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An implementation study of a remote monitoring platform to increase access to specialist care in Motor Neuron Disease

1. Abstract

The aim was to examine the engagement and acceptability of Telehealth in MND (TiM) as part of usual care within two specialist centers.

50 people with MND (pwMND) completed questionnaires. Eight pwMND and carers participated in interviews.

In Sheffield, 163 pwMND were invited to TiM with 52% registering and 85% engagement. In Dublin, 98 pwMND were invited to TiM, with 63% registering, and 95% engagement.

High levels of acceptability were reported, with users rating TiM as very low in burden. Similar findings were demonstrated within the interviews, with ease of use a strength. However, participants discussed a need for more regular feedback from TiM. Future opportunities relating to integrating TiM with community services were discussed.

TiM is feasible and acceptable to pwMND. The high engagement can generate a wealth of data facilitating solution-focused clinical appointments. The study’s findings support the further implementation of TiM in other MND services

2. Keywords

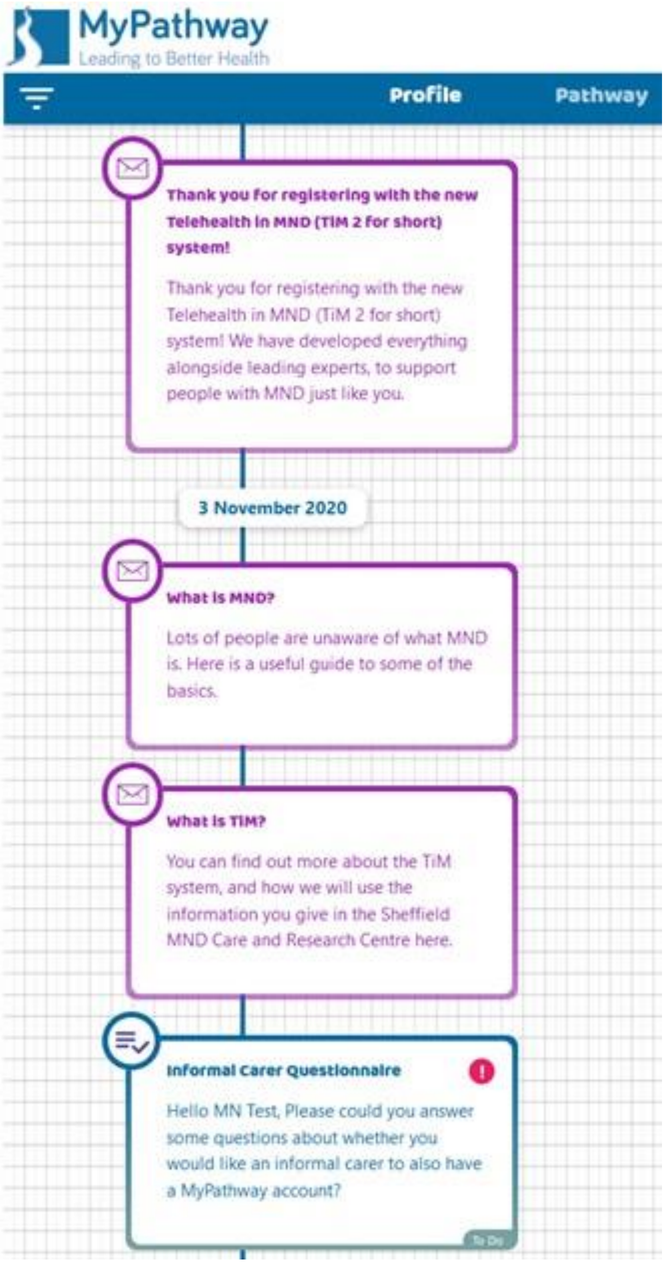
Motor Neuron Disease, Telehealth, Engagement, Acceptability, Mixed Methods.

3. Introduction

Healthcare professionals (HCPs) need more information about people with Motor Neuron Disease (pwMND) between clinical appointments, to enable more responsive care and provide a better-quality service [1]. MND symptoms, such as the decline in limb function, swallowing and breathing difficulties, and the impact of these on mental health, can change rapidly [2-4]. There are 5,000 pwMND in the UK and the worldwide prevalence is 3.37 per 100,000 people [5,6]. Current guidelines recommend appointments once every three months [7,8], but changes between these appointments may delay treatments.

Telehealth systems have been suggested as a method to provide more responsive care to pwMND [1,9]. Questionnaires submitted digitally by pwMND are non-inferior to those completed in a written format [10], demonstrating the validity of telehealth services. These systems are easy to use and enable HCPs to provide support based upon submitted responses; however, user engagement can be low [10,11]. Further research is required to explore user engagement when the telehealth intervention is implemented as a clinical service [1].

The Telehealth in MND on MyPathway (TiM) system is a clinical service that aims to increase the communication between HCPs, pwMND and their carers in between clinical appointments [12,13]. PwMND and their carers can access the TiM system through any internet connected device and answer regular questionnaires relating to a wide range of symptoms (Figures 1-3).



Thank you for registering with the new Telehealth in MND (TiM 2 for short) system!

Thank you for registering with the new Telehealth in MND (TiM 2 for short) system! We have developed everything alongside leading experts, to support people with MND just like you.

3 November 2020

What is MND?

Lots of people are unaware of what MND is. Here is a useful guide to some of the basics.

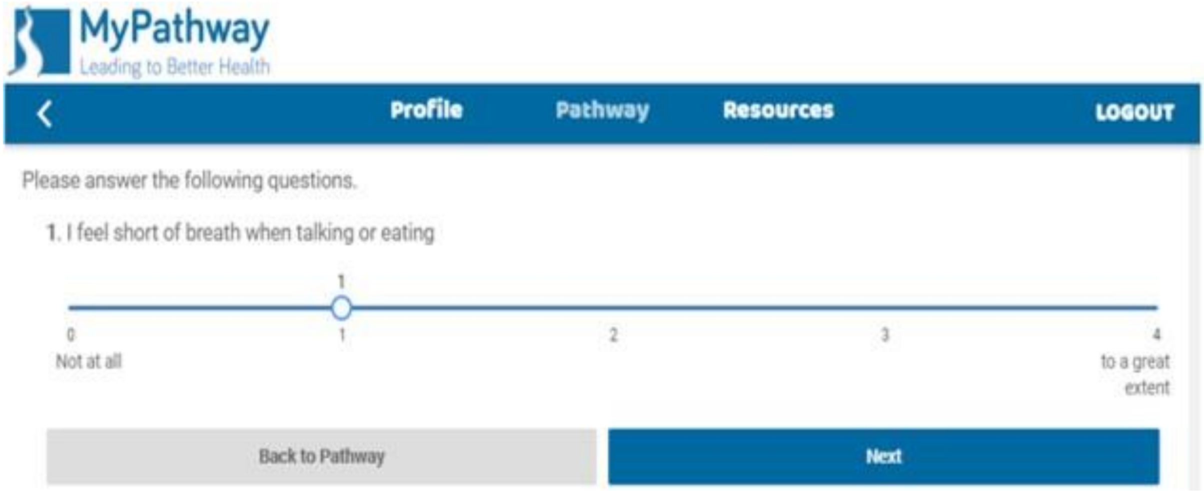
What is TiM?

You can find out more about the TiM system, and how we will use the information you give in the Sheffield MND Care and Research Centre here.

Informal Carer Questionnaire

Hello MN Test, Please could you answer some questions about whether you would like an informal carer to also have a MyPathway account?

Figure 1: TiM pathway for pwMND and carers.

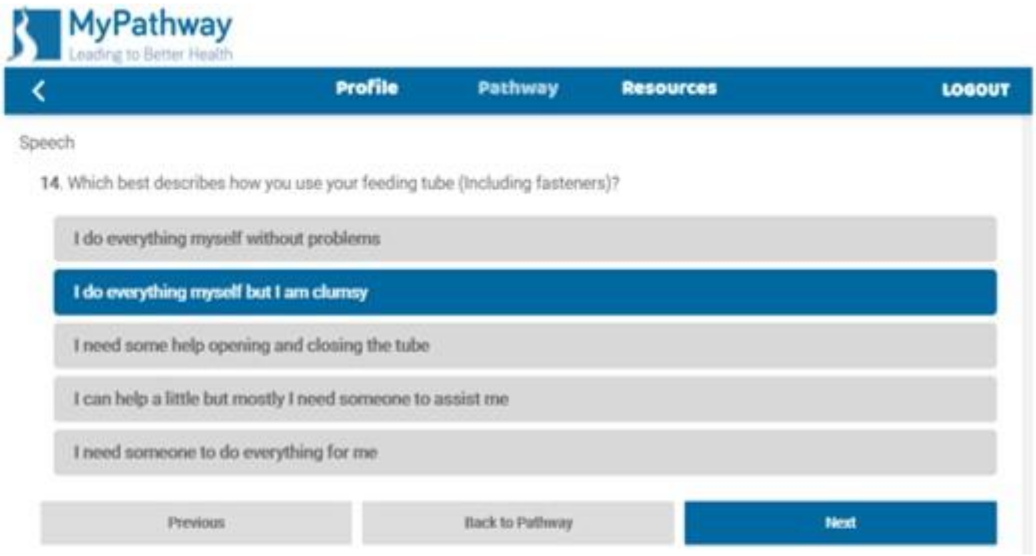


Please answer the following questions.

1. I feel short of breath when talking or eating

1

Figure 2: Example of TiM questionnaire with slider response options



Speech

14. Which best describes how you use your feeding tube (Including fasteners)?

- I do everything myself without problems
- I do everything myself but I am clumsy
- I need some help opening and closing the tube
- I can help a little but mostly I need someone to assist me
- I need someone to do everything for me

Figure 3: Example of TiM questionnaire with text-based response options

For example, pwMND automatically receive fortnightly questionnaires on their function, weight, breathing and mental health, whereas carers answer questions regarding carer strain and mental health. All responses to the questionnaires are securely sent to the HCPs who can make clinical decisions based on the information received. HCPs can also send information back to pwMND and carers through TiM, such as information leaflets or reassuring messages.

The TiM system was co-produced alongside pwMND, their carers, and HCPs [13] and when implemented as a research intervention in a single center was found to be acceptable for users [12]. PwMND and carers reported that they could use TiM, even with significant disability (e.g., hand weakness), would like to continue to use the system after the study ended and that it was particularly helpful if they could not come to the clinic. HCPs found the information helped them to make clinical decisions, and that the system enabled more responsive care; however, TiM did increase the number of alerts that were not always informative [1]. Since the initial evaluation of TiM (9), the system has been further developed alongside a new industry partner. The aims and questionnaires are the same between the versions, but what pwMND, carers, and HCPs interact with has been developed. The alerts were removed based upon feedback.

The aim of this study was to examine the engagement and acceptability of TiM as part of usual care within two MND specialist centers, building upon a previous study that solely explored how TiM was used as part of a research intervention.

4. Methods

This is a mixed-method, cross-sectional study on the engagement and acceptability of the TiM service, with data collected from two sites: Sheffield and Dublin. Ethical approval was provided by Wales REC 4 (21/WA/0067) and by the Clinical Audit & Governance department, Quality and Safety Directorate, Beaumont Hospital CA2021/163.

TiM was implemented as a clinical service within two specialist care centers in 2020: Sheffield and Dublin. At Sheffield, all pwMND were invited to the system by post and the questionnaire answers were reviewed by an MND specialist nurse, who would escalate identified problems to the wider healthcare team. Whereas at Dublin, pwMND were pre-screened by an HCP before being invited in person and various HCPs review questionnaire responses relevant to their specialty (e.g., a dietician would focus on weight and appetite).

Engagement was assessed by examining rates of TiM registration, regular engagement with the platform, and duration of regular engagement. Rates of registration were defined as: the proportion of pwMND who were invited and created an online account. Rates of regular engagement were defined as the percentage of fortnightly questionnaires the user completed on the TiM platform. Duration of regular engagement examined the length of time pwMND completed at least one questionnaire every two months.

Acceptability was conceptualized using the Theoretical Framework of Acceptability (TFA) [14], which separates the construct into seven components that reflect how much a healthcare intervention is considered appropriate, based on expected or experiential cognitive and emotional responses. Self-efficacy is the participant's confidence to engage in the intervention; Coherence is the extent to which the participant understands the intervention; Ethicality is the extent to which the intervention fits with an individual's value system; Burden is the perceived amount of effort required; Affective Attitude is how an individual feels about the intervention; Opportunity Costs the amount of benefits, profits, or values that must be given up to engage in the intervention.

In Sheffield, all pwMND registered on TiM for six weeks were invited by email to complete one online Qualtrics acceptability survey. In Dublin, the acceptability survey was conducted once by a researcher calling all pwMND registered on TiM for six weeks by telephone. Standardized scores were calculated for each of the TFA concepts. Descriptive statistics are provided in Table 1 for the participants recruited for the acceptability survey from Sheffield and Dublin.

	Sheffield n=23	**Dublin n=27**
Age	65.2 (9.22)	62.93 (6.87)
Gender (n)	17 Male, 6 Female	15 Male, 12 Female
ALSFRS-r	32.4 (7.69)	not recorded
ALSFRS-r upper limb score	7.26 (3.03)	not recorded

Table 1: Descriptive statistics for participants completing the acceptability surveys. Scores are mean and standard deviation in parentheses unless otherwise stated. ALSFRS-r: Amyotrophic Lateral Sclerosis Functional Rating Scale-revised.

PwMND and carers from Sheffield were invited to participate in individual, semi-structured interviews regarding their experiences of using the TiM system. Six pwMND and two carers consented. Their average age was 68 years with four female and four male participants. Interviews were all conducted through Google Meets and took between 45 and 60 minutes. Interview questions (see Appendix) were provided in advance to participants if requested to enable pwMND to record responses to answers (in case of speech difficulties). A deductive thematic analysis was conducted [15], using a Strengths, Weaknesses, Opportunities, and Threats (SWOT) framework [16]. This framework considers internal and external factors affecting the TiM service and can highlight suggestions for future intervention development. The thematic analysis was conducted by LK, an experienced qualitative researcher, who developed the themes using the interview transcripts before fitting these to the SWOT framework.

5. Results

5.1. Engagement

In Sheffield, 163 pwMND were invited to create a TiM account and 85 (52%) registered. In Dublin 98 pwMND were invited, with 62 (63%) registering (between January 2021 and June 2022). The characteristics of the registered populations are displayed in Table 2.

	Sheffield n=85	**Dublin n=62**
Age	65.8 (12.6)	62.0 (9.4)
Gender (n)	38 Male, 20 Female	36 Male, 26 Female
Sheffield, Index of Multiple Deprivation (range 1-9)	6.24 (2.57)	not available
Distance from clinic (miles)	29.7 (29.8)	not available
Distance from clinic (travel time in minutes)	58.8 (38.6)	121.3 (78.25)
Baseline TiM scores		
Self-reported ALSFRS-r (range 0-48)*	29.8 (9.30)	35.6 (7.1)
ALSFRS-r upper limb total score (range 0-12)*	6.23 (3.51)	8.1 (3.4)
MND Dyspnoea Scale (range 0-60)	4.30 (3.94)	1.7 (2.5)
GAD-7 (range 0-21)	2.74 (3.24)	N/A (not collected in Dublin)
PHQ-8 (range 0-24)	4.83 (4.58)	N/A (not collected in Dublin)
SNAQ (range 5-20)*	15.4 (2.64)	15.8 (2.6)
Weight (kg)	72.8 (15.9)	77.4 (17.9)

Table 2: Baseline user characteristics of pwMND who registered on TiM for Sheffield *and* Dublin*. Scores are mean and standard deviation in parentheses unless otherwise stated. Index of Multiple Deprivation [17]; Self-reported ALSFRS-r: Amyotrophic Lateral Sclerosis Functional Rating Scale-revised (adapted from [18]); MND Dyspnoea Scale [19]; GAD-7: General Anxiety Disorder-7 [20]; PHQ-8: Patient Health Questionnaire-8 [21]; SNAQ: Simplified Nutritional Appetite Questionnaire [22]. *Questionnaire is reverse scored, with lower scores representing increased symptoms.*

The mean number of days pwMND actively engaged with TiM between January 2021 and June 2022 was 374 (SD=233) for Sheffield and 220 (164) for Dublin. During this time, the fortnightly TiM questionnaire completion rates remained high, with Sheffield completing 4,479 out of 5270 (85%) and Dublin completing 2,883 out of 3,100 (93%). For pwMND who continued to be actively engaged in the TiM service for longer than six months (Sheffield n=59, 69%; Dublin n=53, 86%), the fortnightly questionnaire completion rate was very high (Sheffield 98%, Dublin 92%).

5.2. Acceptability Survey

Figures 4 and 5 reports the numbers of respondents agreeing or disagreeing that TiM meets each of the TFA concepts at each site. For example, 42 people in total believe that engaging with TiM is worth the time and effort (opportunity costs). The five TiM effectiveness categories show the numbers of respondents that agree or disagree that TiM positively affects each criterion.

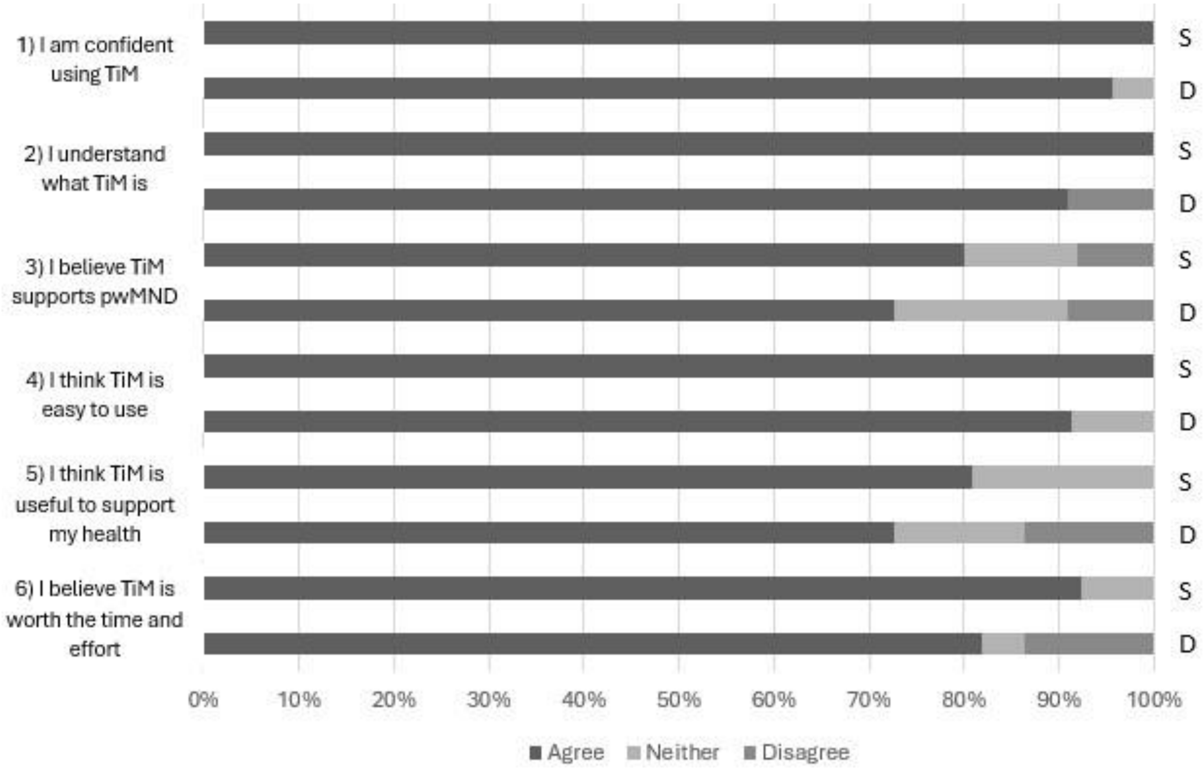


Figure 4: Participant responses to the TFA questionnaire. S= Sheffield*, D=* Dublin*. 1) self-efficacy; 2) intervention coherence; 3) ethicality; 4) burden; 5) affective attitude; 6) opportunity costs.*

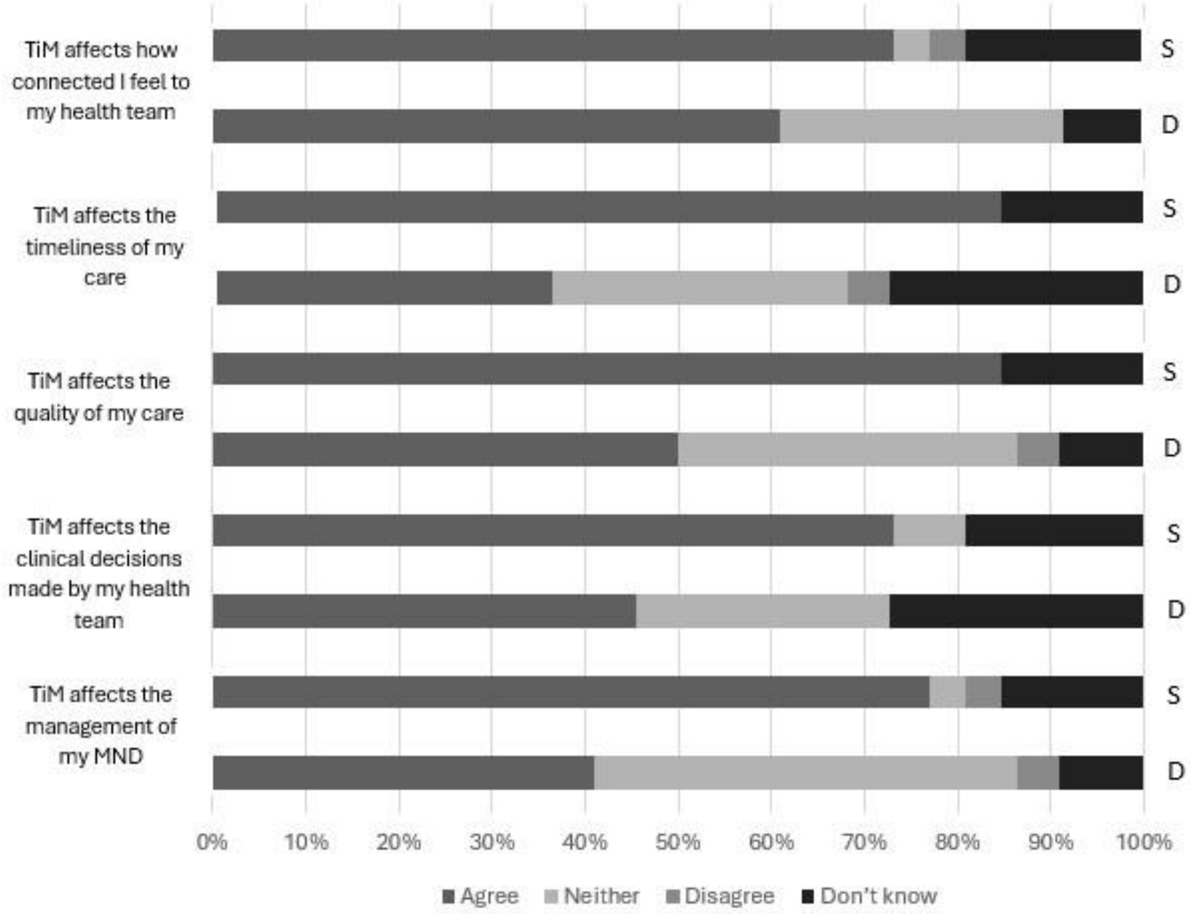


Figure 5: Participant experiences how TiM positively effects various aspects of their care. S= Sheffield*, D=* Dublin*.*

Table 3 illustrates the developed themes, categorized by the SWOT framework.

Description	**SWOT**	**Themes**
The *internal* environment – the situation within the TiM service	Strengths	TiM is easy to use
		Different user motivations for engaging
		The additional benefits for carers
	Weaknesses	A lack of feedback on questionnaire answers
		Standardization limits sensitiveness and the reporting of nuance
The *external* environment – the situation external to the TiM service	Opportunities	Integrating community services
		More questionnaires may provide a more detailed picture
	Threats	-

Table 3: Qualitative themes identified within the SWOT framework.

5.3. Strengths

5.3.1. TiM is easy to use

A key theme that developed from the transcripts was the ease of using TiM and how the service was worth the time and effort to engage.

“I’d describe it as a good system, it’s not time consuming, I think it’s a really good idea and I feel confident with it in place.” P1, pwMND.

This aligns with what was reported in the acceptability surveys (see Figure 4), with respondents indicating that they had no issues with the burden of the system. Participants also discussed how the system typically takes five minutes to complete. Some participants reported that they had created a ‘TiM routine’, with a set time each week where they would answer the questionnaires. However, other participants were more flexible, engaging with the service as and when they had spare time.

5.3.2. Different user motivations for engaging

All participants mentioned positives of using the TiM service; for example, the ability to use the system to support face-to-face appointments and the feeling of reassurance gained from knowing an HCP was reviewing the answers.

“I think with a face-to-face consultation it’s easy for both parties to go off on a tangent and forget what you were driving at. Whereas the TiM system, because it’s methodical, the next question always pops up. And I say I think the two, the two assessment methods complement each other.” P2, pwMND.

“I think it’s a good system. You know, because to me it’s reassuring in a way, that somebody is checking on my progress if you like.” P1, pwMND.

Some participants perceived the main beneficiaries of these positives as themselves, whereas others used TiM to support their clinical team.

5.3.3. The benefits for carers

Although all carers could access the TiM service to report about their own wellbeing, not all pwMND had a carer who had registered with the system. The participants who had their carer using TiM, or were a carer themselves, were very positive regarding the benefits of the service for carers.

“You know it was really nice because, even though I attend [the pwMND’s] appointments and I watch over her, care for her, it’s like somebody’s bothered about me as well. Which is really nice that somebody would take that time to actually say are you okay. Not that there was anything that they could do but it was nice just that [the specialist nurse] picked the phone up [after seeing scores on TiM], and said what’s going on, are you okay, which was lovely.” P3, carer.

5.4. Weaknesses

5.4.1. A lack of feedback on questionnaire answers

Whilst developing the TiM service, the HCP team decided that it would not be feasible to respond to every user every time they answered a questionnaire. Therefore, during the invitation process, pwMND and carers were told that they would only receive feedback when their answers required further discussion or a change to treatment. During the interviews, some participants mentioned that they hadn’t received feedback but thought that this was because nothing had changed.

Despite these expectations all participants felt there needed to be some feedback from the service. Although this could be information leaflets, feedback from HCPs was more commonly mentioned as ideal.

“I think the feedback is important and there are occasions when it’s good to have some sort of direct contact with the clinician, [through TiM] or face-to-face, and to me it’s reassuring that someone’s clearly picking up on the answers that I’m giving”. P4, pwMND.

5.4.2. Standardization limits sensitivity and the reporting of nuance

Participants discussed how the pre-set multiple-choice answers for each questionnaire could be a limitation of the system, particularly for symptoms such as mental health. Participants also discussed how adding a free text option could help.

“Some of the questions don’t enable you to explain what’s prompted you to say a particular answer. It’s not MND, it could be something else, and that was a bit difficult…I kept thinking well I want to say something, but it isn’t strictly related to MND, I found that a bit more difficult”. P5, carer.

5.5. Opportunities

5.5.1. Integrating community services

In the UK, although pwMND are supported by a HCP team in specialist MND centers, between appointments care is often delivered by non-MND specialist community-based teams [2]. Participants discussed expanding what groups of HCPs could access TiM.

“I mean the only question in my mind I suppose about links with community staff and whether it would be feasible and appropriate for the neurological team in the community to have access, you know, to see flagged up people’s answers, whether they’d ever have time to do it, is another issue”. P2, pwMND.

5.5.2. More questionnaires may provide a more detailed picture

Originally HCPs have been concerned regarding the number of questionnaires pwMND are asked to complete as it was perceived that this could be overly burdensome. However, this study found that participants do not perceive the system as a burden (47 out of 50 respondents agree that TiM is of low burden; see Figure 2). Indeed, one suggestion to improve the service further was to increase the number of questionnaires sent to include topics/symptoms that the system currently does not cover.

6. Discussion

The numbers of pwMND engaging with TiM over a prolonged period and the positive results from the surveys and interviews demonstrate that the TiM service is feasible and acceptable for pwMND. These findings mirror a process evaluation when TiM was used within a research setting [12]. Similar results across sites increases the generalizability of these findings and supports the use of the TiM system at other specialist centers.

The high engagement over time with TiM shows that pwMND are willing to use the system on a regular basis. Those who continued to complete TiM questionnaires for more than six months continued to complete them regularly. This regular supply of information about an individual’s condition provides more information to HCPs, who can plan treatment accordingly [2]. The engagement with TiM contrasts previous research, which has shown relatively low completion rates that further decreases over time [23,24]. Regular feedback, or providing other two-way functionality, has been shown to increase engagement [1,11,25]. Although participants discussed the wish for increased feedback during the interviews, it is possible that the feedback already provided explains the high engagement. Alternatively, acceptability survey results demonstrated the TiM service to be highly acceptable, across all seven of the TFA concepts. The system was particularly easy to use, user friendly, and users had high self-efficacy. The interviews also highlighted the low burden. The similar findings between sites suggest that TiM would be acceptable in other centers, supporting the wider implementation of the TiM service. This is also supported by the discussion of multiple benefits by interview participants, and the positives for both pwMND and carers was of key importance to users.

Although most people registered when invited, the number declining to register with a system designed to support usual care is a concern, with 48% in Sheffield and 37% in Dublin not registering for an account. The cause of this is unclear and attempts to collect data on the demographics and perspectives of those who did not register was not possible due to the specific ethical approvals in place and should be examined in future research. Postal invitations were used in Sheffield to invite all pwMND to the service, whereas face-to-face invitations were used in Dublin where pwMND were pre-screened for suitability which may have influenced the uptake. Although the face-to-face method was associated with higher account creation, if this method is not possible (e.g., inability for pwMND to travel to clinic), postal invitations represent a suitable alternative with the ability to register a substantial number of people in a systematic and efficient manner. Based upon the baseline TiM user characteristics (Table 2), it is unlikely that people did not register due to not having the physical ability to use the TiM system. For example, the ALSFRS-r scores demonstrate a marked deterioration in function for those that registered and used the service. One hypothesis is that a key barrier could be the perceived burden associated with the technology [26]; however, this study suggests that in fact, burden is low, which should be communicated at the time of invitation along with an explanation of the reasons for using TiM. The higher baseline ALSFRS-r score for pwMND who created accounts in Dublin (indicating lower level of disability) could represent HCPs only inviting those with more function, representing a bias that future research should investigate further alongside fully understanding differences between who does and does not create a TiM account when invited.

A strength of this study is the collection of data in two different care settings, both with different methods of using TiM. From this, the results can more confidently be extrapolated to other populations and MND services both in and outside of the UK regardless of how services are organized. TiM is designed to be used flexibly to meet the needs of each service, with the results here supporting this use. However, future research may wish to explore the most optimum use of TiM. This is further strengthened by evaluating the implementation of TiM with a clinical service, rather than within a research context. This increases the real-world validity of the findings. Additionally, by including a qualitative component, the study was able to expand on the quantitative results from the engagement study and acceptability surveys. This enabled triangulation of the results and facilitated the exploration of trends within the data and highlight potential causes for the high engagement and acceptability of the TiM service. The SWOT framework described the primary strengths of TiM, but also practical suggestions for improvements to the service, which have already been implemented. However, there was a limited sample size, which creates the possibility of sampling bias. For example, pwMND may have only consented to participate if they were positive regarding the TiM system. Although this can be slightly discounted because the survey participants included users with high and low engagement, future studies are still needed to provide further evidence regarding the acceptability of the system and examine the perspectives of those who did not register.

7. Conclusion

In conclusion, the results from this study alongside previous research [12] demonstrate that the TiM system is feasible and acceptable to pwMND. The high completion of TiM questionnaires can support HCPs to make treatment decisions or facilitate solution-focused clinical appointments. Future research should explore TiM engagement and investigate whether user characteristics can predict TiM use. Once more widespread implementation has been completed, a full evaluation should be conducted to explore how HCPs act on TiM information and the affects the system has on the MND service.

8. Article highlights

- MND is an incurable condition, which progresses rapidly, necessitating greater information for healthcare professionals to provide responsive care
- The Telehealth in MND (TiM) service was developed to provide a digital service to enable greater communication between people with MND, carers and healthcare professionals
- Engagement data demonstrated a high level of usage from users, demonstrating that the service is feasible
- Acceptability surveys and interviews highlighted the low burden of TiM and provided suggestions on how to develop the service further
- This study demonstrates that TiM is feasible and acceptable to people with MND, with wider implementation supported

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11. Disclosure statement

Authors have no conflicts of interest to declare.

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