



Title	Discourses of Long Covid
Application	29827-mae17-ss/ar:english
Created	06/04/2021 22:07:58
Updated	12/05/2021 12:36:29
Status	Complete
State	Approved

Applicant Details

Lead Applicant

Evans, Melanie (mae17)

Principal Investigator

Evans, Melanie (mae17)

Co-researcher(s)/co-applicant(s) Names

O'Reilly, Michelle (mjo14)

Krockow, Eva (emk12)

Welham, Alice (akw12)

Russell, Richard (rjr22)

Zhou, Huiyu (hz143)

Status

Staff

Department

English

Email address(es)

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Contact address(es)

English, School of Arts, University of Leicester

Telephone number(s)

01162297568

Does the study require NHS REC approval?

No

Has your project already been approved by an ethics committee in another institution?

No

Is your project funded?

Yes

Is the project funded internally or externally?

internally

Project aims and research questions

The project Discourses of Long Covid investigates the language and communication practices used to discuss the experience of long-lasting covid symptoms; a condition (or set of conditions) now known as Long Covid. The naming of the condition is unusual, in that it was coined by those experiencing the condition and disseminated via social media networks, rather than being identified and reified by healthcare professionals. Our project explores the significance of language in the conceptualisation and understanding of the condition, the potential differences or similarities in language practices between different social groups, and their likely ramifications for communication effectiveness. It aims to produce recommendations for best practice targeted at healthcare professionals, and guidance literature aimed at those experiencing the condition. It will also provide evidence on how new illnesses are articulated using existing vocabularies, and the interplay between professional, institution and social media in shaping and disseminating discourses of health.

The project is therefore oriented around the following research questions:

- 1) What language (vocabulary, grammar) is used to **articulate the experience and condition of Long Covid**?
- 2) What similarities and differences in language use around Long Covid are identifiable across different groups and communities e.g. individuals experiencing the condition, healthcare professionals, online support networks?
- 3) What are the potential implications of these similarities and differences for effective communication and understanding?

In order to get a rounded perspective on language associated with Long Covid, the project will collect data from several sources.

This ethics application relates to the social media dataset to be collected from Twitter, which is the fourth and final dataset in the project. The data collected from Twitter will capture the role of social media language in the identification and description of the condition. Three snapshots of Twitter activity, with the hashtag #longcovid, will be collected using the Twitter API, spanning the 12 months between April 2020 and March 2021.

An application relating to the other datasets in the project, derived from focus groups, is submitted separately.

The datasets will be analysed using qualitative and quantitative methods. The focus groups and social media data will be explored independently, using techniques from discourse analysis, corpus linguistics and NLP, as appropriate. The findings for all datasets will then be compared to identify the points of overlap and distinctiveness.

Proposed methods/protocol

Review of documents (could include primary or secondary sources, but which might have 'human participant' implications)

Who are the 'human participants' in this research?

The human participants are the creators of the tweets containing the hashtag or expression Long Covid. All tweets will stem from public accounts, in which the users of Twitter consent to their tweets being publicly viewable, searchable and recordable on the social media platform.

Will your research involve the use of human tissue?

No

Clearly describe how you intend to identify, approach and recruit participants.

No participants will be initially contacted. The Twitter data will be collected using the Twitter API, using Long Covid as the search criteria. This is in accordance with the Twitter code of practice. We anticipate that, using the Developer API, we will collect no more than 50,000 tweets (100 requests obtaining up to 500 tweets).

The authors of the tweets will be contacted directly via the platform ONLY if the tweets are to be cited directly in any research papers and publications, in order to gain permission for their use. This approach follows recent best practice guidelines produced by the British Association of Applied Linguistics (<https://www.baal.org.uk/wp-content/uploads/2021/03/BAAL-Good-Practice-Guidelines-2021.pdf>). Further information regarding our approach to contacting these individuals and gaining informed consent is provided later in this application.

The number of participants specified below for this project therefore relates to the number of individuals we envisage contacting, as an absolute maximum, with regards to publication consent.

Enter the number of participants

100

Start date

03/05/2021

End date

31/08/2021

In which country will the study take place?

United Kingdom

Where will the study take place?

The dataset will be automatically collected from Twitter archives during the time-frame specified above. The dataset itself will be drawn from three historical timestamps: April 2020, October 2020 and March 2021.

If the study is to be conducted outside the researcher's home country/place of permanent domicile, what steps are being taken to ensure that the necessary research/ethical/other permissions are secured, and that the researcher is aware of and respectful of any political and cultural sensitivities in that place?

N/A

Will the research described in this application require you to travel outside the UK?

No

Does this research entail more than a minimal risk of disturbance to the environment?

No

Are there any legal, cultural, religious or other implications to conducting the study and if so, how will these issues be addressed?

The Twitter code of practice states that tweets should not be anonymised in research publications. However, best practice guidelines for the social sciences (e.g. British Association of Applied Linguistics) advise that anonymisation is important for the privacy and security of participants. **Consequently, where tweets are cited, we will anonymise** these quotations, whilst also seeking consent from the author. The authors will be advised that tweets are searchable using search engines e.g. Google, and so their material could be traced to them, despite the anonymisation.

How will you gain permission to carry out this research (e.g. obtain data, access to sites etc)?

The Twitter data will be collected using the free Developer API. In accordance with protocol, Twitter will be notified prior to the start of data collection. This will include the commitment to updating the dataset to reflect any changed **permissions (e.g. deleted content); the dataset will be checked using the API tool every three months during the** project period, and prior to the submission of any publications reporting results using the dataset.

The Twitter code of practice states that all users agree, at the point of signing up, for their tweets to be used in research. Therefore no consent is required for the general collection and analysis of twitter material relating to Long Covid at the level of individual users. However, out of respect to the authors, **we will seek permission (informed consent) from users for whom we wish to cite their tweets in research papers and publications.**

What is the evidence you will provide to gain the necessary permissions?

PIS, Privacy Notice, and Consent form for authors whose tweets we wish to cite in research papers/publications.

Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group, residents of nursing home)

No

Does the research involve administrative or secure data that requires permission from the appropriate authorities before use?

No

Will all participants be provided with a participant information sheet and an informed consent form?

Yes

Is consent being sought for the data collected to be used for future research projects and/or with a view to archiving data and making it available and re-usable by other researchers?

Yes

How will you ensure ethical procedures if data is being made re-usable? Remember to include appropriate information in the participant information sheet and consent form.

The Twitter dataset is freely available to anyone using the Twitter Developer API. Consequently, it can be kept and reused for research purposes. However, this includes a commitment to updating the dataset to reflect any changed permissions (e.g. deleted content). The dataset will be checked using the API every three months during the project period, and prior to the submission of any publications reporting results using the dataset.

Consent for tweets to be cited in research publications will encompass all future publications, with the condition of anonymity in citation.

Will you be accessing non-anonymised data without consent?

No

Will the study involve participants who are vulnerable? (e.g. people under the age of 18, people who may lack mental capacity or people who are in institutional settings, such as prisons)

Yes

How will consent be secured for these vulnerable participants? What arrangements are in place to protect vulnerable participants' interests?

As per Twitter code of practice, all users of the social media platform consent to the use of their tweets in research. Should we wish to cite tweets in research publications, we will use all publicly-available evidence (e.g. Twitter bios, tweet contents) to approach authors who are non-vulnerable adults. Our consent process will also help to protect any vulnerable individuals who are inadvertently approached.

Does the research activity proposed require a criminal record check?

No

Does the research involve observing participants without their knowledge?

No

How will the confidentiality and privacy of participants be maintained?

As Twitter is a public platform, the details of users (username, tweets) are in the public domain. The majority of the dataset will be analysed quantitatively, with no individualised identifying criteria preserved in published results. As noted above, if a tweet is quoted verbatim for publication, permission will be sought from the author and the tweet anonymised (i.e. username removed).

Will the study involve discussion of sensitive topics (e.g. victimisations, sexual activity, drug use)?

Yes

Give details and describe the approach taken in recognition of this sensitivity.

Although Twitter users grant permission for their content to be used in research, in practice it is likely that many users are unaware of this. To show respect and courtesy towards Twitter users, especially given the potentially personal and sensitive nature of the tweet contents relating to Long Covid, consent will be sought for any material to be quoted directly in publications. That content will also be anonymised in those publications.

Will research involve the use of the internet or other visual/vocal methods where respondents may be identified?

Yes

Give details about particular issues this raises and the decisions taken as a result.

As noted, Twitter is a public platform and all collected data is part of the public domain. All tweets can be searched for in a search engine and traced back to their original source account. It is at the users discretion how much information they provide in their public accounts. However, in recognition that the use of tweets for research may include some sensitive material that was created without careful consideration of its longevity/repurposing in a research project, we will anonymise any cited evidence from the dataset, thus providing as much protection to the author as possible in our research outputs. We will also seek consent for all material we cite from the dataset.

Are there financial inducements (other than reasonable expenses and compensation for time) to be offered to participants?

No

Are you processing personally identifiable data (i.e. anything that would identify an individual such as date of birth, gender, contact information, ethnicity etc)

Yes

Where will the data come from?

Existing data from other institutions outside of UOL

Does the research project involve any of the following potentially high risk data processing activities?

Processing data where an individual has not been made aware of the processing of their data

Are you responsible for determining what happens with the personal data?

Yes

Do you jointly determine what happens with the personal data?

No

Describe the personal data involved in this processing activity?

Email

Other

Please provide details of the other personal data involved in this processing activity

Twitter handles (i.e. username)

Who will the data be shared with outside of the University of Leicester (present a list of types of recipients of personal data)?

-

Will any personal data be processed outside of the EEA? (a list of EEA countries can be found here <https://www.gov.uk/eu-eea>)

No

What organisational safeguards protect the personal data?

Awareness and training

What technical safeguards protect the personal data?

Access control lists (i.e. a list of individuals with elevated permissions to systems)

Network authentication (i.e. access via a user name and password)

How long will raw data be retained for once the project has ended? (and duration of processing)

The Twitter dataset will be retained in its raw form indefinitely for use in subsequent research, with regular checks conducted to update any material with changed user permissions.

Will the processing require the purchase/use of new IT systems?

No

Procedures

Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?

No

Will blood, tissue or any other biological samples be obtained from participants?

No

Is pain or more than mild discomfort likely to result from the study?

No

Could the study induce psychological stress or anxiety or negative consequences?

Yes

Outline the rationale for this and state how you will ensure these outcomes are mitigated

The research will analyse the Twitter dataset quantitatively, drawing on general trends and themes in the material relevant for our research questions but not traceable to individual users of the platform. However, in some cases we may wish to cite specific examples from the dataset in publications of findings, and in doing so re-contextualise the public tweets of individuals in a way they did not envisage when participating on the social media platform.

Accordingly, consent will be sought from those individuals prior to research publication and all tweets cited will be anonymised.

Will the study involve prolonged or repetitive testing?

No

Are there any other ethical issues that you think might be raised in the research?

No

Declaration

I have read the Research Ethics Code of Practice, University of Leicester

Yes

The information in the form is accurate to the best of my knowledge and belief and I take full responsibility for it

Yes

I understand that all conditions apply to any co-applicants and researchers involved in the study, and it is my responsibility to ensure they abide by them.

Yes

I understand that any significant change to the question, design, methodology or conduct over the course of the research should be submitted as amendment to the original application for re-approval. Departmental Ethics Officers can provide guidance on what is a significant change.

Yes

I understand that at the end of my research I am required to complete a Monitoring Form.

Yes

I understand that further approvals for my research may be necessary beyond ethical approval, including for example the need to complete and have approved a risk assessment and to obtain insurance through the University, and there is a mandatory requirement to obtain University Travel Insurance if I'm travelling abroad to undertake approved research. If you are a member of staff and travelling in relation to your research, please go to this link:

><https://www2.le.ac.uk/offices/insurance/documents/travel-single-trip>. If you are a student and travelling in relation to your research, please go to this link:

<https://www2.le.ac.uk/offices/insurance/documents/travel-student>.

Yes

Please complete the checklist below to indicate any supporting documents included with this application:

Participant information sheet(s)

Consent form(s)

Monitoring Form

Project ID

29827

Project Title

Discourses of Long Covid

Start Date

03/05/2021

End Date

31/08/2021

Actual Start Date

00:00:00

Actual End Date

00:00:00

Declared Number of Participants

100

Actual Number of Participants

0

Reason for Study Closure

-

Summary of Unexpected/Unanticipated Events or Significant Protocol Deviations

-

Final Storage Location of Consent Forms and Collected Data

-

Other Comments

-

Notes

Created By:	Elizabeth Hurren (eh140)
Role Type:	Reviewer
Date Added:	12/05/2021 12:35:10
<p>This is a well-thought through study that is exploring long-Covid and in particular the way that people talk about it on Twitter. The research team will be collecting comments and where appropriate contacting the individuals to seek their permission to include qualitative statements and anonymised data in their study. The research team have adopted best ethical practice in doing this as the comments are in the public domain and strictly speaking can be utilised for research purposes but they have taken the view that people should be asked to reuse their comments with a well-designed Privacy Notice, PI and Consent Form. This study is therefore ready to go forward for full ethical approval, subject to the 2nd reviewer's comments, All best wishes Professor Elizabeth Hurren, Committee Chair.</p>	

Created By:	Elizabeth Hurren (eh140)
Role Type:	Reviewer
Date Added:	12/05/2021 12:36:29
<p>This application has been approved from today for research ethics purposes on 12 May 2021 and you may now commence with the research phase. We wish you all the best with such an important study into long-Covid experiences, Best wishes Professor Elizabeth Hurren, CSSAH Committee Chair</p>	

Attachments

Title	Person	Role	Created
LongCovid_PrivacyNotice_TwitterData.docx	Melanie Evans (mae17)	Applicant	29/04/2021 09:48:28
LongCovid_Consent_TwitterData.docx	Melanie Evans (mae17)	Applicant	29/04/2021 09:48:18
LongCovid_PIS_TwitterData.docx	Melanie Evans (mae17)	Applicant	29/04/2021 09:48:06

Application History

Description	Stage	Person	Date
Approved: Application approved by reviewer: Elizabeth Hurren (eh140)	Complete	eh140	12/05/2021 12:36:29
Assigned: Elizabeth Hurren (eh140) has provisionally approved the application.	Review	eh140	12/05/2021 12:35:15
Assigned: Philip Shaw (ps14) has provisionally approved the application.	Review	ps14	12/05/2021 10:17:18
Assigned: The following reviewers have been assigned to your application: Lead Reviewer: Elizabeth Hurren (eh140) Secondary Reviewer: Philip Shaw (ps14)	Review	ep258	07/05/2021 14:48:03
Assigned: Application marked as FastTrack	Admin Review	ep258	07/05/2021 14:47:35
Assigned: The following Committee administrators have been assigned to your application: Rhys Johnstone (raj29) Isobel Woodliffe (ijw3) Steph Collins (sc484) Ellen Puurman (ep258) Louise Taylor (lm40)	Admin Review	mae17	07/05/2021 14:05:46
Approved: Co-Applicant: Alice Welham (akw12) approved the application. All co-applicants have now approved the application.	Co-Applicant Approval	akw12	07/05/2021 12:59:08
Assigned: Co-applicant: Michelle O'Reilly (mjo14) approved the application. The application can not yet progress as at least one of the co-applicants has not yet made a decision.	Co-Applicant Approval	mjo14	29/04/2021 23:09:11
Assigned: Co-applicant: Richard Russell (rjr22) approved the application. The application can not yet progress as at least one of the co-applicants has not yet made a decision.	Co-Applicant Approval	rjr22	29/04/2021 11:48:02
Assigned: Co-applicant: Huiyu Zhou (hz143) approved the application. The application can not yet progress as at least one of the co-applicants has not yet made a decision.	Co-Applicant Approval	hz143	29/04/2021 09:56:34
Assigned: Co-applicant: Eva Krockow (emk12) approved the application. The application can not yet progress as at least one of the co-applicants has not yet made a decision.	Co-Applicant Approval	emk12	29/04/2021 09:50:03
Assigned: The following co-applicant(s) have been assigned to your application: Michelle O'Reilly (mjo14) Eva Krockow (emk12) Alice Welham (akw12) Richard Russell (rjr22) Huiyu Zhou (hz143)	Co-Applicant Approval	mae17	29/04/2021 09:48:43
Created: Draft application created by Melanie Evans (mae17)	Draft	mae17	06/04/2021 22:07:58