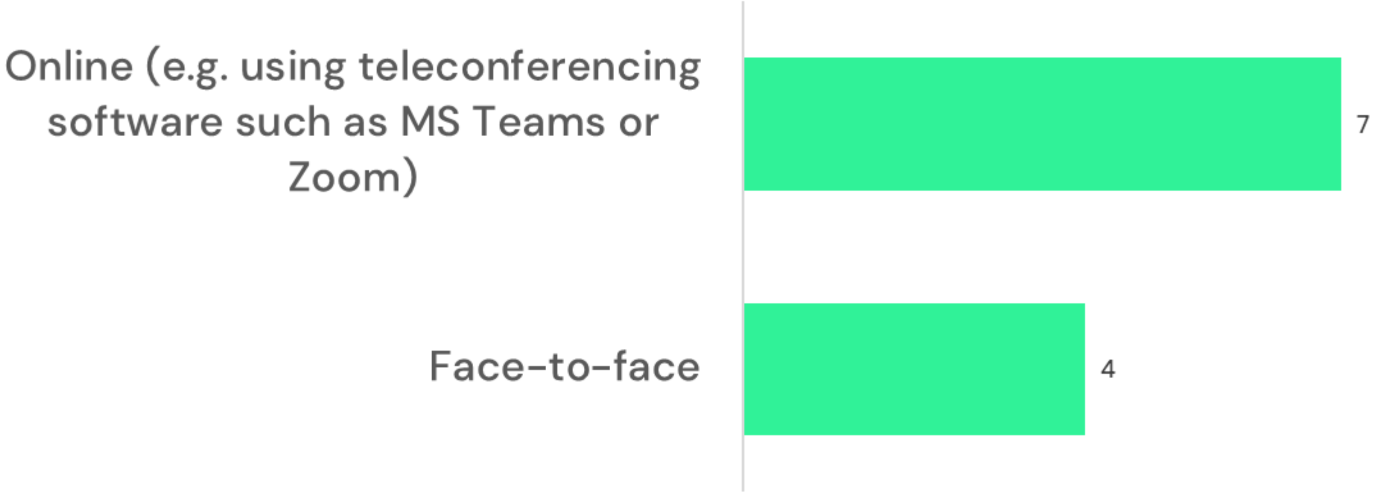
Source: Facilitators survey (n=14)

- Average patient attendance to each *programme* (as reported in the survey) ranged from 5 attendees up to as many as 15. On average (accounting for all the facilitators that reporting having delivered programmes) each facilitator had reached around 18 MS patients.
- In total, survey respondents had facilitated FACETS programmes for 199 people with MS.

The 3 facilitators that had not delivered any FACETS programmes said they intended to do so in the future. However, they had all completed the training some time ago (in 2022 or before). They did not specify why they had been unable to deliver any programmes to date.

Facilitators were more likely to deliver the FACETS programme online

How have you delivered the FACETS programme to people with MS? *(n)*



Source: Facilitators survey (n=11)

- There was a mixture of online and face-to-face delivery reported by survey respondents. Facilitators were slightly more likely to deliver sessions online (7 of 11) compared to face-to-face (4 of 11).
- The delivery modes were generally mixed between interviewees of different roles and locations – with the exception that all 5 of the respondents based in Ireland delivered the training online.
- Interestingly, no one reported using a hybrid delivery approach (combining online and face-to-face delivery).

- Programmes took place online for convenience for people with MS, but also facilitators. Online sessions were accessible for patients, and avoided the need to travel to risky hospital settings where the likelihood of contracting a contagious illness would be heightened (given that some people with MS have compromised immune systems).
- Online sessions also allowed a level of anonymity to be achieved that would not be possible with face-to-face sessions.

“Most of our programmes [including the FACETS programme] are now online and it's really around convenience for participants. They don't have to deal with transport. They don't have to deal as much with their symptoms to get themselves into building. It's one of those sorts of issues that are that are kind of well-known at this stage. Those are the barriers and online just seems to circumvent them really.”
(Interviewee)

“I feel I would prefer to deliver in-person but it was appreciated by participants that they could do it online from home. I did an evening course delivery and that also worked well for participants.”
(Survey respondent – Community worker/ Case worker)

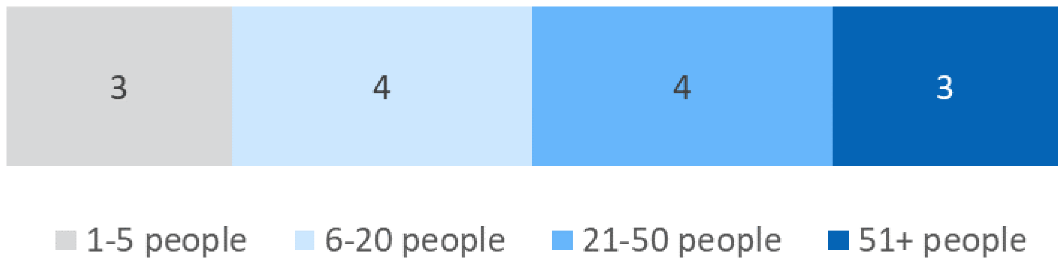
“Being online, there's a level of anonymity like because you're not in a room with people. That has opened out this programme to a whole cohort of people that I don't think would have attended. They would have been a lot less likely to engage, so some of the feedback has been interesting from that point of view.”
(Interviewee)

Facilitators were using FACETS principles to support people with MS in settings other than the FACETS programmes

Everyone participating in the evaluation (all survey respondents and both interviewees) had used the FACETS principles in one-to-one discussions with people outside of the FACETS programme delivery.

- Evidence suggested facilitators were taking away knowledge from the FACETS facilitator training course and using it in interactions with people with MS: the 14 survey respondents had reportedly used the FACETS principles in one-to-one discussions with approximately 561 people with MS.
- Responses ranged significantly between participants, however, with some using the principles with a much larger number of people than others (ranging from 3 people for one facilitator, up to 200 people for another).

Approximately how many people with MS have you spoken to on a one-to-one basis using FACETS principles? *(n)*



Source: Facilitators survey (n=14)

- Both interviewees used the FACETS concepts to support people with MS who struggled to attend FACETS programmes on a one-to-one basis. These conversations were described as being unstructured, with facilitators bringing in relevant ideas where they thought the individual could benefit, based on the fatigue-related challenges they were experiencing.

"For me, it definitely improved my knowledge and my interactions with people on a one-to-one basis outside of delivering group programmes … I recently did a home visit with an OT and because I was going to end up doing the form filling for adaptation grants and stuff for a bathroom, for a gentleman with primary progressive MS. When the OT was doing the home assessment and we were all in the bathroom, I asked some questions around, 'do you find that your fatigue is triggered when you've had you have a hot shower', etcetera. I asked some of those more pointed questions, which the OT hadn't asked, but when I asked them, [the OT said], 'oh, yeah' - she hadn't thought of it, really. So from my point of view, it was a real value add to the to the interaction, and the overall kind of experience of the client."

(Interviewee)

Facilitators experienced some challenges when delivering the FACETS programmes themselves (1)

When delivering the FACETS programmes to patients with MS, some challenges were identified. Some facilitators found ways to overcome these challenges.

Programme attendance was a challenge, with some patients being unable to complete the programme due to relapsing and struggling with MS symptoms.

According to one research participant, some patients would drop out during the 2 hour sessions, so they have condensed the sessions they deliver to 90 minutes.

A research participant found that some patients were unable to receive leave from their employer for all 6 sessions, so they condensed the programme into 5 sessions (combining the first and second session).

Staffing pressures resulted in facilitators having limited time to deliver the programme, especially due to the time needed to prepare for the sessions (e.g. printing and sending out materials to participants).

One research participant has relied on support from their administration colleagues and MS Society staff to deliver the sessions, due to being the only person to have attended the FACETS facilitator training course from their organisation.

One research participant will no longer be delivering the programme due to a colleague leaving (see Slide 36).

Delivering the programme online was sometimes difficult, with facilitators trying to simultaneously manage discussions and the chat box while presenting. Some patients appeared disengaged online, especially as a result of some of programme activities not working well when delivered online (such as the Session 6 Bingo activity). Facilitators who had dated IT equipment also found it was unsuitable for online programme delivery.

Facilitators experienced some challenges when delivering the FACETS programmes (2)

The examples used were not relatable to all patients with MS, and appear outdated.	One organisation were considering developing new case studies for wheelchair users as they could not relate to the examples.
The homework diaries are not accessible for some patients with upper limb difficulties.	A research participant has been in discussions with a FACETS training trainer about the creation of a digital toolkit or app to complete homework, which patients can use on their devices.
Some patients would like more time to engage with one another and check-in after the programme ends.	To give patients an opportunity to reflect and consider progress, one interviewee started to facilitate a 30-minute follow-up session for each cohort two months after delivering a programme.
When patients introduce themselves, they often start having discussions which can take time away from the content in Session 1.	A research participant is considering adding an introductory session (Session 0) to their programme delivery.
Some experience is required in managing conversations when facilitating the session.	One organisation matched colleagues delivering the programme based on their level of experience (matching colleagues with more facilitating experience with those who have less) as they felt learning how to be authentic while facilitating was a necessary skill for delivering the FACETS programme.

Patients having limited prior awareness of what the programme would involve (such as the reflection work and emotive topics covered) due to facilitators not realising the importance of patients receiving a brief overview of what to expect of the programme beforehand.

"I think that to be able to deliver this programme in person would be the idea however due to resources, funding, accessibility and time commitments and constrains for participants, online is a valuable tool to be adapted. However the management of a group online when dealing with emotive topics facilitators need to be able to do this online. I think your facilitating skills are very important in supporting and delivering the information so people can process at there own time. Cognition at times was a real barrier to managing the homework tasks for participants."

*(*Survey respondent – Community worker/ case worker)

"My ability to deliver a FACETS programme in my workplace has been limited by staffing pressure. I find it frustrating that we aren't able to deliver the service we would like to because of the current caseload / capacity issues which have been ongoing since the pandemic."

(Survey respondent – Physiotherapist)

"I have emailed multiple times to request alternative solutions for patients that have upper limb difficulties and are unable to fill out the booklets for homework but have had no response. It would be good if you could provide electronic versions of the participant workbook that those with upper limb difficulties can complete on their devices if they can't use a pen."

(Survey respondent – OT)

"Resource Book could be updated with newer examples. feel some of booklet is out dated."

(Survey respondent – Community worker/ case worker)

"I think there needs to be a notable mention in the training of prep for pwMS, they need to be ready for this course and the reflection/work it requires + understanding it may bring up strong emotions."

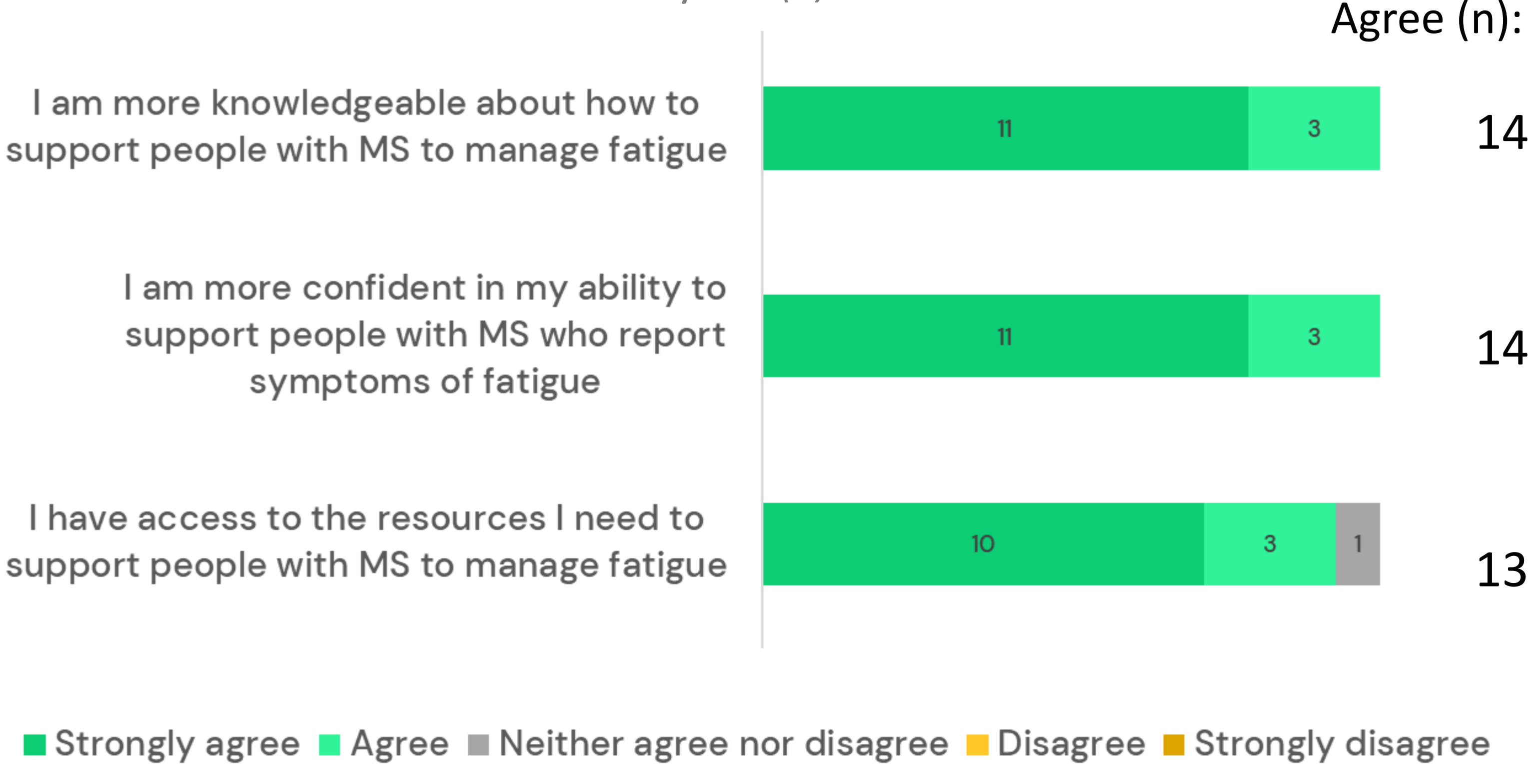
(Survey respondent – Community worker/ Case worker)

The FACETS facilitator training course offered various benefits for facilitators

Facilitators were very positive about the benefits the FACETS facilitator training course had on their ability to support people with MS to manage fatigue.

- All respondents agreed they were more knowledgeable in how to support people with MS to manage their fatigue, and they felt more confident in their ability to support people with fatigue.
- Nearly all respondents (13) agreed they had access to the resources needed to support people with MS to manage fatigue.

To what extent do you agree or disagree with the following statements about the impact that undertaking the FACETS facilitator training had on you? *(n)*



Source: Facilitators survey (n=14)

The experiences of interviewees help to explain the benefit FACETS training provides to facilitators

Both interviewees had the knowledge to deliver a standardised, structured programme to help people with MS manage fatigue. For one interviewee, the training had improved their understanding of how people with MS experience fatigue and the possibilities to manage it. They felt the FACETS facilitator training course acted as a “toolkit” which they could use with all MS patient struggling with fatigue.

The FACETS facilitator training course also allowed facilitators to support multiple patients struggling with fatigue simultaneously through delivering the FACETS programme. This was especially useful for one interviewee with a high case load, who would have previously spent considerable time repeating the same information to different MS patients in one-to-one discussions.

One interviewee also felt more confident to engage with material on fatigue management.

Sustainability of the impacts

Both interviewees felt the benefits for them as professionals would be sustained, as long as they continue to deliver the FACETS programmes. One interviewee felt facilitators would need to keep up-to-date with new developments in the field relating to fatigue management (such as the use of technology to manage fatigue, including apps).

“It’s improved [my] understanding of a symptom [fatigue] that the vast majority of people with MS have… I think it’s really important. It’s an important programme, to 1) be aware of, but 2) if you work with people with MS, you really need to have a good understanding of the impact of fatigue, but also of the possibilities to manage it. I think we all have an obligation to really [understand fatigue] and be asking those questions as standard as opposed to waiting for the client to [ask for support] – we need to be proactive around that. I think the programme helps as part of a toolkit if you like, to approaching those kind of interactions.”
(Interviewee)

“Really great programme and course. Am really enjoying delivering the course - have learnt a lot about fatigue whilst delivering it - both from course material and from group participants.”
(Survey respondent - OT)

The FACETS facilitator training course provided benefits to the organisations employing facilitators too

Both interviewees felt their organisation had benefitted from their participation in the FACETS training, and consequent delivery of the FACETS programme:

- Delivering the FACETS programme had improved the organisation's profile according to an individual working for an organisation known for supporting people with MS.
- Facilitators' colleagues appreciated being able to refer MS patients to an MS-specific internal programme for fatigue management. One research participants' previous fatigue management support offer consisted of providing patients with an extensive fatigue management booklet, which could be overwhelming for patients, and difficult for people struggling with fatigue to engage with.

> *"I think it's certainly looked good for the organisation and it's improved our profile for sure."*
> (Interviewee)

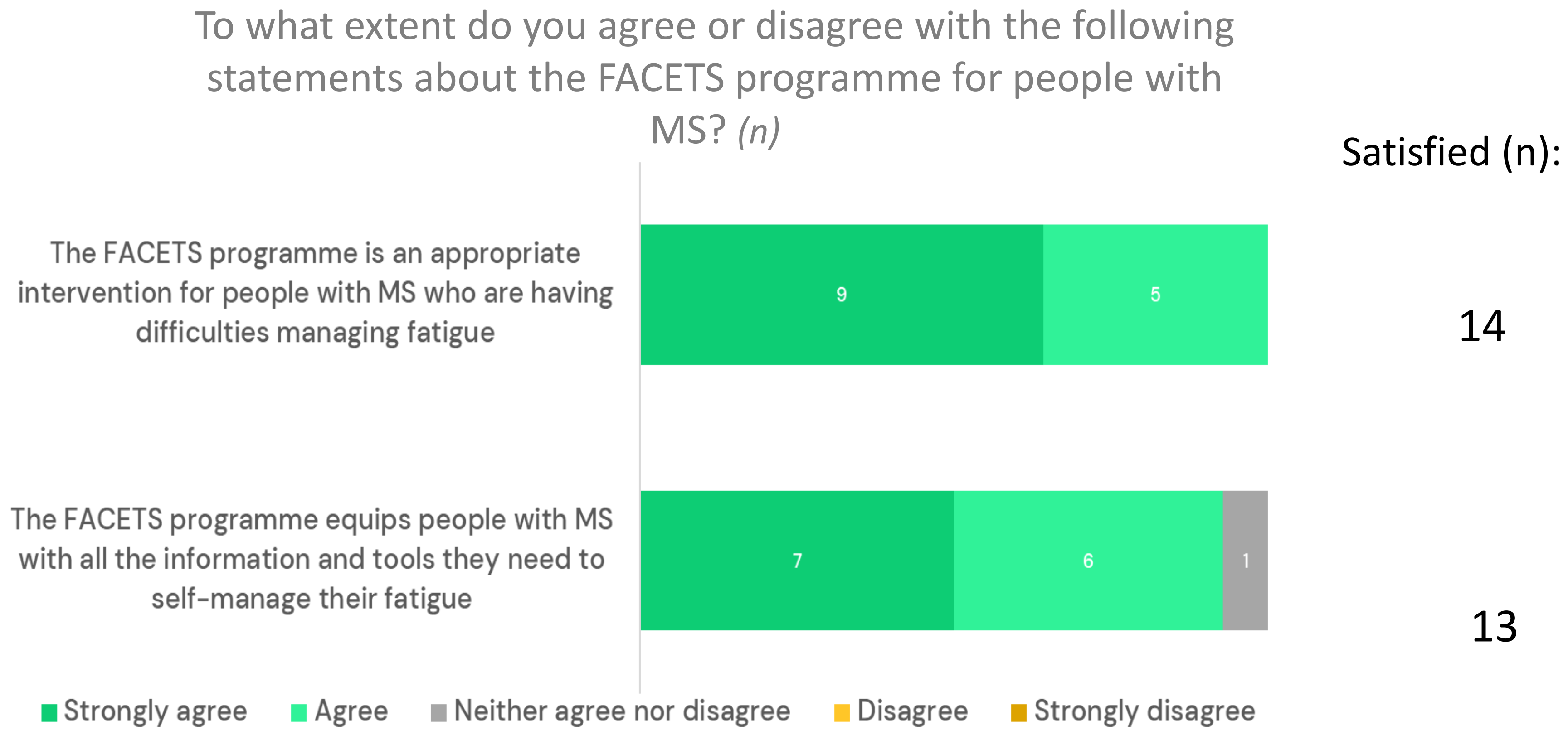
What would have happened without the FACETS facilitator training course?

Without the training, the two interviewees would not be providing specific fatigue management training:

- One interviewee would still be referring patients with MS to a wider fatigue management course for all neurological conditions (which included content that wasn't always relevant to MS patients); and,
- One interviewee would have continued providing more generic regional training for chronic conditions, which included a section on fatigue management.

FACETS programmes were seen as a valuable intervention for people with MS

- All survey respondents and interviewees agreed that the FACETS programme is an appropriate intervention for people with MS who are having difficulties managing fatigue.
- There was also a high level of agreement that FACETS programmes equipped people with MS with the information and tools they needed to self-manage their fatigue (13 of 14). Interviewees similarly observed that patients with MS gained tools and tips that assisted in managing fatigue, and gave them the confidence to implement these tools.



Source: Facilitators survey (n=14)

Interviewees identified other benefits for people with MS attending FACETS programmes too

Patients received peer support from others in the group, and appreciated the opportunity to connect with and confide in others with similar challenges. Patients had retained these connections after the programmes and formed support networks, keeping each other accountable and providing advice on managing fatigue.

FACETS programmes were felt to support patients' mental health: one interviewee noted peer support received through the programme helped in reducing isolation, while the other commented on the benefits of the tools discussed during the programme in helping patients to contextualise their worries and prevent their mental health from declining (including breathing tools to help with relaxing, and techniques to help with prioritising).

Patients appeared to recognise the importance of obtaining support to manage fatigue after the programmes, and felt confident to articulate their needs for support, to others, including their employers (see Slide 34).

Sustainability of the impacts

Both interviewees felt the sustainability of impacts for patients with MS would be dependent on whether learning had been incorporated routinely into their lives. While one interviewee had facilitated follow-up sessions after their FACETS programmes to encourage respondents to stay in touch and remain accountable, the other interviewee felt refresher sessions may also encourage the implementation of learning to be sustained.

"For a lot of people that we work with, they're used to either minimising their issues, masking their issues and trying to just get on with it and what that peer interaction and support does is it allows people to be themselves and to show their real selves. I think the impact around quality of life in that regard is well, it's very difficult to measure, but we hear all the time how important it is and this is one of the tools in which we can allow that to happen in a way that's structured."

(Interviewee)

"We have found one of the benefits the attendees of our FACETS course have found, is meeting other people with MS and realising they are not alone. They can learn from each other and have made friendships that they keep after the course has finished."

(Survey respondent - MS Specialist Nurse)

"People find being in a group really beneficial and find being able to talk to each other about their experiences [is] very helpful. One group now meet for coffee every month and support each other."

(Survey respondent - MS Specialist Nurse)

Case studies: patients managing their fatigue to enable them to work

A patient learnt to manage her fatigue, enabling her to obtain a part-time job

An interviewee was working with a female patient who was new to the area and was suspected to have MS (although the patient was reluctant to accept it). She was isolated, rarely leaving her home, and was struggling with fatigue. The patient also struggled to focus and sleep due to feeling overwhelmed.

The symptoms described by the patient were very similar to those experienced by people with MS, so the facilitator invited the patient to a FACETS programme. Despite not believing she had MS, the patient attended the sessions and completed the programme.

During a follow-up session after the programme with all programme attendees, the patient announced that she had secured a part-time job. After learning about how to manage fatigue, the patient recognised fatigue management as a priority in her day-to-day life. She considered when she had most energy, and how she wanted to spend that time, and so decided to get a job that would be allow her to rest when needed. The job allowed her to work 9am-12pm, giving her time to rest in the afternoon.

The facilitator felt the patient's outlook on life had changed, and she was finally prioritising her physical and mental health: *"Absolutely a different lady – being positive, planning holidays… actually following all of the FACETS principles."*

A patient returning to work after an MS relapse adjusted her working arrangements

A female patient with relapsing-remitting MS was on sick-leave after experiencing a relapse, which caused her to be very unwell. The facilitator invited her to attend the FACETS programme, which was taking place while the patient was on sick-leave, to provide her with tools for managing her fatigue when going back to work.

The facilitator also had a one-to-one session with the patient to discuss how she could implement the learning from the programme when returning to work.

When attending a follow-up session after the programme, the patient described all the ways they had actively tried to manage their fatigue at work. Specifically, she discussed her needs with her employer, and they agreed on some reasonable adjustments to support her ability to work, such as changing her schedule to work around her changing energy levels and allowing her to take necessary breaks. The patient appeared much more positive about her work-life balance as a result of the changes made.

Case studies: patients managing their energy when completing day-to-day tasks

A patient implemented pacing to avoid fatigue

One patient with Secondary Progressive MS was struggling to manage their fatigue. She has been unwell for a considerable amount of time, and the facilitator had been supporting her to generally manage her MS.

The patient attended a FACETS programme delivered by the facilitator to support this process.

At the time of the interview, the facilitator had recently visited the patient, and found she was doing "really well".

The improvements were in-part attributed to her attendance at the FACETS programme, as the patient remembered different techniques from the programme and had started to integrate these into her daily life. Specifically, she had implemented learning around pacing, giving the example that she would only now hoover one room at a time, to avoid becoming fatigued.

A patient started conserving their energy

A patient with Secondary Progressive MS was struggling to manage his fatigue day-to-day. He had a scooter to aid his mobility, which he was reluctant to use.

The patient attended a FACETS programme delivered by one of the facilitator's colleagues.

After attending the training, the patient attended the facilitator's office to give an update on his progress. Through attending the programme, he learnt the importance of conserving energy, and so had used his scooter that day to go shopping. He said he had finally 'bit the bullet' and used his scooter to ensure he would have energy to do something with his wife that afternoon.

Most facilitators planned to deliver FACETS programmes to people with MS in the future

- Of the 14 survey respondents, 12 planned to deliver FACETS programmes in the future.

Both interviewees also planned to deliver FACETS programmes in the future, given the value they had seen from delivering previous FACETS programmes.

> *"It's been a really positive development [to the organisation's service offers]."*
> (Interviewee)

> *"I think it's a really useful starting point for people with MS who are having difficulties managing fatigue."*
> (Interviewee)

Plans for future delivery

- One interviewee plans to continue delivering FACETS programmes on a periodic basis, including five sessions to cover the programme content, and one follow-up session two months after the FACETS programme for patients to reflect and consider progress.
- The other interviewee (in conjunction with their colleagues) plans to continue delivering the FACETS programmes, specifically experimenting with:
  - providing the programme for "stratified groups" (e.g. newly diagnosed patients, patients diagnosed for 10+ years, wheelchair users); and,
  - developing some case studies that are more reflective of the lived experience of wheelchair users, to integrate into the training.

- Reasons given by the two survey respondents not planning to deliver FACETS programmes in the future were:
  - Due to retirement
  - The colleague they were delivering the programme with leaving: *"I was delivering the programme with an OT who was employed in the MS service, she has now left."*

Conclusions and key learnings

Conclusions (1)

While the evaluation findings should be treated with caution given the lack of data available, facilitators who engaged with the evaluation were largely positive about their experience and the associated impact of the FACETS facilitator training course and subsequent FACETS programme delivery.

1. Is the delivery of the FACETS facilitator training course suitable and effective for facilitators supporting people with MS?

The delivery of the FACETS facilitator training course is both suitable and effective for facilitators supporting people with MS, with training elements that complements the widescale delivery of fatigue management approaches.

- The FACETS facilitator training course content and resources have equipped facilitators with the information and evidence-base needed to deliver the FACETS programme to people with MS, while the online delivery mode has ensured facilitators nationally can undertake the training without the associated travel time and expense.
- Facilitators attending the training have had access to knowledgeable and engaging trainers, who have provided guidance on adapting the FACETS content for online programme delivery.
- However, the pace and length of the training posed a challenge due to the extensive content covered during the training day, which was taxing to engage with online. There was also some confusion around the intended attendees for the training, and a lack of clarity around the extent to which facilitators could adapt the FACETS programme delivery to the experiences and needs of their patients.
- Facilitators receiving resources after the training felt they would have benefited from viewing these during the training session, while missing sections of the FACETS manual also presented facilitators with a challenge.
- Additionally, facilitators were keen to understand the impact of their FACETS programmes for MS patients, but felt they did not have the appropriate tools to do so.

Conclusions (2)

2. How, and to what extent, are facilitators undertaking the FACETS facilitator training course disseminating the learning to people with MS?

Dissemination of FACETS principles by facilitators has taken different forms.

- Most facilitators that engaged with the evaluation had delivered at least one FACETS programme to people with MS, and approximately 199 people with MS had attended one of those programmes.
- Facilitators were delivering FACETS programme online and in-person, but no one was taking a hybrid approach. Online delivery was felt to provide accessibility for patients with MS.
- Beyond the FACETS programmes, all facilitators reported using the FACETS principles in one-to-one discussions with MS patients. The reach in doing so was significant, with an estimated 561 people with MS benefitting from these discussions.

3. What is the impact of the FACETS facilitator training course on facilitators supporting people with MS, and people with MS?

The FACETS facilitator training course equipped facilitators with the knowledge and confidence to support patients with MS to manage fatigue, and patients attending the programmes were perceived to better self-manage their fatigue.

- The FACETS facilitator training course equipped facilitators with the knowledge to support people with MS to manage their fatigue (and provide a structured programme offer for doing so). Facilitators felt more confident in their ability to provide appropriate, MS-specific fatigue management advice. They also praised the resources for aiding their ability to provide fatigue management support.
- The benefits for people with MS who attended FACETS programmes identified by facilitators included increased awareness about how to self-manage their MS-related fatigue, peer support from others with MS, access to tools that improved their mental health, and increased confidence to communicate their needs for support to others. However, without directly engaging with people with MS, these suggested impacts cannot be confirmed.

Key learnings for delivery

- Delivery of the FACETS facilitator training course could be improved by:
  - Ensuring training resources and materials are quality-assured and disseminated to facilitators prior to the commencement of the training.
  - Considering slowing the pace of the FACETS facilitator training course, by delivering the training it in shorter sessions over 2-3 days.
  - Ensuring facilitators are aware that FACETS programme content can be emotive, so they feel prepared and can inform their MS patients who show interest in attending the programme.
- Delivery of the FACETS programme for people with MS could be improved by:
  - Using a structured approach, develop new case studies, with consideration for the range of mobility MS patients may have (e.g. developing case studies for people in wheelchairs).
  - Exploring the possibility of a digital toolkit or app that may be used by MS patients to complete the homework.
  - Reviewing the current FACETS programme for people with MS to ensure all activities are appropriate for online delivery.
  - Providing guidance to facilitators on how they could adapt the FACETS programme delivery to suit their patients (e.g. the length and number of programme sessions, the categorisation of programme attendees and the addition of follow-up sessions).
- Additionally, encouraging multiple staff members from each organisation to attend the FACETS facilitator training course may help to ensure those who attend the training have the necessary support to go on to deliver the FACETS programme.
- Being explicit in communications that the FACETS facilitator training course is open to a wide range of job roles may help to ensure it continues to reach those supporting people with MS in the community and voluntary sectors (who may perceive it to be for health care professionals in health services only).

Considerations for future monitoring and evaluation

Systematic monitoring and evaluation may help to further strengthen the evidence-base for the FACETS training and FACETS programmes for people with MS.

This could include:

- Developing outcome measures or Key Performance Indicators (KPIs) that the FACETS training and programmes can be assessed against
- Developing an approach to share with facilitators on how they can collect corresponding data from people with MS, including providing them with tools for evaluating impact (e.g. a survey or data collection template). Tools developed as part of ICF's evaluation (such as the survey for people with MS) could help with this process.

While the reason for the low response rate to the surveys carried out as part of this evaluation was unknown, the response rate to future surveys could potentially be improved in the future by:

- Promoting monitoring and evaluation activities during the training delivery, including emphasising the importance of facilitators' engagement with them.
- Disseminating any data collection tools (e.g. surveys) to each cohort within set timeframes after they complete the training, to increase the likelihood that they can recall it and are willing to take part.
- Providing facilitators with assistance in navigating any data protection requirements within their service which present a barrier to their ability to disseminate surveys and/or collect outcome data from people with MS.
- Building and maintaining relationships with facilitators where possible, to increase their level of buy-in to any monitoring and evaluation activity.