

## Impact case study (REF3)

<b>Institution:</b> Bournemouth University		
<b>Unit of Assessment:</b> 3		
<b>Title of case study:</b> Reducing the impact of fatigue in people with Multiple Sclerosis using a novel fatigue-management programme		
<b>Period when the underpinning research was undertaken:</b> 2006 – 2019		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Professor Peter Thomas	Professor of Health Care Statistics & Epidemiology	1996 – July 2020
Dr Sarah Thomas	Deputy Director of BUCRU and Senior Research Fellow	2017 - current
Dr Andy Pulman	Post-Doctoral Researcher in Digital Health and User Experience	2017 - June 2020
Dr Sarah Collard	Lecturer in Psychology	2015 – current
Dr Huseyin Dogan	Principal Academic in Computing	2012 – current
Dr Nan Jiang	Associate Professor in Human Computer Interaction	2010 - current
<b>Period when the claimed impact occurred:</b> 2013 – 31 December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>Approximately 2,500,000 people worldwide (130,000 in the UK) have multiple sclerosis (MS), a neurological condition affecting the central nervous system. Fatigue is one of the most debilitating symptoms, experienced by over 80% of people with MS. Bournemouth University (BU) researchers developed a fatigue management programme blending cognitive behavioural and energy effectiveness approaches (FACETS). Evidence shows the proportion of FACETS group participants reporting a clinically important improvement in fatigue levels is more than double that of those receiving just their usual care. Roll-out and dissemination of FACETS via healthcare professionals, policy and digital applications now enables access across four continents.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>Fatigue is one of the most common and debilitating symptoms of MS, an 'invisible' symptom that encroaches on many aspects of life. It is the main reason why People with MS (PwMS) stop working early, is one of the MS Society's most accessed topics for support, and is third (after cure and prevention) in the James Lind Alliance research priorities for MS.</p>		

Drug treatments for fatigue are not always effective and while cognitive behavioural therapy (CBT) has proved helpful in other conditions, there is a lack of evidence supporting its effectiveness for managing MS fatigue. This prompted Thomas and her team to conduct a scoping exercise, funded by the MS Society, and a Cochrane review [R1], both of which confirmed the evidence gap in psychological treatments for MS fatigue. Recognising potential benefits to quality of life, BU researchers collaborated with Poole Hospital to develop FACETS (Fatigue: Applying Cognitive behavioural and Energy effectiveness Techniques to LifeStyle) [R2].

FACETS is a group-based fatigue management programme with supporting manual and participant materials, designed to be easily implemented in clinical practice. The programme, designed for ambulatory people with MS, is offered in six weekly sessions with groups of 6 to 12, facilitated by 2 healthcare professionals [R2]. FACETS aims to support people with MS to normalise their fatigue experiences, learn helpful ways of thinking about fatigue and use available energy more effectively [R2]. The programme format incorporates short presentations, group activities, discussions and homework tasks designed to equip attendees to make changes to their lifestyle and attitudes towards managing fatigue.

Following encouraging findings in a preliminary evaluation [R2], the MS Society funded a formal evaluation. This was a pragmatic multi-centre randomised controlled trial involving 164 PwMS, taking place between 2008 and 2009. Outcomes for PwMS randomised to receive FACETS in addition to their usual care, were compared with those receiving usual care only. The estimated cost of FACETS was GBP453 per person [R3]. At one-month follow-up, FACETS was effective in increasing self-efficacy - a person's confidence in their ability to accomplish tasks or handle a challenging situation [R3]. At four months, there were also improvements in fatigue severity, with the majority of FACETS attendees reporting successful implementation of fatigue management strategies [R4]. At one year, improvements were largely maintained, along with additional improvements in MS-specific quality of life [R5].

In 2016, the MS Society commissioned Bournemouth University to undertake a consultation with healthcare professionals and PwMS to explore digital delivery of FACETS via their website to expand the programme's reach [R6]. This highlighted that PwMS wanted the flexibility of being able to complete FACETS homework tasks on a mobile device. As there were no suitable free apps available the team developed and tested a prototype Android digital toolkit incorporating the FACETS homework tasks using participatory design techniques, qualitative focus groups, and usability testing [R6].

### 3. References to the research (indicative maximum of six references)

**R1-R6** have been rigorously peer-reviewed in internationally recognised journals.

**R1.** Thomas, P.W., Thomas, S., Hillier, C., Galvin, K. and Baker, R., (2006). Psychological interventions for multiple sclerosis. *Cochrane Database of Systematic Reviews*, (1). [10.1002/14651858.CD004431.pub2](https://doi.org/10.1002/14651858.CD004431.pub2)

**R2.** Thomas, S., Thomas, P.W., Nock, A., Slingsby, V., Galvin, K., Baker, R., Moffat, N. and Hillier, C., (2010). Development and preliminary evaluation of a cognitive behavioural approach to fatigue management in people with multiple sclerosis. *Patient Education and Counseling*, 78(2) pp.240-249. [10.1016/j.pec.2009.07.001](https://doi.org/10.1016/j.pec.2009.07.001)

**R3.** Thomas, S., Thomas, P.W., Kersten, P., Jones, R., Green, C., Nock, A., Slingsby, V., Smith, A.D., Baker, R., Galvin, K.T. and Hillier, C., (2013). A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry*, 84(10) pp.1092-1099. [10.1136/jnnp-2012-303816](https://doi.org/10.1136/jnnp-2012-303816)

**R4.** Thomas, S., Kersten, P., Thomas, P.W., Slingsby, V., Nock, A., Jones, R., Smith, A.D.,

Galvin, K.T., Baker, R. and Hillier, C., (2015). Exploring strategies used following a group-based fatigue management programme for people with multiple sclerosis (FACETS) via the Fatigue Management Strategies Questionnaire (FMSQ). *BMJ open*, 5(10).

<http://dx.doi.org/10.1136/bmjopen-2015-008274>

**R5.** Thomas, P.W., Thomas, S., Kersten, P., Jones, R., Slingsby, V., Nock, A., Smith, A.D., Baker, R., Galvin, K.T. and Hillier, C., (2014). One year follow-up of a pragmatic multi-centre randomised controlled trial of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *BMC neurology*, 14(1) p.109. <https://doi.org/10.1186/1471-2377-14-109>

**R6.** Thomas, S., Pulman, A., Thomas, P., Collard, S., Jiang, N., Dogan, H., Smith, A.D., Hourihan, S., Roberts, F., Kersten, P. and Pretty, K., (2019). Digitizing a Face-to-Face Group Fatigue Management Program: Exploring the Views of People With Multiple Sclerosis and Health Care Professionals Via Consultation Groups and Interviews. *JMIR Formative Research*, 3(2) e10951. [10.2196/10951](https://doi.org/10.2196/10951)

#### 4. Details of the impact (indicative maximum 750 words)

##### Healthcare guidelines and policy

FACETS was included in the National Institute for Health and Care Excellence (NICE) guidelines for managing MS, noting that it is likely to be cost effective given its beneficial impact on fatigue [E1]. FACETS research was a top three finalist in the MS Society's 2014 'Research of the Year' award and was commended by the Scottish Parliament as a "proven fatigue management programme that is being adopted around the world" during MS Awareness Week 2019 [E2].

The MS Society recommends FACETS to its online visitors via its fatigue pages. The downloadable booklet, 'Fatigue' summarises FACETS' core principles, and describes its underpinning evidence base [E3]. Drawing upon the research teams' consultation findings, the MS Society has created an online fatigue management course based on FACETS [E4a]. Since its launch at the beginning of 2020, 715 PwMS have accessed the course, with an 87% completion rate [E4b]. An evaluation by the MS Society found that over 72% of participants would recommend the course and feedback showed that not only did fatigue decrease, but that participants "reported feeling happier, less anxious, more satisfied with life and that the things that they do in life are more worthwhile".[E4b, E4c]

##### Healthcare professionals (HCPs)

The MS Society supported the national roll-out of FACETS via delivery of a one-day facilitator training course developed by the research team. To date, 305 HCPs have been trained across 18 UK courses [E5]. Evaluations by HCPs have been extremely positive:

"We love it because we see the benefit to the patients. Patients love it because they benefit."

HCPs also highlight the group-based cognitive behavioural approach which sets FACETS apart from other fatigue management programmes:

"It's much more powerful than I thought it was going to be. I thought it would just be running a fatigue management programme and, but it's really... it's a lot of movement, shifting of ideas" [E6].

##### People with MS

Fatigue is a significant problem for PwMS, affecting all aspects of life from mobility to mood, relationships and work [E7]. Feedback from PwMS who have attended FACETS indicates they like the programme's positive approach to making lifestyle changes:

"This course has been amazing. It's an awesome thing to do to provide a point of contact/connection for MS sufferers, that perspective gained from shared experience is excellent... it's genuinely changed my life."

Attendees have described a transformative effect on their lives:

"I am now more accepting, kinder to myself and happier to be open about my needs to friends and family." And: "I am now able to regulate my energy and better prioritise my time. As a

consequence I no longer suffer from 'brain fog'. This is a HUGE step forward. I am now able to enjoy activities to the utmost. I have even been brave enough to join a gym!! Unheard of before this course. The quality of my life has improved” [E7].

An estimated 13,931 PwMS in the UK have participated in FACETS programmes, based on HCP facilitators trained [E8] – around a fifth of ambulatory PwMS with fatigue in the UK. The CEO of the MS Society confirms the impact of FACETS on PwMS: “Our feedback from people with MS has shown the positive impact that the FACETS programme has on their lives, making a real difference”. [E4c].

The infographic below captures further feedback from PwMS after attending the FACETS course.



**MS and employment**

An estimated GBP35,000 per person is spent annually on MS medical and care costs. There are other indirect economic impacts, such as fatigue reducing the probability of people working. The MS Society recommended FACETS within its response to the ‘Work Health and Disability Green Paper: Improving Lives’, acknowledging many PwMS cannot work, but describing FACETS as “helpful to employees with MS” for those who could [E9, page 61]. This has also been reflected in attendee feedback [E7]:

“The course has been very valuable to me. I have concrete information to share with my employer as evidence.”

**A global resource**

Use and adoption of FACETS continues to increase, enabling the expansion of benefits globally. In Europe, it is being delivered in Ireland, Germany, Denmark and France [E4c]. The Norwegian translation has enabled it to be incorporated into the programme at a residential rehabilitation centre for PwMS (MS-Senteret Hakadal), where, based on the number of people treated, it is estimated to have been delivered to over 900 PwMS in 2018 and 2019 [10a, 10b].

In the rest of the world, FACETS is being used at the Kessler Institute, New Jersey, USA and a Spanish translation has enabled its use in Spain and Argentina. In New Zealand an iOS app has been developed called MS Energise, which uses FACETS IP. Training has been delivered to 25 HCPs in Australia, enabling the Australian MS Society to deliver FACETS face to face and via webinar. Collaboration with Tasmania to develop ‘MS WorkSmart’ an online fatigue management programme drawing upon FACETS, is aimed at supporting people to remain in employment using an app – MySymptoMS.



**5. Sources to corroborate the impact** (indicative maximum of 10 references)

- E1.** NICE (2014), *Multiple Sclerosis: Management of Multiple Sclerosis in Primary and Secondary Care*. Clinical guideline No. 186. Methods, evidence and recommendations, Available from: [https://www.nice.org.uk/guidance/cg186/evidence/full-guideline-pdf-193254301 pp. 307,315,382,397,399 & 400](https://www.nice.org.uk/guidance/cg186/evidence/full-guideline-pdf-193254301_pp.307,315,382,397,399&400) [Accessed on 25 September, 2018].  
Webcite – <http://www.webcitation.org/72hH96b7u>
- E2.** Scottish Parliament (2019), *Official Report - Parliamentary Business: Scottish Parliament on 13/03/2020 at 18.56*, p.117 [online]. Available at: [http://www.parliament.scot/parliamentarybusiness/report.aspx?r=12053&mode=html#iob\\_10906\\_9](http://www.parliament.scot/parliamentarybusiness/report.aspx?r=12053&mode=html#iob_10906_9) [Accessed on June 15, 2020].
- E3.** MS Society (2016) *Fatigue*, pp.18, 19, 32.
- E4a.** Multiple Sclerosis Society UK (2016) *Online MS Fatigue-Management Course*. [online] Available at: <https://www.mssociety.org.uk/about-ms/signs-and-symptoms/fatigue/managing-fatigue/online-fatigue-management-course>. [Accessed on June 15, 2020].
- E4b.** MS Society (2020) *Fatigue Self-Management Course Survey Results*.
- E4c.** MS Society (2020) *Testimonial Letter*.
- E5.** MS Society (2016) *FACETS Facilitators Survey: Numbers of HCPs trained and location and numbers of people with MS that have attended the programme*.
- E6.** MS Society (2016) *FACETS Facilitators Survey: Impact Testimonials from Healthcare professionals*.
- E7.** MS Society, Pullman, A., (2019) *Impact Testimonials from people with MS*.
- E8.** Pullman, A. (2020), *Number of FACETS participants globally*.
- E9.** Weatherly, L. and McIntosh, K. (2017) *MS Society Response To Improving Lives: The Work Health And Disability Green Paper*. [online]. Available at: <https://www.bl.uk/collection-items/ms-society-response-to-improving-lives-the-work-health-and-disability-green-paper> [Accessed 25 September 2019].  
Webcite - <http://www.webcitation.org/72hGknzI3>
- E10a.** MS-Senteret Hakadal. n.d. *Prosjekter | Fagutvikling | MS-Senteret Hakadal*. [online] p.2. Available at: <http://www.mssenteret.no/mssenteret/ms-forskning/prosjekter/> [Accessed 17 November 2020].  
<https://translate.google.com/translate?hl=en&sl=no&u=http://www.mssenteret.no/&prev=search&pto=aue>
- E10b.** Nyhaus, J., (2020) *Årsrapport MSSH 2019*. [online] Akershus: MS-Senteret Hakadal, p.5 (table). Available at: <http://www.mssenteret.no/sfiles/48/28/2/file/arsrapport-2019.pdf> [Accessed 17 November 2020].
- E10c.** Ms.org.au. n.d. *FACETS - Fatigue Management | MS (MS Education)*. [online] Available at: <https://www.ms.org.au/support-services/education/facets.aspx> [Accessed 13 March 2020].