To cite: das Nair R. Hunter R.

Garjani A, et al. Challenges

of developing, conducting,

analysing and reporting

a COVID-19 study as the

bmjopen-2021-048788

Prepublication history for

this paper is available online.

To view these files, please visit

the journal online (http://dx.doi.

org/10.1136/bmjopen-2021-

Received 06 January 2021

Accepted 14 May 2021

study. BMJ Open

048788).

COVID-19 pandemic unfolds:

an online co-autoethnographic

2021;11:e048788. doi:10.1136/

BMJ Open Challenges of developing, conducting, analysing and reporting a COVID-19 study as the COVID-19 pandemic unfolds: an online coautoethnographic study

Roshan das Nair,^{1,2} Rachael Hunter,³ Afagh Garjani ^(b),^{1,4} Rod M Middleton,⁵ Katherine A Tuite-Dalton,⁵ Richard S Nicholas,^{5,6} Nikos Evangelou^{1,4}

ABSTRACT

Objectives To capture the complexities and unique experience of a newly formed multidisciplinary and multicentre research team developing and deploying a COVID-19 study and to identify lessons learnt. **Design** Co-autoethnographic study.

Setting Staff at two UK academic institutions, a national charity and two major UK hospitals.

Participants Researchers, clinicians, academics, statisticians and analysts, patient and public involvement representatives and national charity.

Methods The sampling frame was any content discussed or shared between research team members (emails, meeting minutes, etc), standard observational dimensions and reflective interviews with team members. Data were thematically analysed.

Results Data from 34 meetings and >50 emails between 17 March and 5 August 2020 were analysed. The analysis yielded seven themes with 'Managing our stress' as an overarching theme.

Conclusions Mutual respect, flexibility and genuine belief that team members are doing the best they can under the circumstances are essential for completing a time-consuming study, requiring a rapid response during a pandemic. Acknowledging and managing stress and a shared purpose can moderate many barriers, such as the lack of face-to-face interactions, leading to effective team working.

Check for updates

© Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Professor Roshan das Nair; Roshan.Dasnair@nottingham. ac.uk

INTRODUCTION

The COVID-19 pandemic resulted in hundreds of papers being published over the last year. The speed with which studies have been conceptualised, conducted and results disseminated has been impressive. Whilst this rapid delivery of research may be common for some specialities, for many (including us), the speed at which we had to work during the pandemic posed new challenges needing new solutions fast.

Only few COVID-19 studies have considered ethnographic approaches to understanding

Strengths and limitations of this study

- We had a good record of all emails and other messages the team exchanged, which served as rich source data.
- The COVID-19-MS study evolved very quickly, so the memories of key interactions and events remained fresh.
- Because we were all experiencing the same pandemic and UK lockdown, this created a shared understanding of our predicament.
- We started this study 1 month after the main COVID-19-MS study began, so some data were possibly lost.
- We did not have a single ethnographer whose sole role was to record and interpret actions in real time.

phenomena of interest. Studies, for instance, have considered religious worship,¹ crisis communication² and social experiences of lockdown,³ but none have focused on how a team is formed and works to develop and deliver a COVID-19 study.

This co-autoethnographic study covers COVID-19 and multiple sclerosis (MS) research. MS results in different degrees of disabilities. Many people with MS are prescribed disease-modifying therapies (DMTs). Early in the pandemic, clinicians were uncertain whether COVID-19 would disproportionately and adversely affect people with MS because of their disabilities or the immunomodulatory effects of DMTs. Various national (eg, Association of British Neurologists) and international (eg, MS International Federation) organisations offered guidelines on this topic but acknowledged that these were not based on empirical research.⁴⁵ Therefore, there was an urgency for this gap to be addressed.

BMJ

National disease registries offer an opportunity to collect data from many patients quickly. We worked with the UK MS Register ('the Register') on the COVID-19-MS study. Launched in 2011 and funded by the UK MS Society, the Register collects real-world data from people with MS and National Health Service (NHS) sites across the UK. The Register can also rapidly deploy additional questionnaires to its participants. Therefore, it could host the COVID-19-MS study.

The COVID-19-MS study explored issues in biopsychosocial terms (eg, association between DMTs and COVID-19, impact of anxiety on MS symptoms and loneliness during the pandemic). This is an ongoing longitudinal study that follows up people with and without COVID-19 approximately fortnightly. The details of the study until April 2020 have been published.⁶ We have been updating and presenting the findings at national and international meetings, and further results have been submitted for publication.

Within this context, the rationale for conducting this co-autoethnographic study was to offer a reflexive and critical perspective of our own team working and to refine our ways of working; to keep a log of our own thoughts, feelings and experiences to enable us to work more effectively as a team; and to offer a product (this paper) to others who may find themselves in a similar situation in the future, and to help others develop more effective studies in other natural experiments or pandemics.⁷ Indeed, the value of such ethnographic research has been highlighted by Manderson and Levine,⁸ and we felt this was pertinent in the COVID-19 era.

Aims

Our aims were to:

- 1. Examine the process by which this national research on COVID-19 and MS unfolded in real time.
- 2. Explore the challenges the team faced at different stages of the research, as understanding about COVID-19 evolved, and the UK government reacted to this knowledge.
- 3. Identify lessons learnt that could prepare the research team (and others) in rapidly designing, conducting and disseminating similar studies during future waves of COVID-19 or other pandemics.

METHODS

[•]*Ethnography is the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities*^{•,9} The emphasis is on exploring the nature of a complex social phenomenon, covering relatively unchartered territory, with multiple 'actors', and needing a deep understanding of the issues from within a system. In this case, the 'system' was the research team developing and delivering the COVID-19-MS study, and the 'actors' were ourselves as the researchers, who came from a range of disciplines (eg, neurology, psychology, research, and communications).

The in situ presence of the research team, acting as both participants and researchers, makes this an autoethnographic study. We also define this as an 'online' autoethnographic study because of the technology-mediated interactions necessitated by the restricted face-to-face contact during the pandemic,¹⁰ and 'co'-autoethnographic because the of the coconstructed nature of the ethnography, including mutiple authors.¹¹ Autoethnography is a postmodern research method. Postmodernism rejects the possibility of having 'objectively' known 'truths' and recognises that multiple actors can arrive at different contrasting and converging truths (in plural), without privileging any one position. Autoethnography is linked to a hermeneutic phenomenological and social constructionist epistemology. Hermeneutic phenomenology relates to the subjective nature of experience and the meaning-making process that we engage in to make sense of phenomena, and social constructionism avers that all knowledge is developed ('constructed') and is socially situated and context dependent.¹²⁻¹⁴ It is beyond the scope of this paper to review the rationale and descriptions of autoethnographic research; we would like to refer the reader to Wall¹⁵ for an overview of autoethnographic research.

The sampling frame was everything we (the participants of this study) discussed or shared among ourselves during the COVID-19-MS study. Data sources included personal and collective memories and reflections, minutes and notes from meetings, observations made during meetings and emails related to the study. Newspaper articles communicating government decisions around the pandemic, and COVID-19 related publications were 'cultural artefacts' (cultural artefacts relate to any 'objects' or human 'creations' that convey information and insights about daily life within a certain place and time) that we considered as additional sources to help contextualise our data. The lead author also led focused discussions with all team members individually to explore their views and perspectives on the research process. Triangulation was possible whereby we compared data or positions from multiple sources of data.

Standard observational dimensions of ethnographic research were followed:⁹ actor, activities, artefacts, events (activities that people carry out), time (sequencing of events), goals (what we were attempting to achieve) and feelings (emotions expressed). Because of the online nature of data, we could not observe space and objects, but noted people's kitchens (and their crockery), living rooms (and their bottle of wines), hospital offices (including personal protective equipment) and distractions (children and pets), and were alluded to during discussions.

Data analyses initially began in an inductive thematic manner.¹⁶ The primary reason for starting with an inductive analysis was, in line with Thomas,¹⁷ 'to condense extensive and varied raw text data into a brief, summary format'. Once the thematic structure was consolidated, we began to approach and seek data in a deductive manner

that fit within our pre-existing themes, but we always kept an open mind for new themes to be elicited. This was enabled by being reflexive of our own and others' positions during data analyses and interpretation processes. Themes were corroborated by other team members, and any discrepancies were resolved through discussions and referral to the raw data.

We followed the ethical guidelines for autoethnographic research.¹⁸ All parties consented to participating and contributing to data collection, analyses, interpretation and write up of this study. We are unaware of specific guidelines for assessing and ensuring quality in autoethnographic research but have addressed the issues of rigour based on Le Roux,¹⁹ focusing on subjectivity, selfreflexivity, resonance, credibility and contribution.

Agreement for coding and themes was reached through discussions (RdN and RH), efforts to ensure triangulation was achieved through comparing the raw data, the emerging themes and related literature, and differences of opinion were resolved through discussion.

Patient and public involvement (PPI)

People with MS were consulted during a PPI meeting about the perceived value of this study. We have an MS PPI group that meets regularly. During such meetings, we discuss various MS studies that are being planned or ongoing and seek their input in terms of perceived value of the research and/or process when involving people with MS. One of our authors has MS and has shared their views as both a person with MS and as an academic/ researcher. As an autoethnographic study, we were both the researchers and participants.

RESULTS

Data from 34 group meetings comprising over 2000 min and over 50 emails between 17 March and 5 August 2020 were analysed. Results are organised thematically based on the temporal order of the study progress. The analysis yielded seven themes with '*Managing our stress*' as an overarching theme.

Developing the study team

The COVID-19-MS study was supported by the Register's funding body (UK MS Society) who expedited funding within 2weeks of receiving our proposal. Pre-existing relationships enabled rapid communications between the team and the funder. The initial study was a simple questionnaire designed by the Register team (RMM and KAT-D), in conjunction with a neurologist (RSN), in response to a blog posted on the Barts MS Blog,²⁰ which is popular in the MS community. This questionnaire covered COVID-19 diagnosis, symptoms, sources of COVID-19 information for people with MS, DMT use, self-isolation practice and hospital admission. Another neurologist (NE) independently contacted the Register enquiring about setting up a COVID-19-MS study, and he and a research fellow (AG, who served as the primary

clinical analyst) were co-opted into the team. At this stage, the study follow-up questionnaires were developed and launched. Then, a clinical psychologist (RdN) contacted the Register to enquire whether psychological wellbeing could be captured in the next iteration of the survey. There was some initial reluctance among the largely medically-focussed team about including a psychologist; however, it was agreed that the study of psychological wellbeing would be valuable and that RdN would provide experience in large studies, ethics and analysis plans.

With a team that came together in an 'organic' fashion, with some people not having worked with others, there were research cultural differences, resulting in heated exchanges and delays in arriving at a consensus. An early bone of contention was the need for PPI in the study, with some members feeling this was crucial while others questioning it. A resolution was reached, and a PPI member (RH), known to the Register, was invited to join the team. The 'core' team was in place 13 days after the initial survey was designed. As the study evolved and data collection progressed, there was a growing consensus that engaging a statistician would have been/would be a useful addition to the team.

Working together

As a new team that had not worked together before, there was a period of adjustment to different people's personalities and styles of working. Communication between members improved once people adjusted to the online technology and each person began to appreciate the expertise others brought to the team. We began to recognise the pressures we were all working under, and the Register's standard operating procedures was clarified to all, in terms of what could be modified in the questionnaires and what was non-negotiable.

As members were from different academic disciplines, sometimes confusions arose simply because of the differences in academic 'languages' spoken. We overcame this by asking for clarification on how certain words were being used by different parties.

The team had two co-principal investigators (PIs) who had not previously worked closely together. There was no clear demarcation of their roles, so when disputes arose, team members tended to support each PI based on previous alliances. In such instances, it was helpful when a team member managed the conflict as independently and objectively as possible, keeping the team goal oriented. The issue of leadership was resolved over time, with their division of labour being discussed and agreed by the PIs outside of the whole team meeting. Despite these challenges, having co-PIs was helpful to ensure continuity of the study (when PIs had clinical or other responsibilities, or if one became ill, which was a concern during the pandemic).

Finding time to meet regularly was a challenge with some people working on the NHS frontline and others having new responsibilities because of the pandemic (eg, extra childcare), but a quick, agenda-driven meeting twice weekly at pre-arranged times was agreed. The online platform to 'meet' was mutually agreed (based on technology that was available for and familiar to all), and one person took responsibility for organising meetings and maintaining meeting notes. We also agreed on where documents could be stored and shared, how we would review and feedback documents such as the study protocol, analysis plan and manuscripts, and who had editorial responsibility of each document. This reduced issues with version control.

Outside meetings, members communicated with each other separately, advancing issues that they considered essential without input from other members. These interactions were triggered by the meetings and occurred mainly among members who had pre-existing working relationships or common professional interests, although not exclusively. These interactions reduced the time needed for full meetings and kept the agenda focused, but also, at times, resulted in actions that surprised other members not privy to these plans. Occasionally, this led to some members feeling that the 'team approach' to the project was being undermined.

We felt that some issues we faced were related to the technologies we were using. For instance, working together using online video conferencing and emails did not facilitate team building the way that face-to-face meetings would allow. However, this enabled coworking and increasing the frequency of meetings in a way that would have been impossible to arrange in-person (especially given the wide geographical spread of members).

(Re)Designing the study

The team were mindful that many of the standard 'rulebooks' for designing and conducting good quality research could not be applied in this research, because the study was being conducted *during* a pandemic evolving in real time. For instance, new symptoms of COVID-19 (eg, anosmia) were identified,²¹ which were not captured in our original questionnaire, and therefore, we had to rapidly revise it. Government guidelines for public behaviour changed over time, meaning that our initial questions quickly became redundant. However, we had already had responses from participants, so there were challenges in combining these data. The way the study and the pandemic unfolded in the UK is depicted in figure 1.

Two months into the study, it became apparent that some details of the study were not fully agreed on by the whole team. Although the design had changed from a cross-sectional study to a longitudinal one, disagreements ensued about the nature of the follow-up questionnaires (whether they should remain unchanged, addressing issues identified at the study onset, or be adjusted based on the changing knowledge and needs).

Another issue was the limited testing for COVID-19 across the UK. When the study began, only those admitted to hospital were tested. Therefore, clinical confirmation of who was COVID-19 positive was a challenge. The team

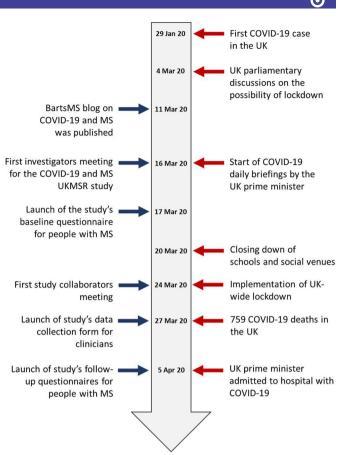


Figure 1 Timeline of the COVID-19-MS study and the pandemic with national/government guidelines and events depicted on the right and study developments on the left. MS, multiple sclerosis.

agreed to address this by asking respondents: (1) about COVID-19 symptoms,²² (2) whether they had been tested for COVID-19 and (3) whether a healthcare professional had made a clinical diagnosis. Additionally, a neurologist telephoned a sample of participants to confirm their symptoms and clinical diagnosis. We also requested clinicians at all UK MS centres to report anonymised data of those diagnosed with COVID-19.

Conducting the study

One big advantage was the existence of the Register, which had systems and staff in place to host new studies that helped us to act quickly. However, because the Register mainly supported studies that were planned, agreed and fixed months in advance of survey deployment, this new way of working (that required several changes being made in a very short time) caused some tension between the Register staff and other team members. The Register staff had to schedule this new study while ensuring they completed other planned studies. The speed with which the pandemic was spreading added further pressure. The Register staff were also concerned about questionnaire fatigue among respondents, so were reluctant to introduce additional questionnaires in case it adversely affected future response rates. The Register had general ethical approval from the UK NHS Health Research Authority to contact registrants with new questionnaires. Additional ethical approvals for non-MS 'control' groups were obtained through university ethics committees, who had established fast-track appraisals for COVID-19 studies. The implementation of these new policies during the COVID-19 pandemic enabled us to quickly deploy additional questionnaires.

As the study progressed, we observed gaps in the questionnaires caused by emerging issues due to the pandemic or government restrictions, and gaps in our own expertise (eg, there were reports of increased domestic abuse,²³ but we did not have anyone in our team with expertise in this field). While there were important questions to be asked, we were concerned about 'mission creep' and its impact on respondents who would face longer questionnaires, risking respondent fatigue. There was also concern about the impact of adding new collaborators on the fragile equilibrium that the new team had just achieved. A compromise was reached by having an expert advisory team who would meet monthly and offer external scrutiny to the conduct of the study, provide feedback and help interpret findings.

Another challenge was that clinicians within the team were busier than usual, managing both their routine clinics and frontline work. This made them less available for research meetings and tasks (eg, telephoning respondents). We had funding to appoint new staff, but due to cashflow problems at universities and hospitals, there was a staff recruitment freeze. We considered offering consultation fees for system analysts for specific tasks to be completed, but the time taken to train them would not have made this a feasible option.

Some people with MS became ill with COVID-19 and were hospitalised. Therefore, there was a possibility that this group and those who were very ill either do not respond to the questionnaires at all or drop out after the baseline questionnaire. This would have skewed responding. We attempted to address this by following up the Register participants and by complementing our patient-reported data with clinician-reported data.

Analysing data

The changes we made to the questionnaires created challenges in merging data from their original and later versions. We were, however, able to do this because all our data were time-stamped through the Register system.

Once the data coding was revised based on the merged questionnaires, the analysis was hampered by the data analyst contracting COVID-19. However, because we had assigned deputies for each task in the project, we were able to continue with data cleaning and analysis with minimum delay.

Good practice dictates that healthcare research have a documented analysis plan before they begin.²⁴ However, this was not entirely possible, because although the primary research questions were clear, additional questions were emerging as the pandemic and government

restrictions unfolded. Therefore, some aspects of the analysis plan had to be modified, leading to certain risks (eg, over-analysing).

The speed of funding approval allowed for dedicated analyst time to be funded. Without this, it would have proven difficult to complete the analysis within the rapid pace of the study timeline. The study data generated were made available for analysis to two to three individual analysts and all members of the team. The analysis was done using various statistical software by different analysts producing almost identical results. This reinforced the reliability of the findings.

Interpreting data

While not having a 'control group' for aims specific to MS (eg, DMT use) was not a problem, other generic aims (eg, impact of self-isolation) needed a non-MS cohort. This was a challenge because the Register only includes people with MS. We resolved this in two ways, we: (1) contacted researchers conducting population-based, disease non-specific COVID-19 research collecting comparable data (eg, mood questionnaires) to share their data and (2) obtained additional ethical approval to request the Register's respondents to send the questionnaire to people they believed not to have MS. In the former case, while some researchers responded positively, others were less receptive of collaborating. Engaging with other researchers also raised the question of who counted as a collaborator and who would earn co-authorship.

A further complication arose with public reports of the changing symptom cluster of COVID-19, with the public becoming aware of such new symptoms increasing the risk of hypervigilance and over-reporting. This could have resulted in increased false-positive diagnosis, particularly when based on subjective symptoms and in the absence of objective tests to confirm COVID-19.

Reporting our findings/data sharing

One of our aspirations was to provide the MS community with regular updates of our findings (as the project was born out of the need for immediate data-driven answers). This was important in such a longitudinal study, where ongoing participation is vital. However, it caused several challenges: (i) we needed dedicated staff to clean and analyse the data while performing all other tasks of the study. (2) We needed to determine how best to disseminate the data. With PPI input, we decided to produce short videos of the results, distributed on YouTube and the Register every fortnight. (3) The results were not peer reviewed, so we opted to provide mostly descriptive data, staying close to the raw data. (4) We needed to balance the risks of sharing data and losing ownership. Early on, we encountered an instance where our data were used without attribution to us. Therefore, we decided to register our study on ClinicalTrials.gov (NCT04354519) and include our branding and a statement of copyright on all our outputs. We were concerned whether our findings would be published in a reputable journal if they were already in the public domain.

We were clear from the outset that we wanted to share our data and methods. Therefore, on the day the original survey was launched, the Register shared the data dictionary with delegates of the MS International Federation.²⁵ This enabled other registries globally to use our questionnaires and coding framework, allowing for future crosscountry comparisons.

Managing own stress

We had no doubt that our stress during the pandemic (clinical and research work, additional family and childcare responsibilities, sickness, the lockdown, etc) impacted on our ability to conduct this study. Furthermore, as the team were spread so widely geographically, there were inevitable differences in pressure according to whom the pandemic was affecting more at different times. This pressure contributed to tension, that was most acutely felt in our interactions, and the level of tolerance we had for each other. This, combined with the time pressure of distributing the questionnaires, analysing the data and disseminating the results continually, created at times a tense atmosphere and inevitably led to some mistakes being made (eg, coding errors, later corrected).

We consider this an overarching theme because the impact of the stress could be found on every aspect of the study. Where disagreements emerged, these were attempted to be resolved through an informal majority

Table 1 The key	Table 1 The key issues encountered and recommendations for developing and conducting the study				
Theme	Issue	Recommendation			
Developing the study team	Deciding on the team members	Even if organically developed, once the core team is formed, it would be helpful to quickly identify what further input is needed and which professional or patient groups to involve. Agree in advance the roles and responsibilities of each team member and decide on whether or how new members will be approached or included. Team members from different disciplines may make the study stronger, but the team needs to be small enough to resolve conflicts and act quickly.			
	Having an advisory group	Consider having an external study advisory board with experts in the field, but be clear about their roles and remit, and how they will be credited in the publications. Using the group as a sounding board may help in terms of interpreting the data as they come in.			
	Patient and Public Involvement (PPI)	Involve PPI early. Having pre-existing PPI members involved in disease-specific research is helpful because they would have had the required training and experience to be able to offer their input within high-pressure, fast-pace, research encounters. PPI members can help develop a Plain English Summary and comment on concerns about questionnaire fatigue. Develop one early, so that it can be used for publicity to help improve recruitment, but also for funding bodies, ethics applications and dissemination. PPI members also help researchers keep the needs of the patient at the forefront.			
	Two people per role	Having two people per role (eg, two neurologists, two psychologists, two Register staff) created some differences in opinion, but also ensured continuity (in case people became ill). While this doubling up of roles is helpful, clear primary and deputy roles and responsibilities need to be agreed in advance of the study commencing.			
Conducting the study	Survey platform	Use pre-existing disease-specific national registers to host new studies where possible; however, be aware that their pre-existing workload may delay new studies. Where registers exist, consider whether they can be adapted to include 'control' participants' data also (where this is not available as part of the register). Where registers do not exist, consider developing local registries. Explore which platforms (eg, REDCap and Qaultrics) have been recently used successfully by members of your study team.			
	Ethical approval	Consider and enquire with relevant ethics committees whether amendments to previous ethical approvals will be sufficient for the new study, rather than having to apply for fresh ethical approval (which could be time-consuming). Explore whether universities and institutions have any emergency, fast-track ethical approval processes.			
	Ever-growing questionnaire – adding new questions	Be prepared for the questionnaire needing to change—so prepare for the change—and reflect on what needs to be put in place to enable or facilitate the change. There are bound to be gaps in questionnaires. Weigh up the benefits of asking certain questions and the risks of increasing the length of the survey and resultant respondent fatigue. Beware of and manage 'mission creep'.			

vote. Where necessary, the two or three members who could not agree on specific points met outside of team meetings to find a compromise, which was then communicated to the team.

DISCUSSION

The motivation for this ethnographic study was borne out of: (i) the novelty of the experience for us working without a framework for developing and deploying a study *during* a pandemic and (2) our desire to share the lessons learnt through this process. Our reflections on developing and conducting the study, working together and managing stress, and producing and disseminating findings are captured as recommendations in tables 1–3, respectively.

We were affected by the pandemic we were researching. We had to work within the restrictions and challenges to personal and professional life that the pandemic created. However, these pressures, the fast-paced responses required and the unique shared experience, undoubtedly, contributed to the drive and commitment required to maintain study continuity. Indeed, from starting our study in March 2020, we were able to submit our first manuscript for publication in June, with it being published in August.⁶

Effective interprofessional teamworking processes remain relatively unexplored.²⁶ The challenges of our research seemed to be moderated by the members' (or 'actors') shared lived experience of the research focus (the pandemic), despite their differences in professional backgrounds, research perspectives, etc. This co-autoethnographic study supports evidence that working towards a shared purpose may build trust and may contribute positively to team relationships through moderating conflict within teams. This is a team process rarely discussed in the literature^{27 28} but does feature in Allport's Intergroup Contact Theory.²⁹ This theory posits that contact between members of different groups can facilitate better understanding and reduce prejudice and intergroup conflict. Future research could explore the mechanisms through which common goals and shared experiences facilitate disparate team membership.

Given the multiple geographical locations of the team members, the quantity and quality of communication were impacted by 'space and time'.³⁰ The online nature of the teamwork enabled us to bypass these geographical challenges but did not prevent the development of strong working alliances between members. This supports the

Theme	Issue	Recommendation
Working together	Setting and managing expectations	An early explanation of how systems (such as Registries) work and the limits of tolerance for change of the system can set and manage expectations. Agree on the roles and responsibilities of each team member and clear timeframes for actions to be delivered.
	Online/remote communication	Find and agree on the online platform to be used to hold meetings. Provide support to and be patient with those unfamiliar with the platform. If agreed, share mobile phone numbers in case the online technology fails. Consider a back-up online platform for communication if one fails. Communicate your personal email 'style' with others, so that people do not 'misread' the 'tone' of the emails.
	Speaking different 'academic languages'	Consider creating and sharing the operational definition of terms. Consider developing an ongoing glossary of terms. Recognise the differences in how different professionals understand a term or construct.
	Break-away meetings	Having smaller, break-away meetings are beneficial to reduce the time for the full team meetings, but these need to be agreed in the full team meeting, and their remit clear. Unscheduled break-away meetings may risk team fragmentation, causing teams to split.
	Version control and editorial leadership	Agreeing on how documents should be stored and modified (eg, using Microsoft Teams) will enable co-working on a single document, ensuring version control. Agreeing on who has final editorial responsibility enables issues raised by co-authors to be resolved and that everyone is working from the 'cleanest' possible version.
	Team members becoming ill	As an ongoing pandemic, with everyone being susceptible (particularly those working on the frontline), therefore, ensure early that each major task can be performed by at least one other person in the team, or have a mechanism to bring in someone new to the team to complete this.
Managing stress	Individual stress affecting team and study	Be aware that unusually high stress levels among the team are possibly inevitable and that this might make it difficult to always achieve agreements quickly. Plan for break- away meetings to iron out differences. Follow a time-limited agenda-focused meeting schedule. Be mindful of your actions and how you communicate with others. Remind yourself that everyone is working under pressure. Recognising that the tone of emails can be misinterpreted especially when sent or read in a hurry, and informing others of own email style, and agreeing on basic communication standards may be helpful. Do not delay apologising if you feel you have hurt someone.

notion that online connections enable 'hyperpersonal' relationships even for multiprofessional teams in occupational settings.³¹ The implications of this are potentially far-reaching, for example, enabling the development of effective working collaborations that may not have previously been deemed possible nor effective. However, it should be noted that these interpersonal relationships were also influenced by projections of 'intentional identity', pre-existing relationships and smaller working groups outside the main team discussions, reflecting the multilayered nature of online team communications. Geach describes intentional identity as, 'when a number of people, or one person on different occasions, have attitudes with a common focus, whether or not there actually is something at that focus' (p. 627).^{32 33}

Our study highlighted differences of opinion among team members regarding the value and effectiveness of PPI. This points to a need to better understand, evaluate and disseminate research about the benefits and purpose of PPI.³⁴ It seems essential that we expand our understanding of how such interpretations shape how user involvement is put into practice.

Strengths and limitations

The strength of this study was that we had a record of all messages we exchanged as a team, serving as rich source data. The COVID-19-MS study evolved very quickly, so the memories of key interactions and events remained fresh. Because we were all experiencing the same phenomenon, we developed a shared understanding of our predicament.

We started this study a month after the COVID-19-MS study began. Therefore, some data were possibly lost. However, this also meant that the participants did not modify their actions (a key criticism of such studies), and if they did, these modifications would have been noticed by others. We did not have a single ethnographer. Instead, we opted for a democratic way of having all 'actors' as researchers sharing and interpreting observations. Interestingly, this process engendered greater reflexivity and awareness within team members and improved our working relationships and wellbeing.

CONCLUSION

Some COVID-19 studies are done voluntarily (ie, without payment for some researchers) and are time consuming. This study suggests that mutual respect, flexibility, and genuine belief that team members are doing the best they can are essential ingredients for completing such studies during a pandemic.

Although sustained face-to-face team collaborations are regarded as essential for transforming a group of individuals into an effective team, this autoethnographic study

Theme	Issue	Recommendation
Analysing data	Ever-growing questionnaire – coding and merging data	Changes to surveys may be inevitable during an unfolding pandemic. Planning for how to code changes and having all data time-stamped will enable merging and cleaning of data.
	Ever-growing questionnaire – managing data analysis	Where possible, do have a draft analysis plan. It will add focus to the study, highlight specific data needed to answer specific questions, will save time later during data analysis, will restrict mission creep, and will result in a more robust study.
Interpreting data	Control group	Consider in advance whether a control group is needed and how such data can be obtained. Linking in with other researchers working in related studies and agreeing on a common minimum questionnaire set may be beneficial to all parties.
Reporting findings/data sharing	Ongoing reporting	Have a clear dissemination policy and a plan for how, when and how frequently to release data or report findings. Having PPI input at this stage is vital to ensure that the intended patient group can understand the data. Be clear that the study is ongoing, so the findings may change when more data accrue, and as the pandemic and resultant government policies change.
	Having clear messages	Being clear of the outputs, and not losing sight of the original questions and what is important for the clinicians and patients, may help structure the messages. Keep messages simple. Having PPI input at this stage is important.
	Protecting intellectual property	Register the study on an online study registry, like ClinicalTrials.gov. Have a clear copyrigh statement and provide contact details of key authors to respond to data sharing requests.
	Data sharing	Consider having a data-sharing policy early on. The MRC has produced a useful guide for researchers http://www.methodologyhubs.mrc.ac.uk/files/7114/3682/3831/ Datasharingguidance2015.pdf
	Authorship	Having a plan for authorship at the start of the project is helpful. Use the International Committee of Medical Journal Editors guidelines as a starting point http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html

MRC, Medical Research Council; PPI, patient and public involvement.

suggests that acknowledging and managing stress, and a shared purpose, can moderate many barriers and create unlikely but effective team working.³⁵

Author affiliations

¹Mental Health and Clinical Neurosciences Academic Unit, University of Nottingham School of Medicine, Nottingham, UK

 2 Institute of Mental Health, Nottinghamshire Healthcare NHS Foundation Trust, Nottingham, UK

³College of Health and Human Science, Swansea University, Swansea, UK
⁴Department of Academic Clinical Neurology, Nottingham University Hospitals NHS Trust, Nottingham, UK

⁵Department of Population Data Science, Swansea University, Swansea, UK ⁶Department of Cellular and Molecular Neuroscience, Imperial College London, London, UK

Acknowledgements We would like to thank the participants of the UK MS Register and those who took part in the COVID-19 study. We would also like to thank all MS teams that have encouraged and supported people with MS throughout the pandemic at National Health Services sites across the UK.

Contributors RdN and RH conceived the idea of the study and were involved in the execution of the study and analysis of data along with AG, RMM, KAT-D, RSN and NE. The manuscript was drafted by RdN and RH, revised by AG, with intellectual contributions from all authors.

Funding This work was supported by the MS Society, grant reference number 131.

Competing interests RdN is the Chair of the NIHR Research for Patient Benefit East Midlands Research Advisory Committee; he has received funding to prepare and deliver lectures on cognitive rehabilitation in multiple sclerosis from Novartis and Biogen. AG, RMM and KAT-D have received a grant from the MS Society as part of the UK MS Register. RSN has received support for advisory boards and travel from Novartis, Roche and Biogen. He has received grant support from the MS Society. He is a member of a NICE HTA committee. NE is a member of the advisory board for Biogen, Merck, Novartis and Roche. He has received grant income from the MS Society, MRC, PCORI and NIHR.

Patient consent for publication Not required.

Ethics approval Ethical approval for UKMSR studies was obtained from South West-Central Bristol Research Ethics Committee (16/SW/0194).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID iD

Afagh Garjani http://orcid.org/0000-0001-9271-346X

REFERENCES

- Addo G. Worshipping on Zoom: a digital ethnographic study of African Pentecostals churches and their Liturgical practices during Covid-19. Malmö universitet/Kultur och samhälle, 2020.
- 2 Governmental Response to the COVID-19 Pandemic-A Quantitative Ethnographic Comparison of Public Health Authorities' Communication in Denmark, Norway, and Sweden. *ICQE* (International Conference on quantitative ethnography) 2020, online, January 30-February 2, 2021. Aalborg University, 2020.
- 3 Zuev D, Hannam K. Anxious immobilities: an ethnography of coping with contagion (Covid-19) in Macau. *Mobilities* 2020:1–16.
- 4 Association of British Neurologists. ABN guidance on COVID19 and MS therapies 2020, 2020. Available: https://www.theabn.org/ news/492925/ABN-guidance-on-COVID19-and-MS-therapies.htm [Accessed 11 Dec 2020].

- 5 MS International Federation. Global COVID-19 advice for people with MS 2020, 2020. Available: http://www.msif.org/wp-content/uploads/ 2020/03/MSIF-Global-advice-on-COVID-19-for-people-with-MS. docx-1.pdf [Accessed 11 Dec 2020].
- 6 Evangelou N, Garjani A, dasNair R, et al. Self-diagnosed COVID-19 in people with multiple sclerosis: a community-based cohort of the UK MS register. J Neurol Neurosurg Psychiatry 2020. doi:10.1136/jnnp-2020-324449. [Epub ahead of print: 27 Aug 2020].
- 7 Craig P, Cooper C, Gunnell D, et al. Using natural experiments to evaluate population health interventions: new medical Research Council guidance. J Epidemiol Community Health 2012;66:1182–6.
- 8 Manderson L, Levine S. COVID-19, risk, fear, and Fall-out. *Med Anthropol* 2020;39:367–70.
- 9 Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ* 2008;337:a1020.
- 10 Hine C. Virtual ethnography. Sage, 2000.
- 11 Cann CN, DeMeulenaere EJ. Critical co-constructed autoethnography. Cultural studies? *Critical Methodologies* 2012;12:146–58.
- 12 Allen-Collinson J. Intention and epochē in tension: autophenomenography, bracketing and a novel approach to researching sporting embodiment. *Qual Res Sport Exerc Health* 2011;3:48–62.
- 13 Ellingson L, Ellis C. Autoethnography as constructionist project. In: Handbook of constructionist research. 445, 2008.
- 14 Reed-Danahay D. Auto/ethnography: rewriting the self and the social. Routledge, 2021.
- 15 Wall S. An Autoethnography on learning about Autoethnography. Int J Qual Methods 2006;5:146–60.
- 16 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.
- 17 Thomas DR. A general inductive approach for qualitative data analysis 2003.
- 18 Sikes P. Ethical considerations in autoethnographic research 2015, 2020. Available: https://www.sheffield.ac.uk/polopoly_fs/1.586562!/ file/SREGP-Autoethnography-2015.pdf [Accessed 11 Dec 2020].
- 19 Le Roux CS. Exploring rigour in autoethnographic research. Int J Soc Res Methodol 2017;20:195–207.
- 20 The MS Blog. It seems that our experiment is going to happen by default, 2020. Available: https://multiple-sclerosis-research.org/2020/ 03/it-seems-that-our-experiment-is-going-to-happen-by-default/ [Accessed 14 Dec 2020].
- 21 Kaye R, Chang CWD, Kazahaya K, *et al.* COVID-19 anosmia reporting tool: initial findings. *Otolaryngol Head Neck Surg* 2020;163:132-134.
- 22 Menni C, Valdes AM, Freidin MB. Real-time tracking of self-reported symptoms to predict potential COVID-19. *Nat Med* 2020:1–4.
- 23 Campbell AM. An increasing risk of family violence during the Covid-19 pandemic: strengthening community collaborations to save lives. In: Forensic science international: reports. 100089, 2020.
- 24 Simpson SH. Creating a data analysis plan: what to consider when choosing statistics for a study. *Can J Hosp Pharm* 2015;68:311.
- 25 Multiple Sclerosis International Federation, 2020. Available: https:// www.msif.org/ [Accessed 14 Dec 2020].
- 26 Baxter SK, Brumfitt SM. Professional differences in interprofessional working. J Interprof Care 2008;22:239–51.
- 27 Firth-Cozens J. Organisational trust: the keystone to patient safety. *Qual Saf Health Care* 2004;13:56–61.
- 28 Jackson D. Collegial trust: crucial to safe and harmonious workplaces. J Clin Nurs 2008;17:1541–2.
- 29 Allport GW. The nature of prejudice: Cambridge. MA: Addison-Wesley, 1954.
- 30 Oandasan IF, Gotlib Conn L, Lingard L, et al. The impact of space and time on interprofessional teamwork in Canadian primary health care settings: implications for health care reform. *Prim Health Care Res Dev* 2009;10:151–62.
- 31 Henderson S, Gilding M. 'I've never clicked this much with anyone in my life': trust and hyperpersonal communication in online friendships. *New Media Soc* 2004;6:487–506.
- 32 Walther JB. Computer-mediated communication: Impersonal, interpersonal, and hyperpersonal interaction. *Communic Res* 1996;23:3–43.
- 33 Geach PT. Intentional identity. J Philos 1967;64:627-32.
- 34 Fudge N, Wolfe CDA, McKevitt C. Assessing the promise of user involvement in health service development: ethnographic study. *BMJ* 2008;336:313–7.
- 35 Reeves B, Read JL. *Total engagement: using games and virtual worlds to change the way people work and Businesses compete.* Harvard Business Press, 2009.