

REFUEL-MS

Patient and Public Involvement (PPI) Report

**Developing, optimising, and implementing a
blended digital self-management
treatment for fatigue in multiple sclerosis**

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Section 1

Report Introduction

What is PPI?

In England, according to the National Institute of Health and Care Research (NIHR), research collaborations with stakeholders are known as patient and public involvement (PPI) (NIHR, 2021). These stakeholders can include compensated patients, members of the public, and relevant charitable organisations, who participate as advisory group members or co-researchers (Sidhu et al., 2024). PPI partnerships typically begin during the study design phase and extend through the development of interventions, trial setup and execution, data analysis, and dissemination of findings (Sidhu et al., 2024). In REFUEL-MS, PPI with patients, patient advocates, diversity experts, and healthcare professionals (HCPs) has been incorporated extensively throughout all stages of intervention development. This report outlines the rationale behind the approaches used, the different stages of involvement, and how PPI has helped refine the REFUEL-MS intervention.

Rationale for the use of PPI

REFUEL-MS is a blended, app-based digital treatment for MS-related fatigue ('MS fatigue'). Digital health interventions (DHIs) are increasingly used to enhance treatment access and reduce NHS costs, but they face specific challenges. Unless developed to allow flexibility, DHIs can struggle with real-world implementation (Greenhalgh et al., 2020). Moreover, patient engagement in DHIs is crucial but often low (Molloy & Anderson, 2021), with completion rates ranging from 4% to 43% for fatigue DHIs in MS, cancer and chronic fatigue syndrome (Abrahams et al., 2017; Foster et al., 2016; Janse et al., 2018; Moss-Morris et al., 2012; Pottgen

et al., 2018; van Kessel et al., 2016). For example, a mobile app for cancer-related fatigue saw users engage only 3 days on average over 12 weeks (Spahrkas et al., 2020).

Low engagement and implementation failures in DHIs may stem from low acceptability, which is influenced by the user's context and social norms (Greenhalgh et al., 2017; Perski et al., 2017). To ensure acceptability, considering the patient perspective and context is crucial. User-centred design from the outset can enhance this, especially for self-management DHIs (Greenhalgh, 2018). Self-management depends on personal disposition, support networks, and the socioeconomic and cultural environment (Hinder & Greenhalgh, 2012). Therefore, interventions must account for the varied contexts in which people living with MS (pwMS) self-manage fatigue, and how this can impact both their fatigue and engagement with DHIs and behaviour change.

REFUEL-MS aims to increase acceptability by using a Person-Based Approach (PBA; (Yardley, Morrison, et al., 2015) and integrating PPI to co-produce the intervention.

Person-Based Approach

PBA is a method of intervention development that emphasises user experience throughout each step of the process (Yardley, Ainsworth, et al., 2015). This method complements theory and evidence-based approaches to enhance intervention acceptability (Yardley, Ainsworth, et al., 2015). PBA relies on qualitative research and PPI to deeply understand user needs and perspectives, ensuring the intervention integrates into their lives and meets their care needs.

Co-production

Co-production has become increasingly popular in applied health research as an extension to PPI (Grindell, Coates, et al., 2022). Co-production involves working in equal and active partnership with end-users, valuing all forms of knowledge and combining patient expertise with that of researchers and collaborators, to make joint decisions throughout the research lifecycle (Grindell, Coates, et al., 2022; Grindell et al., 2020). By involving patients in

commissioning, planning, designing, developing, delivering and assessing interventions (Gheduzzi et al., 2021), co-production aims to create interventions that meet patient-identified needs and are appealing, practical, usable and contextually sensitive, thereby increasing the likelihood of interventions being implemented in real-world settings (Langley et al., 2018). This approach also helps avoid spending resources on interventions that may not engage users (Yardley et al., 2020).

To that end, REFUEL-MS established a Patient Advisory Group (PAG) at the start of the project, consisting of 17 pwMS recruited through the MS Society UK charity. The PAG was involved in generating initial ideas for the programme, providing input on the research proposal and funding application, with a lead member listed as a co-investigator. Together with the PAG, we co-produced a PPI contract to set boundaries and expectations regarding their input, the role of the research team, and how their input would be logged, measured, and compensated. We also established ground rules for meetings and agreed on shared values for the partnership. Currently, we have 14 PAG members who represent diverse backgrounds and experiences, bringing unique perspectives from which to inform the intervention development.

We also maintain a general PPI contact list, comprising 13 pwMS. These individuals were interested in participating in REFUEL-MS PPI opportunities but were unable to join the PAG due to personal reasons, limited group capacity, or the need to ensure diversity within the group. Consequently, we have a substantial pool of pwMS to invite for participation in various PPI opportunities.

REFUEL-MS has also established partnerships with three professional diversity consultants, two of whom are patient advocates, with expertise in culturally adapting interventions. By collaborating with these individuals, we hope to ensure that the intervention is acceptable, appropriate and accessible to as many pwMS as possible.

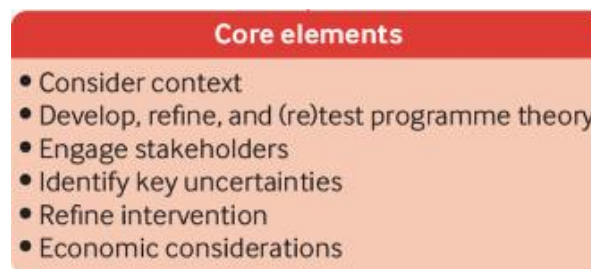
This report highlights examples of PPI and co-production in developing REFUEL-MS, detailing the processes involved and the challenges faced and addressed along the way. This

transparency, often missing in co-production literature, is essential for providing learnings and recommendations for future collaborative research (Grindell, Sanders, et al., 2022).

Medical Research Council (MRC) framework

The Medical Research Council (MRC), alongside the National Institute for Health Research (NIHR), proposed a framework for guidance of how to develop and evaluate any complex interventions (Skivington et al., 2021). The core elements are shown in Figure 1.

Figure 1. Core elements of MRC framework (Taken from (Skivington et al., 2021)).



Consider context: This refers to the setting of the intervention.

Programme theory: This involves the intervention logic model which was based on cognitive behavioural therapy (CBT) principles (included below; Figure 2).

Engage stakeholders: This includes both the target audience of the intervention and those involved in its delivery (Skivington et al., 2021). For REFUEL-MS, this includes pwMS who experience fatigue and healthcare professionals (HCPs) working in MS care, respectively. The guidance emphasises the need for “meaningful engagement” at each stage of intervention development to achieve positive outcomes. This highlights the importance of incorporating PPI throughout the development of the REFUEL-MS intervention.

Section 2

Co-production Workshops

There were two co-production workshops held with pwMS, and one with HCPs, as part of the overall co-production process. This section of the report outlines the objective and rationale for co-production in the process of developing the REFUEL-MS intervention.

Objective

The objective of co-production is to create a space where different forms of knowledge and experience (from patient and researcher expertise and experience) can be translated into new knowledge and action (Wolstenholme et al., 2019). In the context of REFUEL-MS, “action” refers to concrete decisions about practical aspects of the intervention to increase its acceptability, such as app structure, features, and functionalities.

Rationale for Co-Production Workshops

When developing health interventions, writing therapeutic content is crucial to target the desired mechanisms of change. However, in digital interventions, design and functionality are equally important. According to Perski’s conceptual framework of engagement with digital health interventions (Perski et al., 2017), engagement is influenced by the intervention’s context (characteristics of the population and their environment) and its design (both content and delivery). Well-designed features (tools supporting the app’s content) and functionalities (how these features operate) in digital interventions enhance engagement and support behavior change through the integration of behavior change techniques (Michie et al., 2011).

When co-designing these elements with end-users, specifically pwMS and HCPs, in a workshop setting, we aim to ensure that the context in which the app will be used is considered, alongside theory, such as behaviour change techniques. This approach should create an app that is not only theory-based, but fits into an individual user's life and routine, in a meaningful and engaging way.

Developing the Co-Production Workshops

Two co-production workshops were held with pwMS, REFUEL-MS collaborators and co-investigators (June 2023) and one workshop was held with HCPs (November 2023). This part of the report outlines the development process for these workshops.

Co-Production Workshops (1 & 2): pwMS, collaborators and co-investigators

The REFUEL-MS team planned workshops 1 and 2 with two PAG representatives. The workshop objectives were pre-defined in the research programme funding application (see Table 1).

Table 1. Objectives for Co-production Workshops 1&2

- | | |
|---|--|
| 1 | Get feedback on the intervention/app outline and structure. |
| 2 | Discuss how to integrate the programme into daily routines and increase engagement. |
| 3 | Discuss how to tailor the intervention to different characteristics of potential users, including MS subtypes. |

Co-Producing the Co-Production Workshops

Two meetings were held with two PAG representatives to “co-produce” the Co-Production Workshops (1&2) in April-May 2023. In these meetings, we discussed key considerations for the workshop such as objectives and priorities; duration and mode of delivery (in this case, it would be hybrid: online and in-person); who to invite; diverse needs and accessibility requirements; pre-workshop training or materials; how to ensure successful and inclusive facilitation; how to manage expectations about implementing ideas/feedback; how to reach collaborative

decisions; and actions required before and after the workshop(s). We also discussed the planned workshop content including activities and tools to encourage interaction and discussion in a hybrid setting (e.g., Jamboard, Microsoft Teams polls, paper and post-it notes in-person).

We agreed that the workshop should be split into two sessions to cover all objectives and content while offering sufficient breaks to attendees to minimise cognitive burden/fatigue.

We also discussed two pre-workshop surveys that were required: (1) to establish PAG members' demographics and specific needs for the workshop, and (2) to understand pwMS' needs and preferences regarding app features and functionalities.

PAG Demographics and Needs survey

This survey was sent to PAG members to gauge interest, availability and needs/requirements for the Co-Production Workshops. We informed the PAG that we had a limited number of spaces available on the workshop (n=8) and wanted to ensure that we included people from diverse backgrounds, with a range of experiences. With that in mind, we asked PAG members to provide their date of birth, gender, ethnicity, type of MS, as well as their availability and preference for attending online or in-person. We also ascertained their level of familiarity using Microsoft Teams for online meetings on a scale of 0-10 (0 = Not familiar at all, 10 = Extremely familiar), and whether they would like instructions on how to use Teams and/or a practice Teams call with a member of the research team. We also asked how they would prefer information to be presented before/during the workshop ('On screen (during the workshop)', 'Printed copies (during the workshop)', 'Emailed as an attachment before the workshop' and 'Printed copies sent by post before the workshop'). Respondents were asked if they had any specific dietary/access/support requirements that we needed to be aware of to support their attendance at the workshop(s). Ten PAG members completed the survey.

Features and functionality survey

To gain an initial understanding of user needs and preferences regarding features and functionalities before the workshop, a survey was developed for the PAG (Table 2). The survey

was adapted from a similar survey used in a previous digital health intervention, IBD BOOST (Sweeney et al., 2022). Six PAG members completed the survey.

Table 2. Features and functionality survey.

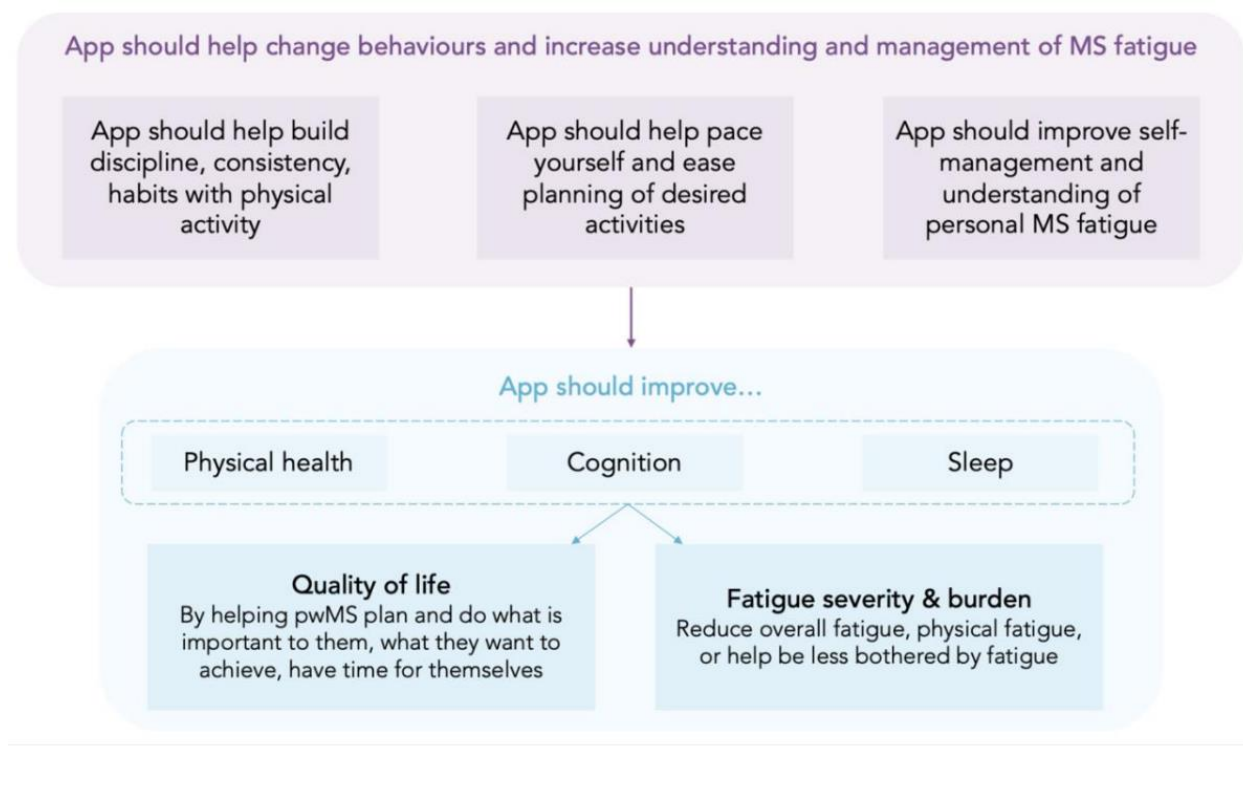
Subheadings	Question topics
Format and delivery of the intervention	- Frequency and timing of app use/sessions - Frequency and scheduling of HCP contact - Format and naming of in-app activities - Preferences for symptom tracking and reminders - Scrolling preferences
Additional features and functionalities	- Choice between several ideas of additional functionalities, and free-text option
Language	- Preference for name of streams - Preference for the name of “vicious cycle” of fatigue

Patient-identified intervention objectives

“Patient-identified intervention objectives” were developed based on the survey results and initial findings from focus groups and interviews with HCPs and pwMS from under-served groups. These have been summarised in the figure below (Figure 3). Initial results showed that pwMS wanted greater understanding of their MS fatigue to improve self-management. They also wanted support with specific behaviour changes such as developing physical activity habits and pacing. The outcomes that pwMS most desired from the intervention were reduced fatigue severity and burden and improved quality of life. Notably, pwMS in this sample did not report needing help with physical balance or mental health. This suggests that this sample would possibly be more interested in the core self-management sessions and the exercise stream over the balance and CBT streams. Therefore, it is important to consider how to present the CBT and balance streams to users who may benefit from them, and how to increase users’ perceived

need of and engagement with these streams. However, it is important to note that only six PAG members responded to this survey so the sample may not be representative of all pwMS.

Figure 3. Patient-identified intervention objectives.



Co-Production Workshop (3): HCPs

Members of the REFUEL-MS team, including a Specialist Occupational Therapist (OT), Health Psychologist, Research Associate, and Research Assistant, co-developed the HCPs Co-Production workshop with two HCP collaborators (a specialist MS physiotherapist (PT) and an OT). The workshop objectives and questions were informed by the programme funding application and initial findings from qualitative focus groups and interviews with HCPs (see Table 3 below). Based on these findings and outputs from Co-Production Workshops 1 and 2, the team also developed specific questions to raise in the HCP workshop (see *italicised text* in Table 3).

Table 3. Objectives and Questions for Co-production Workshop (3)

1	To discuss the usability of the REFUEL-MS app: a) How might HCPs and pwMS use the app in your service? • <i>How far in advance could services pre-book REFUEL-MS appointments, i.e., 1-week?</i> • <i>What are the typical waiting times for appointments?</i> • <i>Would appointments be virtual or face-to-face?</i> • <i>What is the preferred way for pwMS to contact HCPs while using REFUEL-MS (a chat function via the app or via email)?</i> • <i>Time commitment: What is a feasible/realistic time commitment for each pwMS using the app? How long could a pwMS continue to use the app after completing the 16-week intervention (i.e., up to 6-months)?</i> b) Review the barriers and solutions to implementing the app, e.g., • Patient factors: ○ Lack of motivation/readiness for change ○ Lack of engagement ○ Cognitive symptoms ○ Higher disability ○ Lower education/literacy (including digital literacy) ○ Relapse/life circumstances • HCP/service factors: ○ Service constraints – procedures; staff availability; training; time pressures
2	To discuss the training needs of HCPs to support the implementation of the REFUEL-MS app into practice. • <i>What is the allocation for training in your workplace (i.e., time, space, format)?</i> • <i>Do you have any specific in-service training (IST) on MS?</i>

- *Does your service provide any MS fatigue specific training?*
- *What should be included in the REFUEL-MS HCP training? E.g., in relation to the intervention streams (CBT, exercise, balance) what training is required?*
- *Would REFUEL-MS training need to be tailored specifically for OTs, Physios, CNS?*
- *How should REFUEL-MS training be delivered? Online (Teams) / pre-recorded video/resource?*
- *What level of supervision would be required to deliver REFUEL-MS? Would you have onsite support/supervision available for REFUEL-MS?*
- *What level of HCP (i.e., banding, OTA, PTA, apprentice) could deliver the REFUEL-MS app?*

Facilitating the workshops

Co-Production Workshops (1&2): pwMS, collaborators, and co-investigators

The two workshops were held on 12 and 22 June 2023. The first workshop was held online via Microsoft Teams and in-person ('hybrid') and the second was held online via Microsoft Teams. See Table 4 for an overview of workshop attendees and details.

Table 4. Co-Production Workshops (1&2) Attendees and Details

Workshop	Delivery Mode	Duration	Attendees
1 (12.06.2023)	Hybrid: In-person (x8) Microsoft Teams (x9)	3-hours	Total: 17 9 REFUEL-MS team 2 Co-investigators 1 Collaborators 5 PAG members (3 in-person)
2 (22.06.2023)	Microsoft Teams	1.5 hours	Total: 20 9 REFUEL-MS team 3 Co-investigators 1 Collaborators 7 PAG members

Workshop Content

The team presented PowerPoint slides with an introduction to REFUEL-MS and outlined the cognitive behavioural model of MS fatigue. The workshops were then split into 3 parts with specific aims and activities. Part 1 involved an overview of the intervention/app sessions and flowchart; part 2 explored how users could implement the app into their daily routine; and part 3 focused on how to tailor the app for different users/experiences (i.e., cultural background/intersectionality, MS sub-type, levels of social support, other MS symptoms, etc.).

The planning team prepared specific aims, activities and questions for each part of the workshop and highlighted where key decisions were required (see Table 5 below).

Table 5. Co-Production Workshops (1&2) Aims, Questions and Key Decisions

Part of Workshop	Aim(s) & Plan	Questions & Key Decisions
Workshop 1 (12.06.2023)		
Part 1: Treatment/session overview	<u>Aim: To review the session overview and names.</u> - REFUEL-MS team present to whole group: - Session overview - Core sessions - The 3 streams - Review/discuss in small groups (use dot voting). - Review/discuss as a whole group.	<i>What do you think about the length of the intervention (12-weeks)? Any barriers?</i> <i>What do you think about the order and relevance of sessions/streams.</i> <i>Are the session names/content relevant & suitable?</i> Key decisions: - Use of: 'sessions' or 'modules' to refer to an app session. - Core session names (use dot voting). - Names of 3 streams (use dot voting). - Carer access on the app.
Part 2: How to implement the app into daily routine	<u>Aim: Present data from the functionality survey.</u> 2.1 Length of sessions & daily usage.	2.1 <i>What could help with different preferences in length of sessions and daily use of the app? Prompts/survey</i>

	2.2 How to implement healthcare professional support in the app (use reverse thinking activity). 2.3 Barriers to engagement in app activities/tools, e.g., activity trackers	<i>responses: pause button; calendar feature to plan use.</i> <i>2.2 - How could we integrate HCP in a way that would not be helpful? (reverse thinking activity)</i> <i>- Which term is preferred to refer to the REFUEL-MS HCP? 'Healthcare professional' / 'facilitator' / 'guide'?</i> <i>2.3 What are the potential barriers to someone tracking their activity and/or fatigue? Prompts/Survey responses: memory, motivation, app design, energy. And how could we overcome these?</i>
Workshop 2 (22.06.2023)		
Part 3: How to tailor the app for different users/experiences	<u>Aim: to consider different characteristics and potential tailoring of the intervention.</u> 3.1 Discuss how we can tailor the app to account for people's different experiences & characteristics. 3.2 Review patient journey; identify potential barriers &	<i>3.1 How can we ensure activities / examples / suggestions are suitable for people from different cultures/backgrounds?</i> <i>3.2 - What barriers might there be / what could make someone disengage at this point?</i> <i>- What opportunities could there be to tailor the app? E.g., ensure content is appropriate and</i>

	opportunities to tailor the app (in smaller groups).	relevant to the type of MS someone lives with (e.g., relapse information). Use personalization (i.e., someone's preferred name) throughout the app.
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Co-Design Techniques & Facilitation

In the workshops, we used breakout rooms (both in-person and on Microsoft Teams) to enable smaller group discussions between 4-5 participants. One or two member(s) of the research team facilitated the discussions in each 'room' and made written notes of ideas and feedback.

Several creative co-design techniques were used to facilitate discussion and idea generation, including storyboards, proto-personas, dot voting, and reverse brainstorming (see Table 6 below).

These techniques support knowledge creation by (1) supporting the active engagement of participants throughout long workshops, (2) unlocking participants' implicit knowledge and enabling generation of new forms of knowledge and innovative ideas, and (3) combining knowledge using visual and active forms (Grindell, Sanders, et al., 2022). They can also help reduce potential power imbalances that can come from social hierarchies between and within participants and researchers as everyone is faced with an unfamiliar tool that does not require any educational or literacy pre-requisites (Grindell, Sanders, et al., 2022). This allows patient perspectives and ideas to be heard and valued equally with researchers' (Grindell, Sanders, et al., 2022).

Table 6 describes the creative workshop techniques that we considered, used and adapted for these workshops. Figure 4 shows an example of dot voting and idea generation used to explore the names of the 3 intervention streams.

Table 6. Creative Co-Design Techniques Applied in Workshops 1&2

Creative co-design technique	Description	How was this used in REFUEL-MS Co-Production Workshops 1&2?
Dot voting 	Is a simple method for prioritising ideas, features, or concepts. Participants are given a set number of dots (stickers or markers) and can place them on the options they prefer. The options with the most dots are considered the most preferred. This technique quickly gathers group consensus and helps in decision-making processes by visualising collective preferences.	Dot voting was used in Part 1 of the workshop, 'Treatment/session overview', when discussing participants' preferred names for sessions and streams (in small in-person groups). Dot voting was not used online. Instead, facilitators presented the options on their screen (see Fig. 4) and asked participants to use the hand raising function on Teams to vote for their preference and/or suggest an alternative option verbally or in the chat function.
Reverse brainstorming or thinking or "flip it" 	Reverse brainstorming is a problem-solving technique that involves thinking about what could make a problem worse rather than better. Participants identify potential negative outcomes or obstacles	Reverse thinking was used in Part 2 of the workshop, 'How to implement the app into daily routine' by asking – 'How could we integrate HCP in a way that would not be helpful?'

	which can then be flipped to find solutions. By considering the opposite perspective, this technique helps uncover hidden issues and generates innovative ideas for overcoming challenges.	With this question, we aimed to identify what not to do to elicit novel ideas and/or barriers that we may not have otherwise considered.
Storyboards 	Storyboards are effective for communicating complex processes. They often involve visual representations of a user's experience with a product, service or intervention (e.g., a patient's journey through the REFUEL-MS app sessions). They typically consist of a sequence of drawings or images that illustrate key interactions and scenarios. This technique helps stakeholders understand the user's journey, identify barriers or 'pain points' (any discomforts experienced), and generate ideas for improvements.	Text-based storyboards were used in Part 3 of the workshop, 'How to tailor the app for different users/experiences'. We showed an example patient journey through the core sessions of the app and discussed potential options, barriers, pain points and ideas at different stages of the journey. This activity was conducted in breakout rooms with smaller groups.
Proto-personas 	Proto-personas are hypothetical archetypes of potential users based on assumptions and initial research rather than extensive data. They are used early in the design process to	Although we considered creating proto-personas as examples of patients using the app, we decided to encourage participants to create their own

	guide thinking and decision-making. Proto-personas include basic information such as demographics, goals, behaviors, and pain points. They can help the team focus on user needs and create a shared understanding of target users.	'persona' of a patient using the app (considering the patient's demographics and background) to complete the patient journey activity outlined above.
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Figure 4. Example of Dot Voting and Idea Generation for Naming REFUEL-MS Streams

1 - Are there any other names you would like to propose?

 Add a blue sticky note with your proposition

2 - Vote on your favourite name for each stream

 Add a red sticker to the sticky note of your favourite name for each stream (1 vote per stream)

CBT Stream	Exercise Stream	Balance Stream
--- Most Votes ---		
Thoughts, Mood & What We Do Mind, Mood & What We Do	Let's Get Moving	Balance and Strength
--- Other options ---		
General wellbeing Mind Matters	Move More Move My Way Moving More General Activity	Balancing Act Balance Activity Balance
--- PAG Propositions ---		
	Powering up (to refuel!)	

Co-Production Workshop (3): HCPs

The 2-hour workshop was held on 14 November 2023 via Microsoft Teams and included 6 members of the internal REFUEL-MS team, 2 HCP Collaborators, and 3 HCPs working in different MS services and/or charities (2 OTs, 1 PT) across the UK (see Table 7).

Table 7. Co-Production Workshop (3) Attendees and Details

Workshop	Delivery Mode	Duration	Attendees
3 (14.11.2023)	Microsoft Teams	2-hours	Total: 6x REFUEL-MS team 2x HCP Collaborators (1x OT, 1x PT) 3x HCP Participants (2x OTs, 1x PT)

The team presented PowerPoint slides with an outline of the cognitive behavioural model of MS fatigue; an overview of the intervention/app sessions and flowchart; an update on the app and clinician interfaces; and findings from focus groups and interviews with HCPs, particularly around the barriers to REFUEL-MS for both HCPs and pwMS, and ways to overcome these. These materials were presented with the aim to facilitate verbal discussion among the group to answer the pre-specified questions (see above) and to gather feedback about intervention development and inform any necessary changes to ensure that the intervention would be implementable within MS services.

Workshop outputs

Co-Production Workshops (1&2): pwMS, collaborators, and co-investigators

The workshops elicited useful and insightful discussion and ideas from key stakeholders of the REFUEL-MS intervention. Responses to the questions asked in the workshop and subsequent decisions have been outlined in Table 8 below.

Table 8. Question responses and decisions made in Co-Production Workshops 1&2.

Part of Workshop	Question/Key Decision to make	Answer/Suggestions/Decision
Part 1: Treatment/session overview <u>Aim: To review the session overview and names.</u>	Use of: 'sessions' or 'modules' to refer to an app session.	Use 'sessions'.
	Core session names	1. Understanding my MS fatigue 2. Building my routine 3. Improving my sleep 4. My symptoms and setbacks 5. My social support (All include the word 'my' to make sessions personally meaningful to the user).
	Names of 3 streams: 1. CBT	1. Thoughts, Emotions and Actions. (Later changed to

	2. Physical Activity/Exercise 3. Balance	'Thoughts, Feelings & Actions'). 2. Let's Get Moving 3. Balance and Strength (Later changed to 'Balance My Way').
Part 2: How to implement the app into daily routine <u>Aim: Present data from the functionality survey.</u>	<i>What could help with different preferences in length of sessions and daily use of the app?</i> <i>Prompts/survey responses: pause button; calendar feature to plan use.</i>	• Provide a progress bar & add how long an activity may take at the outset. • Allow personalised push notifications. • Specify a deadline by which to complete a task (if applicable). • Give flexibility to postpone tasks. • Concrete goals do not offer flexibility to those with fatigue, differences in preference, commitments or abilities. Allow flexible goal setting. • Tasks should be self-paced, bitesize, a choice/optional.

		• Provide option to “Resume” a session, rather than “take a break”.
	<i>How could we integrate HCP in a way that would not be helpful? (reverse thinking activity)</i>	‘Helpful’ ideas for HCP integration: • Include videos of HCPs throughout the app. • HCPs & pwMS could meet via existing online platforms, e.g., Zoom or Teams. • Appointments could be arranged between pwMS & HCP using an app messaging function. ○ <i>However, need to set expectations that this is not instant messaging.</i> ○ <i>HCPs could have a set time to check messages each week.</i> • HCP support should be optional. • Option to request further HCP support as needed.

	<i>Which term is preferred to refer to the REFUEL-MS HCP? 'Healthcare professional' / 'facilitator' / 'guide'?</i>	Use 'Healthcare professional'.
	<i>What are the potential barriers to someone tracking their activity and/or fatigue? Prompts/Survey responses: memory, motivation, app design, energy. And how could we overcome these?</i>	See Table 9: Barriers and solutions.
Part 3: How to tailor the app for different users/experiences <u>Aim: to consider different characteristics and potential tailoring of the intervention.</u>	<i>What opportunities could there be to tailor the app (to ensure it is appropriate and relevant to people's different experiences and characteristics)?</i>	• Ask questions during registration to determine MS type, level of disability, and identification with under-served/seldom heard group(s). • Ensure there is representation in the app of people living with different types of MS, levels of disability, and from seldom heard groups (i.e., in images and example stories) and that non-stigmatising and

		culturally-sensitive language is used. • Activities and content should only be shown to those for whom it is relevant, e.g., relapse information should only be shown to those who state that they experience relapses or currently have a relapsing-remitting sub-type of MS. • Amount of support that someone wants/needs from their REFUEL-MS HCP should be tailored to individual. • It should be possible to update personal details in the app at any time, i.e., if the pwMS has any changes in their diagnosis, level of disability or has a relapse. • Provide users with a tutorial/step-by-step guide to using the app.
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		• Choose a buddy/avatar (a pwMS) at the start of the app who “joins” the user on their journey through the app. • Selecting intervention ‘streams’ – could there be taster sessions to help pwMS decide a stream or an assessment to complete?
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Key decisions about the app from these workshops included terminology preferences (e.g., using 'sessions' instead of 'modules'), session topic names, and stream names. Workshop attendees suggested features to aid daily use, such as a progress bar, activity duration indicators, and flexible deadlines for tasks. In REFUEL-MS, users are advised to complete one session per week but can do so flexibly, taking breaks as needed.

Attendees recommended integrating healthcare professionals (HCPs) into the app via videos, appointment scheduling via in-app messaging, and optional additional appointments, via platforms like Zoom or Microsoft Teams. The term “My healthcare professional” was preferred for the REFUEL-MS facilitator.

Suggestions were made to tailor the app for pwMS by asking about MS type, disability level, and identification with under-served/seldom heard groups during registration. While such complex tailoring was not feasible, users will complete quizzes throughout the app to determine their content ‘branch’. In the initial ‘Getting Started’ session, pwMS are asked to select what they would like their HCP to know about them, e.g., ‘my home life’, to discuss in

their first appointment to help the REFUEL-MS HCP provide appropriate onward support. The app also ensures diverse representation and uses culturally sensitive language throughout.

In line with suggestions for a user's step-by-step guide, a user manual and onboarding infographic has been developed to assist users, particularly those less familiar with digital technology. Workshop attendees also suggested offering a 'taster' session or an assessment to help users choose a stream. The assessment was deemed more appropriate, involving both a self-assessment on the app and a HCP-led assessment. Users cannot update their personal details such as diagnosis, level of disability and/or a relapse in the app; instead, these details could be discussed during appointments or via messages with their HCP.

There was detailed discussion around potential barriers to pwMS using a tracking feature in the app (e.g., to track their activity and/or fatigue) and ways to overcome such barriers. See Table 9 below for a summary of the barriers and suggested solutions and whether/how these suggestions were implemented in the app.

Table 9. Barriers and solutions for pwMS to track their activity and/or fatigue

Barriers	Solutions/suggestions	Implemented?
1. If the app looks unappealing If the app is visually unattractive, boring or complicated.	1.1 Make it visually appealing and attractive (but also simple). 1.2 App content needs to be: big enough to read; clear; simple; and visually appealing. 1.3 Make tasks interesting, fun and straightforward.	1.1 Implemented. 1.2 Implemented as much as possible (i.e., font size restrictions). 1.3 Added graphics, animations, vignettes, quizzes and guided activities.
2. Digital/internet exclusion If someone has a limited digital access / familiarity	2.1 Optimise usability (make the app user friendly / easy to use). 2.2 Keep it simple (e.g., simple menu).	2.1 Implemented. 2.2 Implemented. 2.3 There will be signposting to resources

(applies to both pwMS & HCPs)	2.3 Offer digital support to those using the app (pwMS) & those providing the app (HCPs). 2.4 HCPs & other pwMS could provide support / encouragement to those using the app, e.g., in testimonials. 2.5 Create a paper version of the app.	and training for pwMS and HCPs to develop digital skills/familiarity with apps. HCPs will receive training on how to use the clinician interface. A user manual (pwMS) and HCP manual has been developed. 2.4 Testimonials will be included in the app. 2.5 A paper version of the app will be co-produced with PPI.
3. Time & other commitments	3.1 Have options to pause and resume sessions. 3.2 Keep things short/simple (e.g., registration).	3.1 Implemented. 3.2 Implemented.
4. If someone is not in the right 'headspace' - Due to symptoms, e.g., cognitive / fatigue) – lower motivation/ability. - If someone is feeling low. - If someone feels overwhelmed by the app	4.1 Have options to pause and resume sessions. 4.2 Make the app flexible to use. 4.3 Allow users to 'turn on' reminders to complete the session/activity another time.	4.1 Implemented. 4.1 Implemented – users can complete 1 app session per week in their own time. 4.3 App users will receive reminders to use the app after periods of inactivity. Reminders/notifications cannot be turned on/off within the app but can be on general phone settings.

- If someone is passive / not motivated / not willing to take ownership		
5. If someone is reluctant/hesitant about certain elements of the app. - e.g., the exercise (activity) stream - sharing personal data during registration – someone may worry about data storage/sharing; someone may resent the idea of being “put into a box” due to certain characteristics.	5.1 Build trust and reassurance: 5.1.1 Outline what is involved from the outset (e.g., what ‘activity’ refers to and involves). 5.1.2 Explain why we need to collect certain information/data; how it will be stored/used; emphasise and ensure confidentiality.	5.1.1 In the first HCP Appointment, HCPs outline what ‘activity’ means in context of REFUEL-MS. Also, explained in first session of this stream. 5.1.2 Implemented in the app Privacy Notice/Terms and Conditions.
6. Lack of understanding If complex language/jargon is used.	6.1 Use simple language, avoid jargon.	6.1 Implemented – where complex language/terms are used in the app, drop-down definitions are provided.

There was also discussion about which features and functionalities should be included in the REFUEL-MS app. Table 10 summarises the suggestions and indicates whether they were implemented.

Table 10. Features and Functionality Suggestions from Co-Production Workshops 1&2.

Feature/functionality aspect	Specific feature/functionality	Implemented?
1. Reminders / push notifications	1.1 Ability to turn off notifications/reminders. 1.2 Not too many – individual control over how many. 1.3 Words of encouragement. 1.4 Personalisation of notifications (users write their own).	1.1 Not possible in the app but possible in phone settings. 1.2 Not possible in the app but possible in phone settings. 1.3 Implemented. 1.4 Not possible.
2. Personalisation/tailoring	2.1 Select which sections/activities you want to complete / skip. 2.2 Welcomed by name. 2.3 Create own reminders & push notifications (some may prefer encouragement / guilt / jokes etc.) 2.4 Calendar – option to sync with individual's existing digital calendar; plan their days using a calendar/diary.	2.1 Although users are encouraged to complete all core sessions, some can be missed and activities can be skipped throughout. 2.2 Implemented. 2.3 Not possible. 2.4 Calendar not built in the app. 2.5 Implemented – users can write their own goals.

	2.5 Set personal individual goals - account for different levels of fatigue. 2.6 Activities should be based on individual ability. 2.7 Ability to change layout of homepage? 2.8 Options to change font size, colour scheme & other visual settings?	2.6 Implemented - users can modify activities; different plans and levels developed for different abilities. 2.7 Not possible. 2.8 Not possible.
3. Track progress visually (e.g., graphs)	3.1 Progress bar (through app sessions / overall intervention). 3.2 Meeting goals / completing activities. 3.3 Fatigue levels.	3.1 Implemented – progress bar through sessions (not overall intervention). 3.2 Implemented- Completed goals move into 'Completed' goals list. 3.3 Implemented – fatigue level graph.
4 Flexibility	4.1 Take breaks within sessions. 4.2 Show deadlines to complete sessions (if applicable) 4.3 Option to postpone /move tasks to another day (a certain no. of times) 4.4 Ability to do multiple 'streams'	4.1 Implemented – app suggests good places to take a break. 4.2 In session, suggest how long to spend on an activity/session.

		4.3 There is flexibility to do 1 session per week in one's own time. 4.4 Not possible at this stage.
5. Peer support and community	5.1 Connect with others using the app (encouragement) on the app. 5.2 Share perspectives of pwMS who have used the app (e.g., testimonials). 5.3 Signpost to a messaging forum that is managed by external sources (e.g., Shift MS). 5.4 Choose a 'buddy' to appear throughout the app (cartoon / avatar).	5.2 Not possible due to additional funding/moderation. 5.3 Implemented – testimonials. 5.4 Implemented – support suggestions in Core session 5. 5.5 Not possible.
6. Incentives/reward	6.1 Sounds 6.2 Ticks of completion	6.1 Not possible. 6.2 Implemented – ticks are shown for completed sessions.
7. Visual	7.1 Images/videos (not too much text) 7.2 Icons/emojis 7.3 Diagrams	7.1 Implemented – images, videos and animations used. 7.2 No, but images, videos and animations used.

		7.3 Implemented – images, videos and animations used.
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Co-Production Workshop (3): HCPs

The workshop resulted in interesting discussions with the HCPs about the intervention/app appearance, features and functionality; how the app would be used in their respective services; and how to overcome potential barriers to patient engagement. We also briefly discussed training needs for HCPs supporting REFUEL-MS. See Table 11 for an overview of discussion topics and feedback given.

Table 11. An overview of discussion topics and feedback given in Co-Production Workshop (3): HCPs.

Discussion Topic	Discussion/Feedback points/Ideas <i>(see in brackets the number of attendees who suggested each point).</i>
General feedback/ideas about the app/intervention: flow; appearance; features & functionality	• (All) Good colour scheme and layout • (All) Modern and straightforward • (x2) Use Zoe app for ideas • (x1) Automated nudges are “naff” – not as effective as personalised communication. There is already a separation between the HCP and patient so it is important to reduce the effects of this.
General feedback/ideas about the clinician interface	• (All) HCPs should be able to see patient’s goals in HCP interface so they can signpost patients elsewhere etc.

	(x1) HCPs should be able to record length of appointments with the pwMS.
How might HCPs and pwMS use the app in your service?	
<i>How far in advance could services pre-book REFUEL-MS appointments, i.e., 1-week?</i>	<i>Not discussed/answered</i>
<i>What are the typical waiting times for appointments?</i>	<i>Not discussed/answered</i>
<i>Would appointments be virtual or face-to-face? Could either work?</i>	(All) The first session should be face-to-face (f2f) but follow up appointments could be via video. Risk assessments are usually done after having met someone f2f at least once. This also builds rapport.
<i>What is the preferred way for pwMS to contact HCPs while using REFUEL-MS (a chat function via the app or via email)?</i>	(All) Liked the idea of chat function for pwMS-HCP contact but would prefer using work email rather than having to log into a separate system. (All) Email option may vary between different NHS Trusts and non-NHS organisations so it might be better to have a standardized approach.
<i>Time commitment: What is a feasible/realistic time commitment for each pwMS using the app? How long could a pwMS continue to use the app (under the HCP's care) after completing the 16-week intervention (i.e., up to 6-months)?</i>	(All) Agreed that 3-hours per patient seems a reasonable amount of time and that REFUEL-MS seems more efficient than current fatigue management approach, e.g., an existing group-based intervention requires 12-hours. (All) The length of time that patients can stay within a service before being discharged varies between Trusts – each Trust has different

	protocol around this. Also, some Trusts measure 'improved outcomes' through discharge rates so they would be less likely to keep patients on caseload. Difficult to say whether pwMS could continue to use the app under the HCP's care.
Identifying/Overcoming barriers	
Motivation/readiness for change	• (All) It is difficult to sustain patient motivation in shorter interventions, even in 1:1 or group settings, so it could be difficult to do this remotely for a longer period of time. • (All) Gamification and positive reinforcement are very important. Could use 'stars' or 'rewards' or some way to congratulate people on their progress. • (x1) Ensure that pwMS' questions are answered promptly (via the app/HCP). • (x1) Need to assess readiness to change during initial assessment and perhaps include a measure for this.
Engagement	• (All) There should be an alert system to inform HCPs if someone's progress reverses or if a patient stops engaging with the intervention. • (All) Suggested peer support. A team member acknowledged there would need to be funding and moderating for this. Alternative suggestion, signpost to a central peer group/forum that users join (e.g., ShiftMS). Could share resources in Core session 5 – My support.

Discussions/Ideas about HCP training	• (All) It is considered 'normal' and standard across services for HCPs to complete educational programmes with related competencies. • (All) Acknowledged healthcare is moving towards app-based treatments so this training would be helpful to keep up-to-date with other treatments and evidence. • (x1) Important to explain in HCP training why patients will only undertake one stream. • (x1) The explanation of the model of MS fatigue was helpful (other HCPs might benefit from this). • (x1) Give HCP clear instructions on how to direct pwMS to a specific stream. In future, the team will seek HCP feedback on the (risk) assessments for each stream.
Other discussions/ideas	• (x1 team member) 'Self-assessment' (self-evaluation) should be no more than 10 questions.

All workshop attendees liked the app colour scheme and layout and agreed it was “modern and straightforward”. One attendee stated that “automated nudges” are “naff” and could potentially reduce user engagement and be less effective than personalised ones. Due to the complexity of such functionality, it would not be possible for the app developers to build personalised nudges, and instead we suggested a two-way messaging platform between the pwMS and HCP. While attendees liked this idea, some would prefer using their work email to contact app users for ease. However, others highlighted that in some NHS Trusts or organisations, it is not possible to contact service users via email so it would be helpful to have a standardised option for all.

This led to the development of a two-way messaging platform within the app, accessible via the clinician interface, with a disclaimer that it is not an instant messaging platform nor to be used for emergencies.

All HCPs agreed that the first appointment with pwMS should be face-to-face (f2f) to help build rapport and conduct risk assessments, with later appointments conducted virtually (via Microsoft Teams). In practice, the team would need to determine how feasible it would be to conduct f2f appointments and consider alternative options.

The HCPs considered 3-hours per pwMS to be an acceptable time allocation over 16-weeks as it would be more efficient than their current fatigue management approach, with an existing 12-hour group intervention. However, they mentioned that time allocation and staff availability would vary between services. They also highlighted that it would be difficult to sustain patient engagement over a 16-week period as it is already difficult to do so in shorter, f2f, group interventions. They suggested ideas to help with this, including gamification and positive reinforcement such as using 'stars' or 'rewards' to congratulate users and acknowledge progress. This was implemented with congratulatory messages and confetti bursts upon session completion.

The HCPs also proposed features for the clinician interface to support patient engagement, including viewing patients' goals, recording appointment lengths, and receiving alerts if someone stops engaging or their progress reverses. While an alert for reversed progress wasn't feasible, other alerts were implemented (see Table 12).

Table 12. Clinician interface alerts

Patient not logged in for 7 days (Trigger): Red (Severity alert): Your patient has been inactive on the app for 7 days. Please send them a message to check in with them.

Patient not self-registered (Trigger): Red (Severity alert): Your patient has not yet self-registered. Please phone or send an email to remind your patient to self-register on the app to get starting with using REFUEL-MS or offer support with registering if needed.

Patient has finished core session 1 (Trigger): Red (Severity alert): Patient has finished core session 1. This is a reminder to book appointment 1 with your patient. If you have not done so already or check to see when it is scheduled. You might want to send a reminder message to your patient by going to the patient profile.

Discharge message (Trigger): Red (Severity alert): Your patient has been registered on REFUEL-MS for 6 months. If you feel your patient would benefit from a further 2 months of usage on the app. Please let them know they can continue with your support for a further 2 months. If your patient has finished, please discharge them by completing the form.

Message received from patient (Trigger): Green (Severity alert): You have received a message from your patient. Check the patient profile to read the message.

You will receive the following notification in your email if you have not logged onto the REFUEL-MS HCP website for a while.

Log in to REFUEL-MS (Trigger): Green (Severity alert): This is a reminder to log into the REFUEL-MS HCP website each week to see how your REFUEL-MS patients are getting on.

HCPs suggested incorporating peer support in the app to increase user engagement. This was not feasible as it would require additional funding for moderation, however, they also suggested signposting users to central peer support groups like ShiftMS. As a result, sources of support, including local groups and charities, are mentioned in Core session 5 of the app, 'My support'.

There was also a brief discussion about HCP training needs for supporting REFUEL-MS. Key suggestions proposed for training included: (1) why pwMS complete only one intervention stream; (2) the MS fatigue model underlying REFUEL-MS; and (3) how HCPs will direct pwMS to specific streams. Formal assessments to assist HCPs in this task were co-developed later.

Overall, the HCP Co-Production Workshop provided valuable feedback and ideas for the REFUEL-MS app, clinician interface, and strategies to enhance user engagement and app implementation.

Limitations of the process

Aligning the theoretical ideals of co-production with practical digital intervention development posed challenges. Co-production emphasises shared decision-making throughout all research stages (Greenhalgh, 2018), but it was not always feasible to incorporate others' suggestions into the app/intervention due to constraints like funding, moderation, and technical capabilities. Thus, not all complex suggestions from the workshops were implemented, and instead required prioritisation based on existing evidence and efficacy in reducing MS fatigue.

Moreover, the HCP workshop relied solely on online video-based discussions, unlike the creative co-design techniques used in workshops 1 and 2. Future workshops could involve more creative methods or design thinking to support idea generation and discussion (Grindell, Sanders, et al., 2022; Wolstenholme et al., 2019). However, this was not feasible for this particular workshop and did not appear to affect the productivity of discussions and input.

A broader limitation of co-production is the potential lack of generalisability due to limited diversity and small participant numbers. While experts argue that generalisability is not the goal of co-production (Williams et al., 2020), it remains a concern for user-centred design aimed at enhancing intervention acceptability. REFUEL-MS has aimed to address this by recruiting participants across the UK from diverse healthcare settings and under-served groups.

Section 3

General intervention development

Initial decisions

Research proposal and funding application

In REFUEL-MS, the PAG has been involved since the outset of the programme. PAG members provided input on the research proposal and funding application, with the lead member of the group listed as a co-investigator.

A combined intervention

We conducted a workshop with the PAG to present evidence from systematic reviews on MS fatigue interventions (Moss-Morris et al., 2021). The evidence demonstrated positive effects of both cognitive behavioural therapy (CBT) and exercise in managing MS fatigue. Consequently, the group decided that REFUEL-MS should be designed as a combined CBT and exercise intervention.

App-based intervention

During the first official PAG meeting in December 2022, we deliberated on whether the intervention should be web-based or app-based. The group members present (n=6) raised concerns about the accessibility of app-based interventions, particularly regarding vision and dexterity challenges common in MS. However, app-based interventions offer the advantage of being usable "on the go," unlike web-based interventions, which are often associated with work and require sitting at a laptop or computer – a setup not readily available to everyone, especially those from underserved groups. Ultimately, we decided that REFUEL-MS would be app-based, acknowledging that it might not appeal to everyone.

Branding and appearance decisions

REFUEL-MS logo

The REFUEL-MS logo that would be used on all future outputs relating to the programme (e.g., study materials: recruitment posters, consent forms, surveys; PPI posters; and other internal documentation) was chosen in January 2023, following lengthy discussion with and feedback from the PAG. See Figure 5 below.

Figure 5. REFUEL-MS Branding logo



App logo and colour scheme

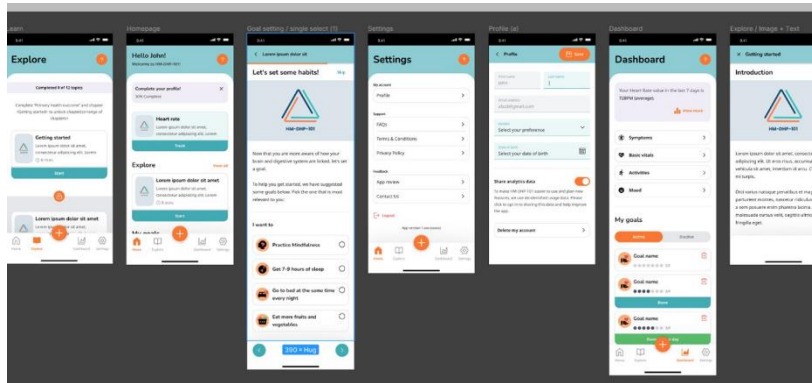
The PAG, internal team and co-investigators were asked to vote for the logo to be used in the app using Microsoft Forms. The options were shared as email attachments and added on the Forms too. Sixteen people voted (8 PAG members, 5 internal team members, and 3 co-investigators). See Figure 6 below for the selected option (based on the greatest number of votes = 8).

Figure 6. REFUEL-MS App logo



The selected logo aligns with the app's chosen color scheme of orange and turquoise. Twenty-one people participated in the vote on the color scheme (7 PAG members, 7 internal team members, 4 co-investigators, and 3 anonymous voters). Sixteen voters favored the orange and turquoise scheme (see Figure 7) over the other options, which included turquoise and dark blue, turquoise and pink, purple and pink, purple and turquoise, and purple and orange.

Figure 7. App colour scheme: Turquoise and orange



The reasons provided by PAG members for this decision are detailed in Table 13 below.

Table 13. Reasons for choosing the app logo and colour scheme: Turquoise and orange

App logo	Colour scheme: Turquoise and orange
<i>The colour orange will naturally associate it with the MS Society, both here in the UK and in America. However, the colour orange is generally quite synonymous with MS these days, so not necessarily a bad thing.</i>	<i>I like the orange - stands out. The pink and purple together, looks quite feminine and I think might be off putting. The use of blue makes the product look professional.</i>
<i>I prefer the cleaner options with the darker font colour.</i>	<i>I personally detest orange to wear but I understand that it is a key colour for the MS society and this is why I have chosen the two that contain orange. My preference is the turquoise and orange.</i>
	<i>I think orange should definitely be a part of it so it can keep the theme of the orange balloon.</i>

App Graphics/Illustration styles

In December 2023, the app developers presented various graphic and illustration style options for the app. During the first round, they shared examples of illustration styles/themes to be used in the app, offering three options (see Figure 8 below). These options were voted on by 9 PAG members, 5 REFUEL-MS team members, and 3 co-investigators. Option 2 received the most votes (n=11) and was subsequently selected. Feedback was gathered on this (Table 14).

Figure 8. Options 1-3 of illustration styles/themes for the app

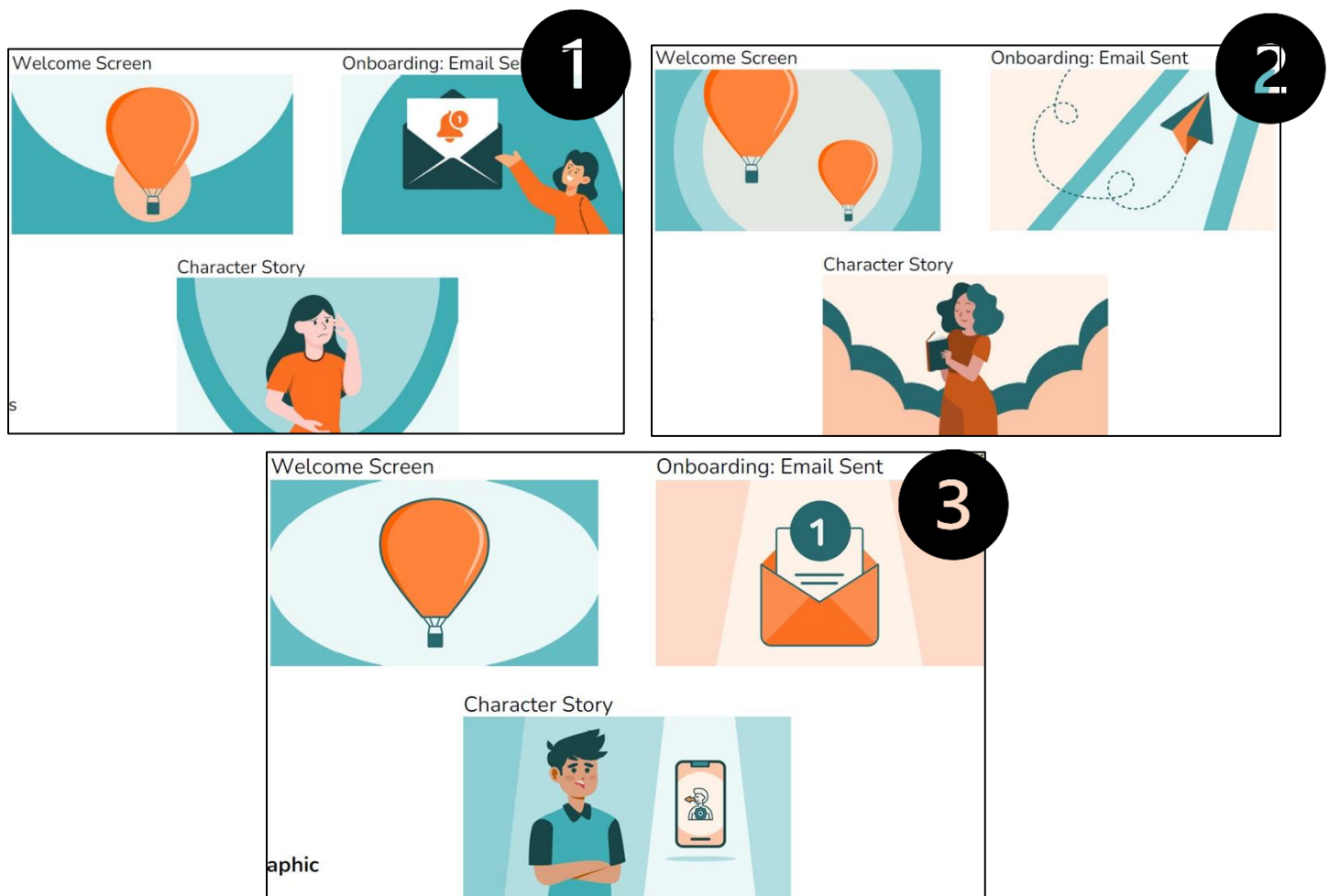


Table 14. Feedback on illustration styles/themes

PAG members	REFUEL-MS team	Co-Investigators
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(Option 2) Maybe change the font as in where you put character story and something a bit more visible to see.	(Option 2) I prefer a minimal use of the darker colours. Option 2 seems the brightest and most positive.	(Option 2) Option 2 character looks a bit more 'happy'. But this may not be relevant, depending on what we want to portray.
(Option 3) All quite similar... I have selected option 3, but all of them seem pretty good.	first pref option 2, second pref option 3	(Option 2) I chose 2 as there will probably be 3:1 women....and option w1 looks distressed
(Option 2) I find option 2 more 'optimistic' somehow & forward moving, which is the direction of travel the app would hope to take us!		(Option 3) I like the colour palettes. although option 3 has more shades than option 1, the images themselves seem cleaner and neater.
(Option 1 & Option 2) I wasn't keen on option 3, it felt like there was something missing from the graphic No 1 was my preferred option.		

(Option 2) Although I have selected option 2, I do like the Character story of option 3 because it uses a smart phone and it feels more connected to current technology and actual habits. If this were included with option 2 in my opinion it would have stronger future proofing.		
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Based on this feedback, the app developers presented additional graphic and illustration options, including revised illustration styles and themes, characters to feature in the app, and thumbnails/icons (e.g., clock icons, lightbulbs for activities). Thirteen people voted (8 PAG members and 5 REFUEL-MS team members), and decisions were made according to the highest number of votes, particularly those from PAG members.

Intervention content: Written feedback and small group discussions

The intervention content was developed iteratively and collaboratively between March 2023 and February 2024. REFUEL-MS team members drafted the initial content and shared it with relevant stakeholders for feedback. This included PAG members, co-investigators with expertise in CBT, exercise interventions, and physiotherapy, as well as diversity collaborators.

In September 2023, the two PAG co-leads at the time were invited to review Word documents of the app's first two core sessions: (1) Understanding My MS Fatigue and (2) My Routine. They provided valuable general feedback applicable across sessions and specific feedback that addressed our queries, significantly shaping the development of these sessions. For examples of the general and specific feedback given by the PAG co-leads, see Table 15.

Table 15. Examples of general and specific feedback provided by the PAG Co-Leads in Core Sessions 1 and 2.

Examples of general feedback:
(Core Session 1 – PAG Co-Lead 1) <i>Assume the underlining will be taken out when this is designed? More accessible/easier on the eye with a header (smaller than the top header).</i> (Core Session 2 – PAG Co-Lead 2) <i>I wonder if a consistent voice is actually needed? Could use both but in different contexts: 'our' when talking more generally and 'your' when it's about the user's experience and programme specifically? Ask PAG for thoughts. It could be quite an individual view so the above approach could cater for variety of views?</i>
Examples of specific feedback:
(Core Session 1 – PAG Co-Lead 2) <i>Suggested alternative wording: Today we will understand the factors that can contribute to MS fatigue and build an understanding of what MS fatigue is like for you, that is your personal 'model' of MS fatigue.</i> (Core Session 2 – PAG Co-Lead 1) <i>Does the phrase boom and bust need to be mentioned at all? It might confuse something that is clear without that phrase.</i> (Core Session 2 – PAG Co-Lead 1) <i>Suggested re-phrasing the following text: 'you should start to feel better able to manage your fatigue' to 'your fatigue should start to feel more manageable'.</i>

In January 2024, we shared Word documents of the intervention content with 9 PAG members and held 5 Microsoft Teams meetings with groups of 1-3 members to gather feedback on session content, language, tone, flow, and ease of understanding. Some members also provided written feedback. Their input was instrumental in finalising the content before the app developers began building the app.

Intervention content/session	Written feedback from:	Discussed via Microsoft Teams with:
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Self-assessment (to help pwMS decide an intervention stream)	2x PAG members (Jan 2024)	-
Core Session 1 - Understanding my MS Fatigue)	2x PAG Co-Leads (Sep 2023: see above) 2x PAG members (Jan 2024)	2x PAG members (Jan 2024)
CBT Session 1 (6A) – Building up my routine	1x PAG Co-Lead (Jan 2024)	1x PAG Co-Lead (discussed in-person: Jan 2024)
Balance Session 1 (6A) – Building up my balance routine	-	2x PAG members (Jan 2024)
Core Session 4 – My sleep	-	3x PAG members (Feb 2024)
Core Session 5 – My support	1x PAG member (Feb 2024)	2x PAG members (Feb 2024)
Exercise Session 1 (6A) – Building up my exercise routine	-	1x PAG member (Feb 2024)

Videos and voiceovers

Between February and March 2024, the REFUEL-MS team created and edited 32 animations and 22 videos for the app. Eleven people with MS (pwMS) and 1 patient advocate volunteered to participate in either videos or voiceovers for the animations. Volunteers were able to edit or adapt the script as needed and were given the opportunity to review and approve the videos and animations they featured in.

This process was challenging due to tight deadlines for delivering the videos and animations to the app developers. It also required significant logistics and planning to accommodate filming around busy schedules and to ensure the timely signing and return of release forms. Although we included a diverse group of pwMS, most preferred to provide voiceovers rather than appear

in videos, which limited the diversity and representation in the app's videos. However, we were able to ensure diverse representation in the animations created by the team using Canva.

Supporting REFUEL-MS Healthcare Professional (HCP) Training

As previously mentioned, the training needs for HCPs supporting REFUEL-MS were briefly discussed in the HCP Co-Production Workshop (see section 2: Co-production Workshops).

Subsequently, the REFUEL-MS team, including a Specialist OT, Health Psychologist, and Research Assistant, developed the HCP training package in collaboration with others. Plans and scripts for REFUEL-MS HCP appointments were reviewed and edited by two HCP collaborators and co-investigators with expertise in CBT (n=1), exercise interventions (n=2), and physiotherapy (n=1), along with two diversity collaborators.

Between June and July 2024, three PAG members and one diversity collaborator participated in a practice appointment with a REFUEL-MS HCP before the REFUEL-MS Acceptability Study. This study is crucial for intervention development, as we aim to gather feedback from pwMS on the app's acceptability and usability to inform further development. These practice appointments were essential in training the REFUEL-MS HCPs and provided an opportunity to receive feedback from pwMS on the first REFUEL-MS HCP appointment, focusing on content and delivery. The participants also offered feedback and suggestions regarding the app (see Table 16 below).

Table 16. Practice HCP Appointments: Feedback and suggestions

Feedback/suggestions to appointment content and delivery: <i>Note: these suggestions have been implemented into REFUEL-MS HCP Training and the relevant HCP Appointment scripts.</i>
• HCPs should introduce themselves (i.e., first name, surname, their HCP role and work location/base) – this openness gives context and helps build rapport. • HCPs should establish boundaries/expectations about the role of the HCP and know where to signpost people to for other concerns.

- HCPs should acknowledge/validate the difficult thoughts and feelings that can come up when completing one's personal model of MS fatigue.
- The importance of flexibility in terms of communication style (e.g., open vs closed questions or direct questions vs implied 'questions' in the form of "I wonder..." statements) to meet participants' individual needs cannot be overstated.

Feedback/suggestions for the app:

Note: these suggestions will be considered as future app enhancements.

- Consider what could help increase user's motivation throughout the core sessions (incentives/rewards).
- There could be a summary or map in the app of what is included in each app session (e.g., describe the videos included in each session) so that users know where to look for a specific video.

Given our focus on working with under-served and seldom-heard groups, it was essential to ensure that HCPs supporting the intervention are culturally competent and able to work with a diverse range of pwMS. Therefore, we developed a HCP training module on 'Cultural Competency and Diversity' specifically related to pwMS fatigue. This module, which includes a roleplay with a pseudo-patient, was reviewed by three diversity collaborators (two of whom are patient advocates) and amended based on their feedback.

Section 4

Think Aloud Usability Testing

This section of the report outlines the procedure of how the Think Aloud usability testing was conducted with PPI within the REFUEL-MS programme. This section will also detail a summary of the findings, and how these played an important part in our intervention development.

Rationale

Think Aloud usability testing is considered an important aspect of digital intervention development as they can help to evaluate the user's perceptions of the intervention and how they may interact with it (Bradbury et al., 2014). For the purpose of REFUEL-MS, concurrent Think Aloud testing was used (Alhadreti & Mayhew, 2018; Ericsson & Simon, 1984). In this approach, the user (in this case the 'pwMS') is asked to talk through their thoughts about the intervention (the REFUEL-MS app) whilst the researcher/test leader is present. This process is considered vital in intervention development to inform necessary changes to the intervention (Bradbury et al., 2014). For example, this process can help identify relevant content that may need to be amended (Bradbury et al., 2014; Yardley et al., 2011). The Think Aloud process is an important part of the aforementioned PBA to intervention development, in terms of assessing the acceptability of an intervention (Yardley, Morrison, et al., 2015).

Previous literature indicates the usefulness of Think Aloud usability testing in informing changes to digital intervention. An existing web-based weight management intervention used this process to identify that users were not setting goals nor planning as the intervention intended, and hence led to this aspect of the intervention being improved (Yardley et al., 2013). This method has also been used to assess usability of a mobile health app within a mental health setting (Storm et al., 2021).

Development of protocol & task analysis

A previous study using Think Aloud methodology employed a two-step process (Storm et al., 2021): first, users were asked to express their initial impressions of an app; second, they completed 'task analysis' whereby users provided feedback on eight specific tasks. For REFUEL-MS, a protocol was developed to follow a similar Think Aloud process, with participants sharing their first impressions of the app's home screen. Users then completed session-specific tasks (e.g., playing a video) and provided feedback. While prompts were used as needed, some tasks, such as locating information drawers, were unprompted to determine whether users could find such information on the app independently.

Think Aloud Procedure

To conduct the sessions, we developed a formal process of conducting the Think Aloud testing. This was to ensure that there was a rigorous way of capturing the data from the sessions and enable us to use this information when writing up our results. This was facilitated by the following documents:

- **A standardised protocol**
 - This contained a structure of how to begin the session, the specific tasks related to that session, any specific prompts that the test leader could use, and how to draw the session to an end.
 - This protocol was then adapted for every REFUEL-MS app session that was tested due to the differing tasks between sessions.
- **A feedback form containing two parts**
 - Part 1: This gave the test leader a structured way of gathering feedback relating to language, content, usage, software bugs and technical aspects, formatting and style, and any other general comments.

- Part 2: This was used to note down the following things relating to each task: Y/N (if the task had been completed or not), hints used by the test leader, number of hints, effectiveness rating (1-3 scale), and ease-of-use average score.
- **Individual screen feedback form**
 - This collated feedback for each individual screen of the REFUEL-MS app, including two columns (positive and negative feedback).

Think Aloud sessions were not recorded so the test leader was encouraged to take detailed notes throughout to ensure as much information could be collected as possible.

Summary of findings

This section of the report outlines the findings of the Think Aloud usability testing. In total, there were nine Think Aloud sessions conducted with eight different participants (one participant tested two different sessions). This involved individuals from our **PAG** and/or people who had signed up for **PPI** activities.

Characteristics of the participants

Demographic characteristics of the participants involved are presented in Table 17 below.

Table 17. Sample characteristics.

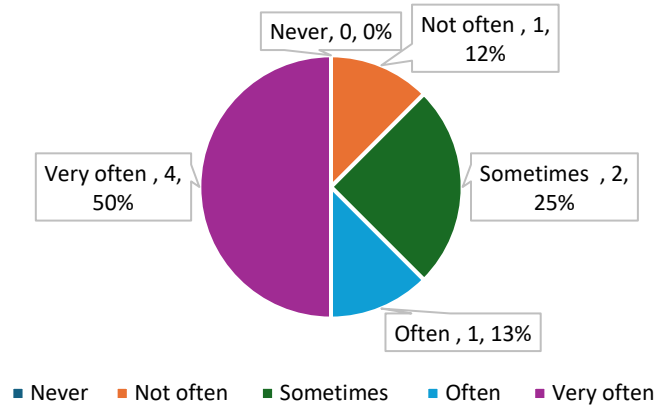
Sample characteristics	N (%)
Age	
18 – 24	0 (0.0%)
25 – 34	0 (0.0%)
35 – 44	4 (50.0%)
45 – 54	1 (12.5%)
55 – 64	2 (25.0%)
65+	1 (12.5%)

Sample characteristics	N (%)
Gender	
Woman	6 (75.0%)
Man	2 (25.0%)
Ethnic group	
White	7 (87.5%)
Mixed/Multiple ethnic group	0 (0.0%)
Asian/Asian British	0 (0.0%)
Black/African/Caribbean/Black British	1 (12.5%)
Other ethnic group	0 (0.0%)
MS-type	
Relapsing-remitting MS	7 (87.5%)
Secondary progressive MS	1 (12.5%)
Primary progressive MS	0 (0.0%)
Sexual orientation	
Straight/Heterosexual	7 (87.5%)
Gay or Lesbian	0 (0.0%)
Bisexual	0 (0.0%)
Other	1 (12.5%)
Highest level of education	
A-level or equivalent	1 (12.5%)
Bachelor's degree	5 (62.5%)
Master's degree	2 (25.0%)
Other	0 (0.0%)

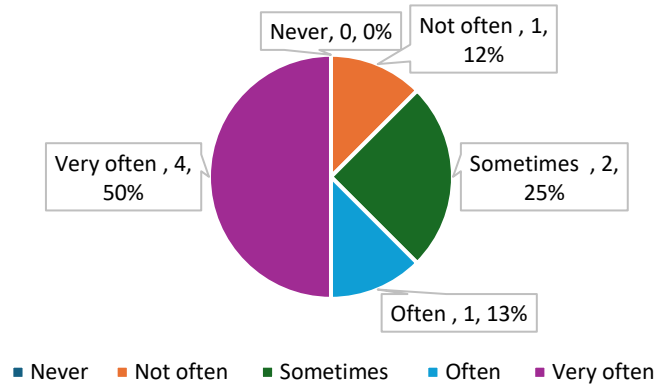
Digital literacy was assessed by asking participants to rate how often they use a smartphone and/or tablet for the following tasks: email, internet surfing/browsing, apps/computer games. They rated this on a 5-point Likert scale ranging from never – very often. The responses have been presented in a pie chart for each of the tasks (Figure 9).

Figure 9. Digital literacy levels.

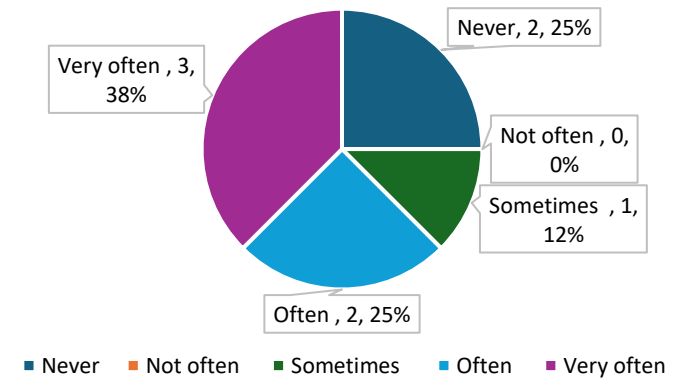
Email



Internet surfing/browsing



Apps/computer games



Quantitative findings

REFUEL-MS sessions

Nine Think Aloud sessions were conducted. This involved 5 different REFUEL-MS app sessions being tested. Table 18 provides an indication of which sessions were tested. The last session was tested by only one participant.

Table 18. REFUEL-MS app sessions tested.

REFUEL-MS app session	n
Core session 1 – Understanding my MS fatigue	2
Core session 2 – My routine	2
CBT session 6A - Building up my routine	2
Exercise session 6A – Building up my exercise routine	2
Balance session 6A – Building up my balance routine	1

Ease-of-use scores

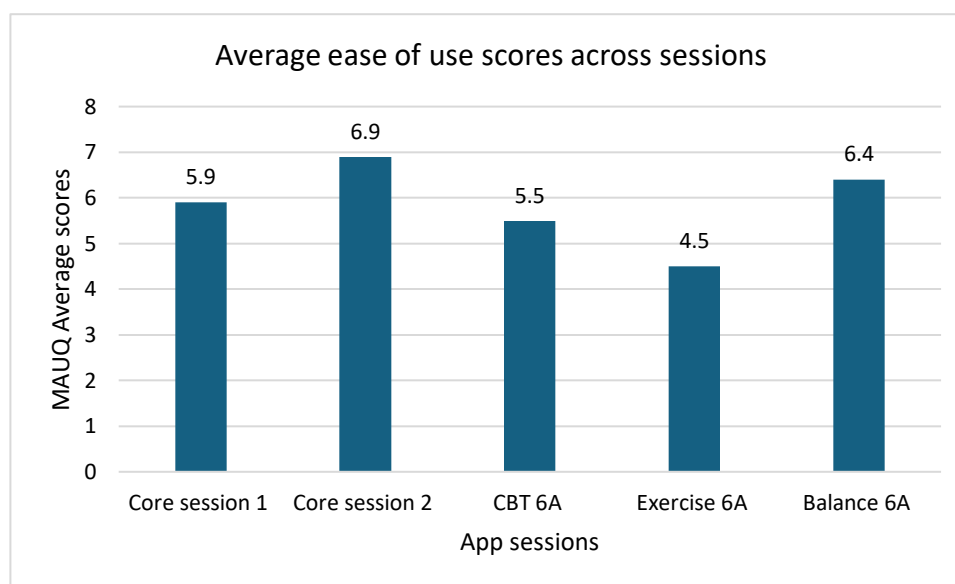
Ease of use average scores were collected from each participant using the mHealth App Usability Questionnaire (MAUQ) ease of use 5-item sub-scale (Zhou et al., 2019). These were scored on a scale of 1 (disagree) to 7 (agree) (see Table 19 for the items used). An average score was calculated across the items. A higher average score indicated that the app was easier to use. The results across sessions are presented in Figure 10 below, where it can be seen that the average score was lowest for the exercise session, and highest for core session 2.

Table 19. MAUQ ease of use items.

MAUQ ease of use items
The app was easy to use
It was easy for me to learn to use the app
Whenever I made a mistake using the app, I could recover easily and quickly
The navigation was consistent when moving between the screens
The interface of the app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by the app

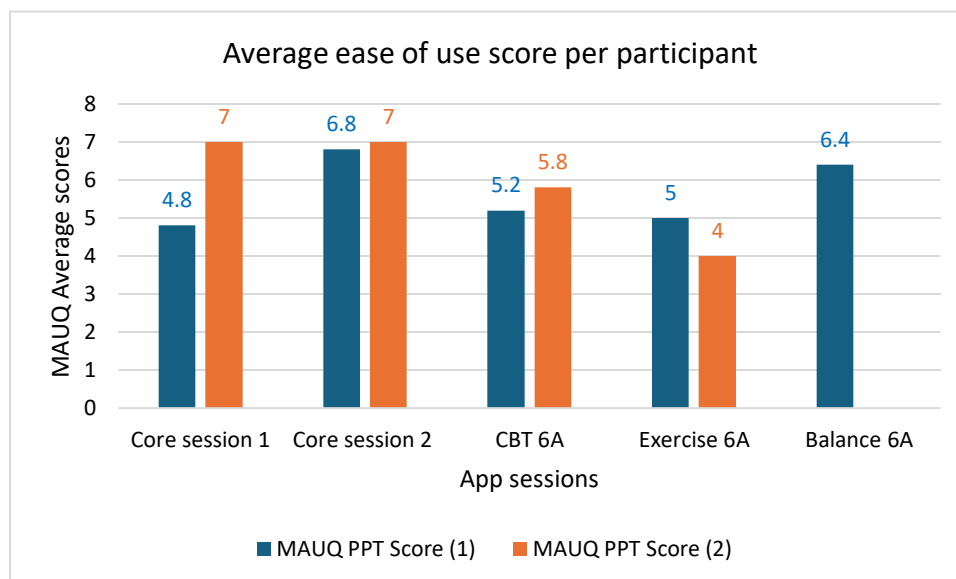
Note: MAUQ – mHealth App Usability Questionnaire

Figure 10. Ease of use average scores across sessions.



However, due to there being only one person testing the Balance 6A session, it was deemed useful to compare individual average scores per session. The results have been presented in a clustered bar chart (Figure 11 below). Scores did not differ greatly between sessions, but it can be observed from this chart that there is a great discrepancy in scores for core session 1. This could potentially be due to differences in the digital literacy levels between the participants. Interestingly, the participant that had an average score of 4.8 had lower digital literacy levels and responded, “Never” in response to how often they use their smartphone and/or tablet for apps/computer games. In contrast to this, the other participant that tested core session 1 scored higher on digital literacy in response to all three digital literacy questions. Both participants testing the exercise session had lower levels of digital literacy and rated “never” or “sometimes” in relation to the use of apps. However, one of these participants was the same who tested core session 1 and scored lower. In addition, one of the participants testing the CBT session had a higher ease of use score (5.8) despite reporting lower levels of digital literacy. However, one limitation of this is that there was not enough power to conduct statistical analyses. Hence, also given the lack of evidence supporting this suggestion, the above points are just inferences made from the data observed.

Figure 11. Clustered graph of individual scores.



Effectiveness scores

The effectiveness of conducting several “tasks” within the Think Aloud sessions was rated on a scale of 1 to 3 (1 = completed with ease when the user was able to perform the task without any help from the test leader and 3 = failed to complete when the subject was unable to complete the task even with some minor hints). Average scores were calculated, however, for ease of interpretation, mode and proportions have been reported (see the clustered bar chart in Figure 12 below). However, due to the number of different tasks between sessions, and also the balance session only being tested by one participant, the data has also been presented in a table, with percentages, for clarity (see Table 20 below). It can be seen clearly from the figure, and the table, that the most common effectiveness rating across sessions was “1” (meaning tasks were mostly completed with ease).

Figure 12. Effectiveness ratings across sessions.

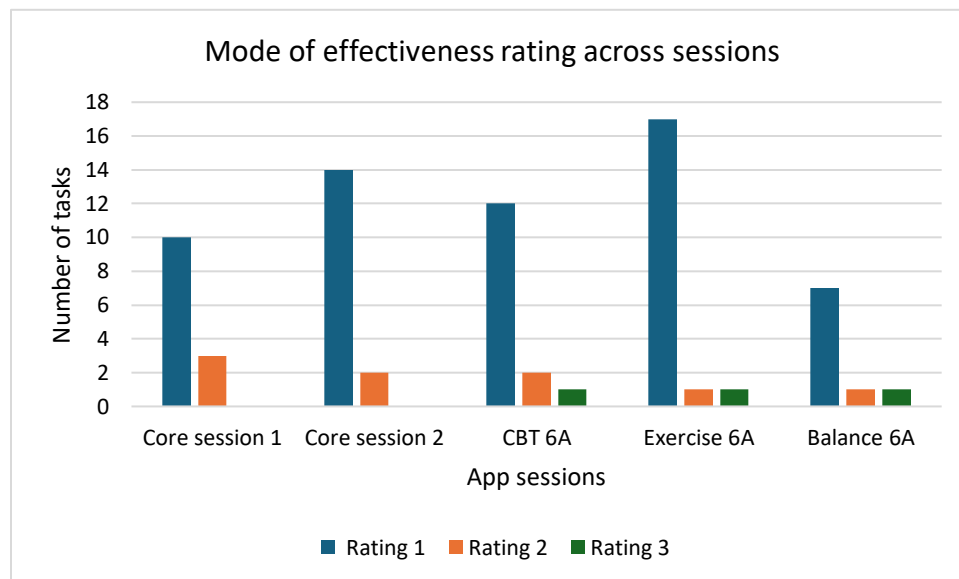


Table 20. Effectiveness ratings across sessions (mode and proportions).

Sessions	Effectiveness rating 1 (N, %)	Effectiveness rating 2 (N, %)	Effectiveness rating 3 (N, %)	Total number of tasks combined
Core session 1	10 (76.9)	3 (23.1)	0 (0.0)	13
Core session 2	14 (87.5)	2 (12.5)	0 (0.0)	16
CBT 6A	12 (80.0)	2 (13.3)	1 (6.7)	15
Exercise 6A	17 (89.5)	1 (5.3)	1 (5.3)	19
Balance 6A*	7 (77.8)	1 (11.1)	1 (11.1)	9

*Note: Balance 6A was only tested by one participant.

Number of hints

Although prompts were part of the standardised protocol, hints differ. Prompts are pre-planned additional instructions given to facilitate the user to “Think-out-loud”. Hints, however, are unplanned guidance given in relation to specific tasks. The number of hints given by the test leader to help facilitate some of the tasks were also recorded. Averages across each session per participant were calculated. However, to ease interpretation of findings, proportions have been reported. It was found that the majority of participants needed 2 hints across tasks per sessions (44.4%). For more detail of the results see Table 21.

Table 21. Number of hints needed across tasks.

Number of hints across tasks	(N, %)
0 hints	2 (22.2)
1 hint	2 (22.2)
2 hints	4 (44.4)
4 hints	1 (11.1)

An important aspect of this data was to observe which task(s) most commonly required hints. The following tasks required hints from the test leader, indicating that some changes would need to be made to these features within the app:

- Navigating to the “Explore” tab [now known as “Sessions”] and the relevant session
- Finding the “My Notes” feature after completing a session
- Playing a video and/or adjusting volume
- Navigating back to the home screen from a session
- Moving to the next screen after a video

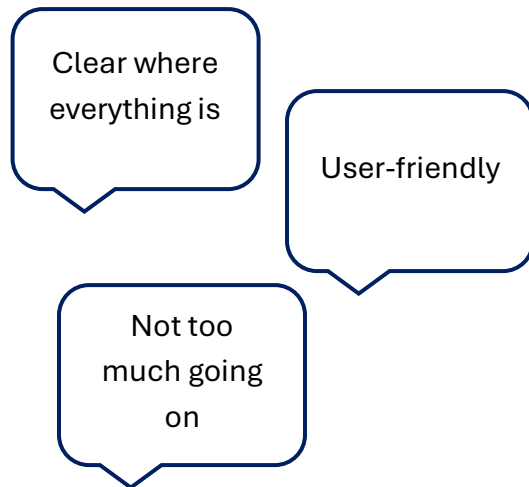
This formed an important aspect of minor changes made to the app to help facilitate these tasks in future versions. Please view the section **‘Changes to the intervention development’** for further information on this.

First impressions of the app home screen

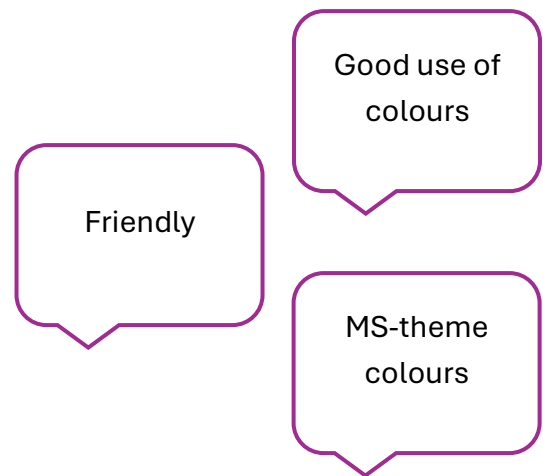
Positive feedback

Please note that the points below have been paraphrased, as verbatim quotes were not recorded during the Think Aloud testing sessions.

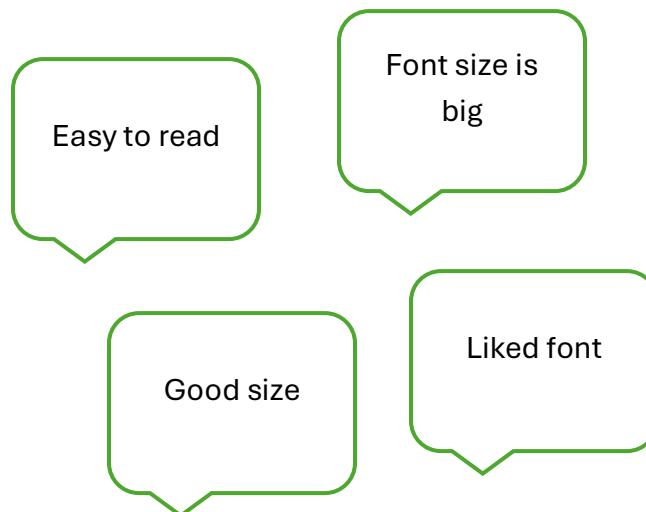
Layout



Design



Font & sizing



Negative feedback

Please note that the points below have been paraphrased, as verbatim quotes were not recorded during the Think Aloud testing sessions.

Layout

Prefers less things to look at on screen

Too wordy

A lot of words

Order of home screen

Too busy

A lot going on

Design

Odd colours

Prefer bigger buttons

Could use more images

Different size fonts - odd

What does this mean?

Layout

There was a mixture of feedback relating to the home screen. Though, in general, it was well-received. There were quite a few comments relating to the home screen being too “busy”. Participants found that there were too many things on the home screen on first view and that there were too many words included.

Design

Overall, the design, font, and sizing received quite a few positive comments. This mainly related to the colours of the app (blue and orange), and that they liked that MS-themed colours, such as orange, were used and one participant acknowledged that it is the colour of the MS Society. However, what was evident from the Think Aloud sessions was that it was difficult to gain a consensus amongst the participants regarding design. Though majority of people liked the choice of colours, one participant found that the colours were an “odd combination”. Likewise, one participant noted that everything was “clear” on the home screen, but another suggested for the order to be changed.

Summary

The key outcome of these sessions was identifying emerging patterns in participant feedback. It became clear that the home screen layout needed to be changed. For more details on the changes made to the app, please refer to the section titled **‘Changes to the intervention development’**.

Tasks

What was completed?

A summary of the various “tasks” that participants were asked to complete has been provided in Table 22 below. This also includes the number of times each task was included per app session.

Table 22. Tasks included in the Think Aloud testing per app session.

Task	Core Session 1	Core Session 2	CBT 6A	Exercise 6A	Balance 6A
Navigating to “Explore” tab and relevant session	2	2	2	2	1
Complete tick boxes [multi-select]	2	2	0	0	0
Open information drawers	2	2	2	2	1
Play video	2	2	2	2	1
Complete personal model of fatigue	2	0	0	0	0
Fatigue check-in tracker	2	0	0	0	0
Navigate back to home screen/exit session	1	2	1	2	0
Complete quiz	0	2	0	2	1
Goal setting [single select or free text]	0	2	2	2	1
Sleep diary tracker	0	2	0	0	0

Task	Core Session 1	Core Session 2	CBT 6A	Exercise 6A	Balance 6A
Free text box activity	0	0	2	2	1
Single select option	0	0	2	0	0
Thought diary tracker	0	0	2	0	0
View "My Notes"	0	0	0	2	1
Exercise tracker	0	0	0	1	0
View responses on "Dashboard"	0	0	0	1	1
Balance tracker	0	0	0	0	1
Moving to next screen after video	0	0	0	1	0
Total	13	16	15	19	9

Note: The "Explore" tab is now known as "Sessions" within the REFUEL-MS app.

What was liked/easy to complete?

Drawers:

- Liked layout of drawers on screens
- Drawers were helpful so that they are not overwhelmed with information

Trackers:

- Fatigue check-in easy to complete
- Liked the Balance tracker and would be more likely to interact with the app if there were more opportunities to track progress
- Sleep diary could be useful, e.g., knowing if they are sleeping too much
- Located the "Thought Diary" tab easily

My Notes:

- Some participants found it easy to locate "My Notes"
- Thought it was a good idea as it can be useful if they forget their response

General:

- Knew which screens were interactive (e.g., tick boxes/quizzes)
- Easy to identify when a video was present
- Some found it easy to locate the "Explore" tab (by clicking on the bottom tab)

What was disliked/difficult to complete?

Trackers:

- Thought diary would be more useful if completed with someone to receive feedback
- Thought diary to have free text under each section (rather than just one)
- Unsure if writing down negative thoughts would be helpful
- Tabs in the tracker too small
- Confusion over two “Balance” tabs under “Dashboard”
- Some confusion over how to enter data in “Sleep diary” tracker

Explore tab/home screen:

- Pressed the “<” button to navigate screens instead of “Previous” button
- Selected the “Getting Started” tool rather than Explore
- Unsure which button to press when navigating back to home screen
- Some difficulty locating the sessions for ‘6A’ because there was confusion of core session 2 (“My routine”)

Other:

- Drawers were not always obvious (occasionally missed)
- Difficulty adjusting volume on videos/animations and pausing videos
- Position of “Previous” and “Next” button changing causing confusion
- “My Notes” would be better at the top of the session
- Difficulty scrolling down video and finding “Next” button
- Did not like writing down responses – feeling more pressure

Session specific feedback

Session-specific feedback was also collected from the test leader by gaining an insight into users' thoughts of each screen.

Core session 1 – Understanding my MS fatigue

What was liked:

- Animations of demyelination and nerve functioning
 - Found pictures “vibrant” and “colourful”
 - One participant replayed the video as they liked it
- Clear
- “Nice, light, and easy” for reading text on some of the screens
- Felt respected with the language and content included
- Resonating with symptoms

What was disliked:

- Complex language used, e.g., demyelination
- Confusion over personal model of MS-fatigue
 - Participants thought it was interactive at first
 - Confusion over environment sub-heading
 - Confusion over double-headed arrows
- Image of fatigue
- Image used to depict “Other MS symptoms” because they did not like the “flying paper” icon used in the image, was not sure what this was meant to represent

Core session 2 – My routine

What was liked:

- Inclusion of activity diary
 - Resonating with boom-and-bust activity pattern
-

- Setting a goal – this was helpful as the end goal of the session was clear to the user after this section
- Simple language; “no jargon” and “clear and everyday” language
- Good useful content (behaviour patterns)
- Boom-and-bust animation and reducing or avoiding activity animation
 - Broken down into steps
 - Cycle at the end
- “Bitesize” amounts of information to read through
- Quiz can be useful to reinforce message of activity patterns

What was disliked:

- Didn't feel like they were being talked to as an adult – being told what they already know
- Animations slow-paced
- Boom-and-bust animation
 - Felt that the “boom” part is more so a normal day's work rather than multiple activities in one day, with multiple activities in one day being shown in the animation
- Information on how to manage these activity patterns would have been more helpful
- Questioning how the quiz would be helpful
- Point at which quiz appears could be changed

CBT 6A – Building up my routine

What was liked:

- Cycles included in the animations (unhelpful activity patterns)
- Free-text options
- Interactive (e.g., multi-select quiz)
- Interested in the ‘My behaviour pattern’ screen – “Is it going to tell you how to change?”

- Bullet points easy to read
- Resonating with “boom-and-bust”
- Liked that there were subtitles in the videos
- Drop-down menus (info drawers)

What was disliked:

- Small font and big graphics
- Text needs to be spread out more
- Would have preferred a summary after the videos/animations
- Example character story in boom-and bust animation maybe is specific (though one participant noted this story may confuse elderly, they still liked the inclusion of this)
- Info drawers not always obvious
- Unsure what the activity diary was for
- Found the graphics “childish”
- Graphic for change in identity – “off-putting”
- Character stories need more introduction in animations
- Does not like writing down their thoughts
- Confusion over goals

Exercise 6A – Building up my exercise routine

What was liked:

- Easily relates to the content
- Looks “professional”
- Nice graphics/visuals
- Liked the different options for “building exercise routine” screen
- Weekly minute goal – gives you something to “work towards”
- Already knew some of the information but it was good to be explained this in clear language
- “Self-explanatory”

- Good examples included in “creating your exercise routine”
- Diversity of males/females in graphics

What was disliked:

- Some language not lay-friendly (e.g., “consistent” or “intensity”)
- Too much text on certain screen
 - Suggestion to break this down using graphics to make more user-friendly
- Would be more useful if font size was larger
- Would like to see diversity throughout
- Unsure on the purpose of the quiz (for own knowledge or will be scored?)
- Slight content suggestion for “why is exercise important to you”

Balance 6A – Building up my balance routine

What was liked:

- Resonated with the boom-and-bust material
- Useful content that they had not known before
- Found it interesting that it was “best to be unsteady” – did not know this before
- Message is “clear” for ‘what will my balance training be like’

What was disliked:

- Found the quizzes “patronising”
- Would want to quickly access the information they are looking for rather than going through the session
- Would not use app at all because “too much information” to go through
- Would prefer if there was a tab with recommended exercises based on their goal
- Found the video for ‘what will my balance training be like?’ to be “1950s housewife” and questioned if it would resonate with younger generation

Changes to the intervention development

This section of the report ties in the previous findings outlined above and how these were key to driving changes to the REFUEL-MS app/intervention. Based on the feedback collated, any suggestions made by participants were added to a MoSCoW table. These changes were prioritised as “**Must have**”, “**Should have**”, “**Could have**”, and “**Won't have right now**” based on group discussions (Clegg & Barker, 1994). This prioritisation technique has been used previously in intervention development decision making, such as increasing adherence to a medical device intervention in cystic fibrosis (Arden et al., 2021). View tables below for more information.

Table 23. Graphic changes.

Issue/Problem identified	Changes that were made
1. Not enough diversity.	Increase diversity across graphics, such including people of different racial and cultural backgrounds, people with mobility aids and/or wheelchairs.
2. “Fatigue” graphic in core session 1 not representing fatigue.	This graphic has now been changed to better represent fatigue.
3. Graphic for “Other MS symptoms” created some confusion over the icons included.	Graphic changed so that the symptoms mentioned in text (such as muscle weakness) are clearly depicted in the image.
4. “Change in identity” graphic shown in the CBT sessions was off-putting.	This graphic has now been changed to be reflective of the content on the screen and to represent someone reflecting/looking in a mirror. The graphic previously used on the screen was representing “fatigue”.

Table 24. “Getting Started” changes.

Issue/Problem identified	Changes that were made
1. Not clear what the "My Notes" feature is and how this can be found.	This feature is now explained in the "Getting Started" tool, with a screenshot outlining what this looks like. This should now allow users to know what this looks like and where to locate this feature once they are finished with the session.
2. Information drawers being missed in sessions.	This feature is now outlined in the "Getting Started" tool, with a screenshot showing what a "drawer" looks like and an example of this appears on screen.
3. Videos/animations: • Difficulty adjusting videos • Videos being "slow-paced"	Both of these problems were addressed in this tool. The user is now informed that all videos play with sound and that this can be adjusted on their device. They are also shown how to change the speed of the video (i.e., 0.5x or 1.5x speed).
4. Difficulty navigating back to home screen	Given that there was considerable difficulty with this, the "<" button was explained in the Getting started tool and that this is used to go back to the home screen.

Table 25. Tracker changes.

Issue/Problem identified	Changes that were made
1. Thought Diary layout	This has now been changed so that there is a free text box under each section in the Thought Diary (situation, feelings, unhelpful thought, unhelpful thinking style). There is now also another activity linked to this that users are asked to complete after a week: to come up with a more helpful thought. This also has a separate box and is outlined by two lines to help separate this from the first activity that users are required to complete.

Issue/Problem identified	Changes that were made
2. Sleep diary	After team discussion regarding the sleep diary, it was deemed that the format of this tracker made it difficult to track the 'sleeping style' that an individual may have (e.g., sleeping too much). Hence, this was changed so that the user's responses could be mapped out graphically. This can make it easier for them to identify the pattern of "hours of sleep" per night and also "number of naps" during the day.
3. Two "Balance" tabs under the Dashboard	The current "Balance My Way" tracker asks for a numerical input, but also contains a select quiz. Hence, previously, under the Dashboard, there would be two tabs: one showing their numerical response on a graph, and one showing their whole written response. The latter has now been removed to avoid confusion (same for "Let's Get Moving" tracker).

Table 26. General changes.

Issue/Problem identified	Changes that were made
1. Information drawers being missed	A sentence was added for "Click here for more information:" in sessions where this was being missed or being made in BOLD. This, alongside the example drawer given in the "Getting Started" tool, should help to draw further attention to the drawers.
2. Confusion over personal model in core session 1 – "Understanding my MS fatigue"	In the session it is now explained that this is an image of a personal model and provides an explanation of what the double-headed arrows mean. This should enable users to know that this screen is not interactive.
3. Too much text on screens for:	Text has been split up on screens for these sessions where there were chunks of text.

Issue/Problem identified	Changes that were made
CBT 6A Exercise 6A Balance 6A 4. Some users noted that they would not interact with the app because sessions are too long (e.g., exercise and balance)	Graphics have also been included where possible to split up text. The first sessions of Balance and Exercise are slightly longer as there is more information that needs to be given before the user can proceed. Hence, to clarify this, a section has been added in the session overviews to remind the user that they may already know some of this information, but this information has been given for safety reasons.
5. Home screen – too much text	The text under the “My goals” and “Fatigue check-in” sections have now been reduced to have less text on this screen. For example, fatigue check-in text now just states: “Rate your fatigue.”
6. Core session 2 – “My routine” • Quiz seems out of place • End goal needs to be made clearer at the beginning	The quiz included in this session has been introduced better to remind the user that they will be looking at some examples of activity patterns and how to make them more consistent.
7. Inconsistency with subtitles not showing throughout on some animations	This has been amended, where possible, on animations that did not have subtitles throughout.

There were, however, some changes that have not been made. This is either because they were not feasible from an engineering perspective, or because we wanted to wait until after our acceptability study to gain further feedback. These have been outlined below.

Changes not made due to an engineering perspective:

- The position of the “Previous” and “Next” buttons could not always remain the same as this is dependent on the amount of text/content there is on the screen.
- Font size being made bigger – this is something that could not be done at this point, but dependent on feedback gathered from our acceptability study this may be changed. In addition to this, the user can zoom into the screen if needed.
- The tabs for the Trackers remained the same size as it was not possible to make them any bigger on the screen, given that there were already four tabs on this page.
- Due to the initial confusion of navigating back to the home screen, a potential good idea would be to have a pop-up appearing when a user clicks the “<” button to ask if they are sure they want to leave the session. However, this was more complex from an engineering perspective and has been left for after our acceptability study.

Changes not made yet – waiting for further feedback:

- Activity diary changes, such as providing further guidance on how to use this and what it is for - will be considered after the acceptability study.
- Removing wheelchair in graphics – though this might cause distress in some users, it is important that people living with MS who use wheelchairs feel included in our app.
- Language changes – there was divided feedback on the complexity of our language as some users suggested that there were complex words used, and others suggesting it was “too simple”. Though some minor language changes were made in certain sessions, we will wait for further feedback on the general language used after the study.
- Tailored quizzes – again, although there was some negative feedback regarding the quizzes, further feedback from a larger number of participants is needed.
- Tab taking you straight to the recommended exercises – this is not the intended flow of REFUEL-MS, and there is certain information that needs to be given for safety reasons before someone can start a stream (e.g., exercise and/or balance).
- Issues with scrolling down on screens where this is a video – this may be a device-specific issue, where some users may be more familiar with how to use an app on their

own device (Think Aloud testing completed using Android tablets). The “Getting Started” tool also explains where the “Previous” and “Next” buttons can be found.

Limitations of the process

As mentioned earlier in the report, one limitation of this Think Aloud testing was the small number of participants, which precluded statistical analyses. Additionally, only one participant tested the balance session, whereas feedback from at least two participants per session would have been more beneficial. Despite recruitment efforts, time constraints limited the testing to eight participants. However, literature suggests that even five participants in Think Aloud testing can yield valuable insights (Noushad et al., 2024; Virzi, 1992).

Another challenge was reconciling differing perspectives and feedback about the app. For example, one participant felt the app's language was “too simple,” making them feel “like a child,” while another appreciated the lack of jargon and simplicity. A third participant noted the use of complex terms like “demyelination”. Balancing this feedback was difficult, however, utilising the MoSCoW criteria (Arden et al., 2021; Clegg & Barker, 1994) helped to prioritise which feedback must/should/could be incorporated into the app at this stage.

A broader limitation of Think Aloud testing is the variation in how protocols are applied in real-world settings. Some researchers advocate for minimal probing to avoid distracting users (e.g., “Why did you do XXX?”) (Ericsson & Simon, 1984) while others suggest that such probes can yield more useful information (Olmsted-Hawala et al., 2010). For the REFUEL-MS Think Aloud sessions, the protocol included non-intrusive probes, such as “What are your first thoughts on this screen?” rather than “What do you see on this screen?”

Additionally, variations in task instructions and prompt timing can occur in Think Aloud sessions between participants and across different test leaders (Olmsted-Hawala et al., 2010). To minimise such variation, the same test leader conducted most of the Think Aloud sessions, with only one session conducted by a second tester. Despite this effort, some variation is inevitable,

even with a single test leader, as it is crucial to ensure participants have enough time to examine the screen and read the content before prompting.

Section 5

Usability testing

To ensure that each version of the REFUEL-MS app was thoroughly tested, REFUEL-MS team members, HCPs, co-investigators and collaborators, participated in an extensive testing process.

User Acceptance Testing (UAT) manual

To facilitate the process of usability testing, a UAT manual was developed.

This involved the following:

- Instructions on how to register on the app.
- A testing timetable for each member outlining:
 - Dates that they were required to test.
 - The specific session(s) allocated to them.
- Tables for each session and trackers in the REFUEL-MS app

To help test leaders keep track of registered users, an "Email Allocation" document was created. This document detailed the email addresses used for each account, the device (if relevant), and the assigned stream.

Sections of the manual

The tables outlined what the user expected to see on each screen (e.g., a video). This involved a screen number, screen heading, and any features that would be expected to be seen on that specific screen. An example row has been outlined below in Table 27.

Table 27. Example row from UAT manual.

Screen	Team member 1 (iPhone)	Team member 2 (Tablet)
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Screen 3 – How does fatigue feel for you Tick boxes should be multi select		
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This table also outlined any “branching” that would be expected for a certain user if they selected certain options on a screen. An example row has been provided below in Table 28.

Table 28. Example row from UAT manual outlining branching.

Screen	Team member 1 (iPhone)	Team member 2 (Tablet)
Screen 7 – What is an MS-relapse? Quiz: If YES: show all screens If NO: skip to screen 16 (Other causes of MS symptoms)	Selected YES	Selected NO

Users were encouraged to test different branches, to ensure a thorough testing process was carried out. Where possible, testing leaders would allocate certain branches to users before a team member began testing (for example, if branch “YES” had already been tested by one user, a different user was then asked to complete the “NO” branch).

Devices

Another thorough aspect of testing was the use of different devices to test the REFUEL-MS app, ensuring that functionalities and features appeared correctly across all devices. For each session tested, at least two different devices or device versions were used. This involved:

- iPhone (different versions e.g., iPhone 8/iPhone 13 Pro etc.)
- Android Tablet
- iPad (to test different screen sizes)
- Android phone

Identifying issues

Users were asked to mark a “/”, “-” or “Y” where no problems were identified on a specific screen. If any problems were identified, they were asked to describe this in detail within the relevant column. One test leader ensured that the manual was regularly checked to report any problems. For branching screens, users were asked to note whether screens were correctly skipped or shown. This helped identify any “branching” issues.

The test leaders used a “UAT excel file” to document all issues detected and feedback any problems to our app developers while testing. This was developed in agreement with the app developers (Avegen) as an efficient manner to communicate any problems.

The UAT sheet involved the following:

- Name of team member reporting
- Session name
- Problem identified (description)
- Screenshot (where relevant)

The app developers used this sheet to note whether the problems had been resolved (“Done”), or not (“Not done”), or “Need further clarification”.

For any issues classed as “major”, e.g., branching issues, word documents outlining the problem were sent to avoid any miscommunication and to provide greater clarity on the issue.

When checking the manual for problems, the following system was used:

- Highlighted in **GREEN** – Reported on UAT sheet
- Highlighted in **RED** – Reported on “Major issues” UAT sheet
- Highlighted in **ORANGE** – To be discussed with team

- Highlighted in **BLUE** – Ignore
- Highlighted in **PURPLE** – Reported on “Graphics” UAT sheet

Rounds of testing

There have been two rounds of testing thus far:

- Round 1 Testing (0.2.10 UAT REFUEL-MS app version)
 - o N = 8 members testing
 - o Dates: 23rd May – 7th June
- Round 2 Testing (0.2.14 UAT REFUEL-MS app version)
 - o N = 8 members testing
 - o Dates: 16th July – 31st July
- Round 3 Testing (this will be the final UAT version)

Clinician interface testing

As well as the app needing rigorous testing, the REFUEL-MS HCP website (known as the clinician interface amongst the internal team) also required testing. A UAT manual was also developed for this, outlining the different “chevrons” and “tabs” that should be visible under each section. The tester reported if all items were present. In this manual, specific tasks were included for testing, e.g., checking if user’s goals appear under the correct tab and if the populated personal model is shown, etc. This also underwent two rounds of testing (with two separate manuals). The “Round 2” testing manual was updated to reflect any changes that had been requested/made (e.g., tab changes). The two rounds of testing were extremely important, as testers in “Round 1” detected a major problem with alerts/notifications not appearing on the clinician interface. This was then discussed and resolved with the app developers to allow for the alerts/notifications to be tested (where possible) for “Round 2”.

Limitations

The first UAT manual focused on testing app screens with specific features (e.g., videos, graphics, or quizzes) rather than text-only screens. However, during testing, some text-only

screens were found to be missing, requiring testers to manually add rows to report these omissions. To enhance the comprehensiveness of the testing, the second UAT manual included all app screens, ensuring that any missing screens were easily identified and reported. Other general limitations include human error. Although an effort was made to ensure thoroughness of team testing by allocating different users to different sessions, the margin for error always remains and issues may have been missed. However, the different rounds of testing that were conducted by the team may have helped to mitigate this error as much as possible. In addition, though efforts were made to explain any problems identified to the app developers as thoroughly as possible, there were at times miscommunications. These were learned as the testing proceeded and came to the mutual decision to communicate more major issues, such as branching problems, through word documents. The use of branching tables allowed us to pinpoint exactly where the problem was. Hence, this reduced the likelihood of further branching issues arising in later versions for those sessions.

Summary

PPI work has been instrumental in shaping the intervention development process for REFUEL-MS. This report has provided an insight into how and why we have used PPI throughout the intervention development stages. This includes co-production workshops, general intervention development (such as providing written feedback on content, helping with decisions relating to the intervention), think aloud usability testing, and helping to inform aspects of HCP training. Limitations of these processes have been identified and, where possible, how these have been addressed.

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