



Research Article

To have and to hold: An exploratory qualitative study exploring why research participants with treatment-resistant depression undergoing transcranial magnetic stimulation treatment requested copies of their research brain MRI scans

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ABSTRACT

Purpose: There has been little research providing an in-depth exploration of the reasons behind research participants, particularly in mental health settings, requesting copies of their research data, such as magnetic resonance imaging (MRI) scans. BRIGHtMIND is a large double blind randomised controlled trial using functional and structural magnetic resonance imaging to create personalised targets for transcranial magnetic stimulation delivery, and a number of trial participants requested copies of these scans.

Methods: Seven participants involved in the BRIGHtMIND trial completed semi-structured interviews exploring their reasons behind their request for copies of their MRI scans. The qualitative data was co-analysed between researchers and patient and public involvement and engagement representatives using inductive thematic analysis.

Results: The interviews produced consistent themes concerning curiosity to visualise their MRI scans, and the hope that their participation would result in a better understanding of the nature and future treatment of depression. Concerns around the rights to access their own personal health data emerged as a clear theme as did their own ability to interpret any radiological information.

Discussion: This study provides insight into the reasons why research participants with depression would like to retain copies of their MRI scans and the perceived role that such techniques may have for improving research and neuromodulation treatments in depression. Such first-hand experiential accounts emphasises the importance of listening to participants perspectives and lived experience, in order to improve research and health outcomes. Future research could aim to provide greater verbal and written information for participants, including details about the accessibility to their MRI scans, the difference between research and clinical MRI scans, and educational materials to help with the interpretation of MRI images.

RÉSUMÉ

Objectif: Peu d'études ont exploré en profondeur les raisons qui poussent les participants à la recherche, en particulier dans le domaine de la santé mentale, à demander des copies de leurs données de recherche, telles que les examens d'imagerie par résonance magnétique (IRM). BRIGHtMIND est un vaste essai contrôlé randomisé en double aveugle qui utilise l'imagerie par résonance magnétique fonctionnelle et structurelle pour créer des cibles personnalisées pour la

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stimulation magnétique transcrânienne, et un certain nombre de participants à l'essai ont demandé des copies de ces images.

Méthodologie: Sept participants à l'essai BRIGHtMIND ont répondu à des entretiens semi-structurés afin d'explorer les raisons qui les ont poussés à demander des copies de leurs IRM. Les données qualitatives ont été analysées conjointement par les chercheurs et les représentants de la participation et de l'engagement des patients et du public à l'aide d'une analyse thématique inductive.

Résultats: Les entretiens ont permis de dégager des thèmes cohérents concernant la curiosité de visualiser leurs examens IRM et l'espoir que leur participation permettrait de mieux comprendre la nature et le traitement futur de la dépression. Les préoccupations concernant les droits d'accès à leurs propres données de santé personnelles sont

apparues comme un thème clair, tout comme leur propre capacité à interpréter cette information radiologique.

Discussion: Cette étude donne un aperçu des raisons pour lesquelles les participants à la recherche souffrant de dépression souhaitent conserver des copies de leurs IRM et du rôle perçu que ces techniques peuvent avoir pour améliorer la recherche et les traitements par neuromodulation de la dépression. Ces récits d'expériences de première main soulignent l'importance d'écouter les perspectives et l'expérience vécue des participants, afin d'améliorer la recherche et les résultats en matière de santé. Les recherches futures pourraient viser à fournir davantage d'informations verbales et écrites aux participants, y compris des détails sur l'accessibilité de leurs examens IRM, la différence entre les examens IRM de recherche et les examens IRM cliniques, et du matériel éducatif pour aider à l'interprétation des images IRM.

Keywords: Depression; Magnetic resonance imaging; Qualitative; Transcranial magnetic stimulation

Introduction

Transcranial magnetic stimulation (TMS) is a brain stimulation technique which uses magnetic pulses to modulate inhibitory or excitatory activity of cortical neurones [1]. TMS protocols such as repetitive TMS (rTMS) and theta burst stimulation (TBS) are established treatments, demonstrating clinical efficacy for Major Depressive Disorder (MDD), particularly in treatment-resistant depression (TRD) [2,3,4,5]. In addition, there is an increasing recognition that Magnetic Resonance Imaging (MRI) coupled with neuronavigation may individualise and improve the precision of neurostimulation therapy for MDD [6].

The [removed for review process] double-blind randomised controlled trial used T1 weighted structural MRI and resting state functional MRI (fMRI) scans to create personalised targets for TMS delivery in participants with TRD [7,8]. Recruitment of participants to the [removed for review process] study commenced January 2019 and finished January 2022. During this period, a number of participants asked for copies of the images that were taken during their MRI scans. This was unexpected and our Patient and Public Involvement and Engagement (PPIE) representatives with lived experience of depression who were involved in the trial, were keen to understand the reasons behind these requests and suggested that a study to investigate the participants motivating factors would be beneficial. Therefore, we took a pragmatic approach to the question by using qualitative interviews to understand from the participants' perspectives their motivations for requesting the MRI scans.

Research exploring the prevalence of being able to access MRI reports and images indicate that 87% of research participants want copies of their MRI results- irrespective of incidental findings and clinical significance, with 91% of participants indicating that receiving MRI reports were a benefit to participating in research [9]. Researchers also suggest that providing access to MRI scans demonstrates respect for an individual's autonomy [10]. However, motivations and reasons for

wanting copies of MRI scans remain unclear. More broadly, it has also been reported that providing individuals with access to their health information, enables people to adhere to and track treatment and management plans, and directly contribute their information to research [11].

Few studies have used qualitative methodologies to examine individuals' experiences before, during and after MRI scans, which may provide some insight into requests for copies of MRI scans. Studies have identified that patients and research participants experience a range of negative emotions, which are frequently related to anxiety of having to undergo the MRI scan and the anticipation of upcoming results [12,13,14,15]. Furthermore, negative emotions experienced during the scan are often seen to be transient and resolved once an individual has acclimatised to the new situation [15], with staff support and communication found to contribute to the experience [12].

Furthermore, in healthy research volunteers and those with physical conditions, there is a curiosity and excitement to undergo the MRI scans [12,15]. Patients with remitted depressive illness have also reported altruistic motives for taking part in MRI research, with a number of individuals reporting that seeing their brain was interesting [15]. Those with physical conditions have additionally reported a personal achievement by completing scans [13], with the perception that the MRI scan could hold the power to legitimise or delegitimise their symptoms [12,14], and help individuals share their health journey, initiating feelings of tenacity and courage to beat diagnosis [14].

Thus, the prior literature has provided a deeper insight into the subjective experience of undergoing an MRI. However, there has been little research that has provided an in-depth exploration of the reasons behind why people want copies of their MRI scans or reports, particularly in individuals with mental health conditions, and those undergoing mental health interventions utilising information from MRI.

Therefore, this paper reports findings from an emergent qualitative arm within the larger [removed for review process] randomised controlled trial [7,8].

This study aimed to:

- (1) Understand the motivating factors leading to participants with TRD requesting a copy of their research MRI scans.

It was thought that such a study could help identify potential reasons why participants would like to retain their research data, which may be transferable to other research, including but not limited to, MRI studies, as well as studies of other mental health disorders and physical health conditions.

Methods

As mentioned in the introduction chapter, our PPIE representatives with lived experience of depression, were keen to understand the reasons behind participants request for copies of their MRI scans and suggested that a study to investigate the motivating factors for such requests would be beneficial. The study was co-designed and co-produced with our [removed for review process] PPIE representatives. They reviewed current literature related to MRI scan requests to support the design of the topic guide and reviewed the essential documents. Based on their own experience, they suggested how to best approach potential participants for this study. At the analysis stage, they took part in the refinement and naming of the themes and sub-themes. After selecting quotes to include in the research report, they reviewed the manuscript and drafted the abstract.

Ethical approval for the [removed for review process] was provided by the Health Research Authority and Research Ethics committee (23/10/2018). This qualitative sub-study then received Health Research Authority approval and Research Ethics Committee approval in a substantial amendment (21/12/2020). Interviews were conducted between 09/06/2021 and 17/03/2022.

Setting

Participant from the main [removed for review process] trial underwent baseline brain MRI scans prior to commencing 20 TMS treatments over 4-6 weeks and follow up brain MRI scans 16 weeks after completing TMS treatments, with the exception of [removed for review process] who completed scans at baseline only. The MRI scans aimed to personalise TMS treatment and explore its mechanism of action. Scanning ranged from 40-55 minutes. Details of the scanning process can be found in the [removed for review process] protocol [8].

The main [removed for review process] trial participant information sheet detailed the purposes, timepoints, and duration of the MRI scans, relaying that the MRI would be noisy and informing participants they would be wearing headphones or ear plugs. The participant information sheet also stated that

the brain scans were obtained for TMS purposes and not processed in the same way as a brain scan obtained to look for neurological abnormalities, and that they could not be used to make a clinical diagnosis. However, it was detailed that if the scans revealed anything that suggested a possible clinical abnormality that potentially required further investigations, the participant, their psychiatrist, and their GP would be informed, so that they might arrange any further investigations that might be required, and that the trial would seek the participants permission for this before obtaining the scan.

Additional information about the MRI process and purposes of the MRI scan were provided verbally through the recruitment process. All MRI scans were performed by experienced radiographers or MR scanning operators and the imaging data was analysed by non-medical researchers at the [removed for review process] site, with the majority of these researchers having a significant number of years in imaging analysis, with less experienced researchers supported by those more experienced. The researchers had backgrounds in radiological sciences or psychology. The MRI scans were not reviewed for diagnostic content specifically, however, if space occupying lesions were identified by the radiographers or the imaging analysis researchers, then these were reviewed by a radiologist following the site specific procedures for reporting incidental findings. This occurred on one occasion. If the imaging analysis researchers identified other potential incidental findings, these were first looked at by the radiographers conducting the scans who indicated whether these needed further clarification from radiologists. There was one occurrence of a further incidental finding, which the radiographers felt was a normal variation, yet wanted clarification from the radiologists. Participants and their clinical teams were only informed of incidental findings that may have required further investigations (not including normal variations), to avoid unnecessary distress and anxiety. Of note these two participants were not part of this sub-study.

Data collection

Participants expressed an interest in receiving their MRI scans by informal and opportunistic discussions with the [removed for review process] research staff, radiographers, or MRI scanning operators. Participants were not offered copies of their MRI scans as part of the consenting process per se, as the MRIs were a small component of a much larger trial. However, the participant information sheets detailed that their rights to access, change or move their information may be limited as we need to manage their information in specific ways to comply with certain laws, and for the research to be reliable and accurate. It was however, verbally reported to participants that they would be able to receive copies of their MRI scans upon completion of the main trial.

Participants who expressed this interest, were sent an invitation letter, reply slip and information sheet for this study via email or mail. The participant information sheet detailed that if the participant decided not to take part in the sub-study then this would not affect their involvement in the main trial and

would not affect their standard of care or legal rights, and that they were free to withdraw at any given time without giving a reason. Those that returned reply slips expressing interest were contacted to schedule an interview at an agreed time and date. Prior to the interview, they were given more information about the content and aims of the interviews and given the opportunity to ask questions before giving verbal consent to participate. As part of the consent procedure, the interviewer recorded reading through the consent form as the participant agreed to each point, and a blank copy of the consent form was emailed to the participant after the interview for reference. During consent recording, participant numbers from the main trial were used to protect the participant's anonymity. All interviews were conducted by (C.B) and completed via telephone call or video-conferencing due to COVID-19 restrictions. Interviews lasted between 9 and 20 minutes.

A semi-structured topic guide was developed based on a review of the literature by our PPIE lead and recommendations provided from our [removed for review process] PPIE representatives (see supplemental material for topic guide). Semi-structured topic guides allow for an open dialogue and a flexible approach of follow up questions and prompts that enables researchers to collect open ended data of the participant experience and thoughts [16]. The interview guide included questions on the participants' experience of undergoing the MRI scan and potential reasons for requesting their scans, such as personal/intrinsic reasons, research/TMS reasons and other/extrinsic reasons. Interviews and verbal informed consent were recorded on an encrypted digital voice recorder, with interviews transcribed using the professional transcription service DICT8 (<https://www.dict8.com/>). Transcripts and consent recordings were anonymised, password protected and saved onto an NHS Trust research drive, only accessible by the research team.

Participants

There were 255 participants to the main [removed for review process] trial, and 35/255 (13.73%) spontaneously asked for copies of their MRI scans. Seven (20%) of these participants returned reply slips expressing an interest in the study and took part in the qualitative interviews. Demographics data obtained from their participation into the main trial revealed that participants included three men and four women, aged 21-65 years, with one from a minority ethnic background and all others white British. Four participants were from the [removed for review process] site, two from the [removed for review process] site, and one from the [removed for review process] site.

Data analysis

An inductive thematic analysis approach was used, following the Braun & Clarke's 6-step framework [17], given the explorative nature of the study, emphasis on the participant experience and thoughts, and that meaning and creating of themes were derived without researcher preconceptions. In step 1- all

Table 1
Themes following thematic analysis

Theme	Subthemes
Curiosity and casual interest	<ul style="list-style-type: none"> • Cool/interesting to see brain • Memento • Artwork • Discussion point/sharing
Hope for better understanding and evidence of depression	<ul style="list-style-type: none"> • Hope for future to reduce stigma • Hope for future for diagnosing depression • Proof of illness • Seeing changes
Right to access their data	<ul style="list-style-type: none"> • Personal data
Meaning and understanding	<ul style="list-style-type: none"> • Interpretation skills • Incidental findings

transcripts were read repeatedly by two research assistants L.W (PhD) & C.B (MSc), to ensure they were immersed in the data [18]. Following this the two researchers both separately used open coding to break down the qualitative data into discrete excerpts, and this was done to ensure consistency and reliability [19]. In step 2- the discrete excerpts were reviewed by both researchers who together generated the initial codes. In step 3- LW, C.B and two [removed for review process] PPIE representatives (A.W & J.G), then had a face-to-face meeting to search for themes within the codes. Each team member at the meeting separately identified codes that they believed shared commonalities and arranged them into categories. In step 4- at this same meeting, team members presented the categories they had developed, and a group discussion followed, in which the team then came to a unanimous decision on the themes and their underlying codes. In step 5- following the agreement in the previous step, all PPIE representatives involved in the main trial were provided with the themes, a breakdown of the theme's interpretations, and a considerable number of quotes to illustrate said themes. A remote meeting then took place between L.W and eight [removed for review process] PPIE representatives (A.W, J.E, J.G, J.O, M.L, M.M, R.M, T.W), whereby the PPIE representatives helped further refine the themes, chose the final naming of the themes, and chose the extracted quotes to be included in the study. All authors agreed on consensus, with coding and themes input into a framework matrix using NVivo 12. In step 6- the research findings were written up by the researchers, reviewed by A.W and J.G, who then completed the abstract for this sub-study.

Results

Four themes were identified that were relevant to the study aim and are reported in Table 1. The themes indicated that participants generally had more than one reason for seeking copies of their MRI scan. There was also a fifth theme identified regarding the participants MRI experience. This was not a direct part of the study's intended aims and has been included in the supplemental material. Themes are described and illustrated with quotes below.

Curiosity and casual interest

This theme included $n = 7$ (100%) participants and describes participants' personal motivation for requesting a physical copy of their MRI scan.

The most frequent motivating factor for requesting a copy of MRI scans was the curiosity, intrigue, and interest in seeing images of their brain. In particular, several participants reported that having an MRI scan is a rare experience, and unlike X-rays where you frequently are able to view these images, they felt you would not routinely get that opportunity with MRI brain scans.

"I think most of us fascinated by the complexity of what is in our heads and the fact that it is my brain and not a generic someone, belonging to other people, someone else, I think it makes it a very personal thing for me" Participant 3

"you get to see the outside of your body regularly, if you break something you get to see x-rays of, you know, your bones and stuff. I have not actually broken anything, so I have not seen those, but you never get to see your brain, and you never get to compare your brain to other peoples" Participant 6

Furthermore, whilst not a main reason for requesting a copy of MRI scans, several participants suggested that they would show the MRI scans to family and friends as a topic of discussion as they too would be curious and intrigued to see this.

"if I do, it would not be very many people, it might be one or two...with the same spirit as you share your holiday photos" Participant 3

"my family is interested in science and things so and would have an interest just to see what these things are" Participant 7

In addition, participants did not see receiving a copy of their scan as a reward for participating in research per se; but rather they felt that receiving physical copies of scans would serve as a memento of the experience of completing the MRI, the study in general, and a reminder of improvements due to the TMS treatments. Several participants suggested they would use the scans for personalised art, which too would serve as a positive reminder.

"I had the treatment I think in 2019 and I have had the longest period ever without being depressed, so now it is more like a memento, because it is kind of a really a big turning point in my mental health, so yes, it feels like I want something to mark that now" Participant 1

"it is also an aesthetic thing, I thought it might be an interesting visual piece of art perhaps that might find its way into a frame and end up on the wall" Participant 5

Hope for better understanding and evidence of depression

This theme included $n = 5$ (71.4%) participants and describes participants hopes for visual evidence of their own illness, legitimising depression as an organic condition, and also

the use of their MRI scans in benefitting future clinical practice and research.

Participants had a diagnosis of treatment-resistant major depressive disorder and did not want a copy of their scans to legitimise depression for themselves. However, they hoped that their scans could be used in the future to reduce stigma and legitimise depression as an organic condition to other people.

"it's validation that you actually have something physically wrong with you, in that there is a physiological reason why you are not, you know, normal" Participant 2

"mental illness, so much of it is invisible but having that kind of visual, I personally think it's going to be very useful in helping legitimise the fact that it is a very real organic, you know, the actual thing just that you can see" Participant 4

Several participants also hoped that in the future MRI scans could be used as a standard for psychiatric diagnoses, and that if physical differences could be identified on brain scans this may lead to improved treatments for depression.

"depression is one of these things where there are no real physical symptoms or similar, so if somebody [1] point to a picture and say "look, look how broken I am", you know, so that people could actually understand that it is not just feeling sad or whatever, it's you know, there is a physical illness there" Participant 2

"it just makes me feel reassured that, one thing maybe we can, scan and go okay you've got this condition based on these topographical features on your brain MRI and I think that would be so great, instead of having to go through your history all over again every single bloody time" Participant 4

Interest in having copies of their baseline and follow up MRI scans to see if there had been any brain changes after receiving TMS treatment, with the hopes that the scans could be more widely interpreted in the future was also reported.

"It would be nice to see sort of the start and end one, and to see what the treatment has actually done. Because again, when you look at things like plastic surgery and similar, there are sort of before and after shots, you know" Participant 2

Meaning and understanding

This theme included $n = 7$ (100%) participants and describes participants concerns regarding interpretation of their scans and the handling of any incidental findings.

Whilst some participants wanted scans to see brain changes after receiving TMS treatment as described above, most participants acknowledged they did not have the interpretation skills to understand scans from an analysis perspective.

"the disadvantage would be not being able to understand it without somebody who can understand it" Participant 6

"I would expect a lot of lay people who look at these will try and compare them and go, "why am I different" and "what's wrong with me?" Participant 2

Therefore, several participants suggested that future research should provide participants with more information on the interpretation of MRI scans, as reading into scans too much by a lay person may cause concern due to misinterpretation.

"it would also be fascinating to have it spoken through with someone who knows what they're talking about" Participant 6

"I don't know whether you get any sort of narrative with it although it would be very useful to have some information that points to something on your brain which tells somebody something and what that is" Participant 5

All participants were aware of why the scans were required for the [removed for review process] study and reported no concerns about incidental findings. The majority of participants reported expectations that the radiographers and MRI analysis team would have identified any abnormalities that existed, which would have been reported to them by now, and this was not a motivating factor for requesting a copy of their MRI scans.

"I assumed my scan was normal otherwise you would have told me that there was something urgent that needed to be addressed or perhaps I would be excluded from the study for whatever reason, so the actual report isn't of that much importance, it's more the actual images" Participant 4

Right to access their data

This theme included $n = 6$ (85.7%) participants and describes participants awareness of and their attitudes to the handling of their personal clinical data.

Several participants reported that they were unaware they could obtain copies of their MRI scans, however asked the researchers out of interest. Some participants also felt they should be able to retain their personal data. In particular, several participants wanted a copy of their MRI scans in case this information could be used as baseline comparisons for future mental or physical illnesses.

"I see it as almost kind of if you go through medical screening procedures and diagnostic tests as part of a study, surely you're entitled to get information just because the test has been done" Participant 4

"in case something happened with your brain in the future, to have something to refer to, as it was before" Participant 1

"I didn't know, no, I raised it myself at one of the early meetings once I knew that it was going to be, and [researcher] said funnily enough other people had asked and there is a possibility, and it will be discussed with you at the end of the study" Participant 5

Discussion

Prior studies have predominantly focused on patients with physical health concerns/illnesses or healthy research partici-

pants and their experience of going through an MRI examination. This study extends on this literature by exploring reasons for requesting copies of MRI scans in a sample of participants with treatment-resistant depression. Unlike these prior studies, the MRI brain scan for the [removed for review process] trial was essential to determine the location of the TMS stimulation. Therefore, whilst some of the themes and subthemes are consistent with prior research, others are unique to this study.

In this present study, the most frequent motivating factors for requesting a copy of MRI scans were the curiosity, intrigue, and interest in seeing images of their brain. This is consistent with prior research, which has shown that individuals are curious and excited to undergo the MRI experience, curious to see images of their internal organs [15,20], and describing the experience as unique, medically advanced, and out of this world experience [12]. Furthermore, curiosity has been reported as a factor to encourage research participation [20,21]. Extending on the prior literature, our participants did not see receiving a copy of their scan as a "reward" for participating in research per se; but rather they felt that receiving physical copies of scans and being able to utilise this as personalised art, would serve as positive reminder of study involvement and TMS treatments. This finding is unique to the context of the [removed for review process] trial, but one likely to be seen more often in the future if MRI scans were to be used to personalise neuromodulations.

Furthermore, research suggests individuals with physical health concerns or illnesses, expect MRIs to provide them with a biomedical diagnosis, which would lead to legitimization and a feeling of control over their disease [22,23]. On the other hand, our findings suggest that for participants with mental health conditions, there is not an expectation for MRI's to currently provide biomedical information. Instead, there is a hope that in the future, such scans could be used to improve psychiatric diagnosis, treatment and legitimise to other people that depression is an "organic condition", equally demonstrating that our participants have a clear understanding of the current mental health field.

In accordance with the suggestion that providing access to MRI scans demonstrates respect for an individual's autonomy [10], our findings indicated that participants felt they should be able to retain their personal data. Several participants also wanted to retain copies of their MRI scans in case they could be used in the future, for example as a standard for psychiatric diagnoses or used for baseline comparisons for potential future physical illnesses. Researchers agree with this notion, and whilst recognising that research MRI scans have limitations compared to clinical scans [24], research structural images could offer useful baseline information that can substantially improve the medical interpretation of any future clinical MRI scans that may be needed [9].

Within our study, concerns regarding incidental findings were not a motivating factor for requesting copies of MRI scans, as there was an expectation that the scanning team would have identified any abnormalities that existed. Whilst our partici-

Table 2

Recommendations for information to provide to participants for future MRI research studies

1. Provide clear written and verbal information of the participants accessibility to their MRI scans.
2. Alongside copies of the participants MRI scans, attempt to include targeted education material to help with health literacy.
3. Provide unambiguous information on whether MRI scans will be reviewed for diagnostic content, who will be reviewing/analysing their imaging scans, and the differences between reading of MRI scans between physicians and non-medical researchers.
4. Provide unambiguous information on the procedure for handling incidental findings, the rate of incidental findings, specific to the type of MRI imaging being conducted, and what feedback would be provided to participants if incidental findings are observed.

Participants were made aware of the differences between research MRI scans and clinical MRI scans, they were informed that if an abnormality was found that required further investigation they and their care team would be informed. Therefore, it could be suggested that our participants expected that those completing the imaging analysis were medically trained to identify incidental findings, which supports prior research which reported that it is not always clear to participants that the reading of MRI scans is different between physicians and non-clinician trained researchers or MRI technologists [24]. This would also support prior literature, which reported 54% of research participants would expect brain abnormalities to be detected, despite the preponderance of participants acknowledging that is unlikely for physicians to review their MRI scans [25]. Additionally, a number of participants reported that they were unaware that they could request copies of their MRI scans. In regard to wider research guidelines, the Royal College of Radiologists (RCR), indicate that research studies should consider radiologists in the appropriate speciality to review research MRI scans, patient information sheets should provide unambiguous information on if the images will be reviewed for medical content and by whom, procedures in place if incidental findings are observed and what information will be feedback to participants, and the likelihood of incidental findings specific to the type of imaging research being conducted [26]. Based on this prior research and our study findings Table 2. provides recommendations for areas of improvement for future MRI research studies.

Finally, our participants were aware that the scans were required for the TMS treatment, and whilst some participants reported that they would not have the interpretation skills to understand the images, several others reported interest in acquiring copies of their pre and post treatment brain scans in case they could observe brain changes. Additionally, there were suggestions that in order to help interpret images, additional verbal, or written information should be provided. They equally acknowledged the risks of misinterpretation by lay people. This is consistent with Johnson et al. [27] who note that if educational resources are not provided, people may seek their own, resulting in people drawing on inaccurate or unwise material. Additional patient-orientated reports and MRI explanations are known to improve patient knowledge and experience in clinical practice [28,29]. However, this may not always be feasible for research studies, due to the costs of requiring radiologists and clinicians to complete such reports. It may therefore be suggested that if research participants receive copies of their MRI scans, targeted educational material to help with health literacy should be included.

Strengths and limitations

This study and its narratives need to be viewed in the context of participants who have a debilitating mental illness which is both poorly understood in terms of aetiology and has limited public awareness of its nature. The desperate, immobilising struggle of treatment-resistant depression may have prompted many to seek an image as a reminder of the personal achievements of completing the course of TMS treatments; fully supporting the hope being held that this intervention will make an important difference. Whilst some of the themes and sub-themes are consistent with prior research, other subthemes like having a memento of positive change or trying to determine change across scans after MRI directed TMS are unique to this study. There was also a high level of understanding of the nature of the research and a desire to influence future clinical practice.

This study was also co-designed and co-produced between researchers and PPIE representatives. This was of significant importance, given that prior studies have shown that PPIE input can provide greater insights, thoroughness of interpretation [30], and help challenge perspectives by viewing data through service users' eyes [31].

Limitations that need to be acknowledged include the small sample size, there was an unbalanced number of participants across three [removed for review process] research sites, with two research sites not sampled. In addition, whilst there were no new codes or themes being identified from the interviews, six out of seven participants had prior experience of undergoing MRI scans. Therefore, further interviews may have modified some of the themes, particularly in relation to the experience of people who had not previously had an MRI. In terms of transferability of our study findings, the curiosity, intrigue, and interest in seeing images of the brain and the request for retaining personal data are likely to be motivating factor for most participants involved in MRI research studies. In addition, if copies of MRI scans are to be provided, targeted educational material to help with health literacy should be included for all research participants. On the other hand, our findings of the hope for scans to be used in the future for improving psychiatric diagnosis, and legitimising depression as an organic condition, is unique to our study but perhaps likely to be seen in the future for MRI research studies of other mental health disorders.

Conclusions

This exploratory qualitative study provides an insight into these participants' beliefs about the utility of MRIs for research

and future neuromodulation treatments in depression, and the reasons why they would like to retain copies of their MRI images. The findings generated from this study may also have value beyond that of the mental health and neuromodulation fields. Furthermore, such first-hand experiential accounts have led to recommendations for future research, which corroborate recommendations made by professionals and researchers, and highlight the importance of listening to the participants' perspective in order to improve research and health processes.

Contributors

All authors contributed to the conception or design of the work, the acquisition, analysis, or interpretation of the data. All authors were involved in drafting and commenting on the paper and have approved the final version.

Collaborators

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Competing interests

All authors have completed the ICMJE uniform disclosure form and declare no conflict of interest. CB, PB and LW declare funding for the research project which collected the

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Ethical approval

Ethical approval for the BRIGHtMIND main trial was obtained from the NHS Research Ethics Committee (ref: 18/EM/0232), with this qualitative sub-study receiving Health Research Authority approval and Research Ethics Committee approval in a substantial amendment (21/12/2020). Informed consent was obtained from all participants.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.jmir.2023.03.028](https://doi.org/10.1016/j.jmir.2023.03.028).

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