



PARTICIPANT INVITATION SHEET
UCL research Ethics Committee Approval ID Number 24531/001

How do parents of children with a long term health condition or disability experience online peer support?

UCL Division of Psychology and Language Sciences

Researchers: Christine David (Christine.david.18@ucl.ac.uk), Dr Sophie Bennett (Sophie.Bennett.10@ucl.ac.uk) Dr Marc Tibber (M.tibber@ucl.ac.uk)

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?

I am Christine David, a postgraduate student in the Department of Psychology at the University College London and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the purpose of the research?

I am conducting research about how parents or carers of children with a long term health condition or disability experience online peer support/forums. I am particularly interested in understanding the range of experiences parents may have had including both negative and positive, helpful and unhelpful experiences. The aim of the research will be to use this information to inform improvements in online peer support and how and when it is offered to parents of children with a long term health condition or disability.

Why have I been chosen?

I am hoping to recruit 12-15 parents or carers of children with long-term conditions or disabilities. I am looking to involve parents who are 18 years of age or over, and are sufficiently fluent in English to be able to talk about their experience of online peer support for up to an hour in an online recorded interview over MS Teams. Participation in the study is entirely voluntary and you can withdraw at any time without providing a reason for doing so or any negative consequences.

What will happen if I take part?

Participants willing to take part in the study will be invited to contact the researcher by email and thereafter you will be asked to provide some basic information about yourself, as listed in the "Privacy Notice" section below. You do not have to provide all the demographics if you do not wish to.

You will then be invited to meet the researcher for a one-to-one interview to be held online video platform (MS Teams) at a time which can be mutually agreed upon between you and the researcher. This interview will be recorded for the purpose of transcribing the interview into writing. In order to take part you will need to consent to being recorded as this will be fundamental to the research process. This transcription process will be completed by the research team with the assistance of approved and secure transcription software (Microsoft Word), and personal identifiable information shared in the interview will be pseudo-anonymised so that you cannot be identified from the information in the transcripts. At the end of the interview you will be asked if you wish to check the transcription once it is completed, that is, to read through what has been transcribed to check it matches with your experience of the interview. This is not obligatory and you do not have to do so if you do not wish to.

Do I have to take part?

It is up to you to decide whether or not to take part. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. You are free to withdraw from the research study at any time without explanation, disadvantage or consequence.

You may also request to withdraw your data, provided this request is made within 2 weeks of when you have completed the interview.

Are there any disadvantages or risks to taking part?

The interviews will involve questions about your experiences of online peer support, this might involve talking about experiences you have had that were distressing or had a negative impact on you and there is a risk that talking about these experiences could result in some distress as a result.

If you experience any distress from taking part in the study, you are free to stop at any point without providing a reason for doing so. The interviewer has extensive experience and training in supporting those in distress and can provide support during the interview if required. In addition, support organisations will be provided in the debrief form at the end of the interview. These organisations are also provided at the end of this participant information sheet. You may wish to save these now in the event that you withdraw from the survey before the end. Additionally, all members of the research team are qualified Clinical Psychologists and Clinical Psychologists in training.

If you have any concerns or complaints during the study, you can contact my supervisors Dr Sophie Bennett on sophie.bennett.10@ucl.ac.uk, or Dr Marc Tibber on m.tibber@ucl.ac.uk. Should you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk

What are the possible benefits of taking part?

We hope that your data will provide valuable information into improving experiences of parents of children with chronic illness and disabilities who access online peer support.

All participants that sign up to the study will be given the option of a £12 Amazon voucher or a £12 donation to a registered charity.

Will my taking part in the project be kept confidential?

As the interviews will be held online over MS Teams you will be able to access the interview from a smart phone, laptop, desktop or tablet. This means confidentiality of this interview will be a shared responsibility between participant and researcher; you will therefore be responsible for ensuring you are able to access the interview from a confidential space. Should unforeseen circumstances occur where the participant or interviewer's privacy is compromised, the interview will be paused or terminated as appropriate.

All the information that we collect during the course of the research will be kept strictly confidential. Your email address will only be used to contact you to ask for the information described above, arrange interview and if you wish to, to arrange for review of your transcribed interview. Your email address and unique ID will be stored on a password-protected file on a secure UCL database. All other data you provide will be kept on a separate password-protected file, only linked to your unique ID code, meaning this data will be pseudonymised. The data will be analysed at group level; therefore your individual responses will not be identifiable. The data file containing your email address and unique ID will be deleted when it is no longer required or by 2028, whichever is sooner. Only the research team will have access to any identifiable data including the recording of the interview. Once analysed, data will be used for the write-up of the research and disseminated as appropriate. You will not be identified in any ensuing reports or publications. Pseudo-anonymised data will be stored indefinitely on a secure UCL database and may be used for future research, it will not be identifiable to you in any way.

What will happen to the results of the research?

The findings will be disseminated as appropriate to a range of audiences (e.g. academics, clinicians, the public), through journal articles, presentations, talks and other relevant articles, as appropriate. You will not be identified in any ensuing reports or publications. If you consent, the researcher can share the final report once it has been finalised.

Privacy notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: <http://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies>

The categories of personal data used will be as follows:

Email Address

The number of children you have, their age, and your child(ren)'s condition or disability

Your age

Your ethnicity

The lawful basis that will be used to process your personal data are; 'Public task' for personal data, and 'research purposes for special category data

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudo anonymise the personal data you provide will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed or if you would like to contact us about your rights please contact UCL in the first instance at data-protection@ucl.ac.uk.

Who is organising and funding the research?

UCL

Who can I contact if I have questions about the study?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: Christine.david.18@ucl.ac.uk (Christine David)

You can also contact my supervisors:

Dr Sophie Bennett (sophie.bennett.10@ucl.ac.uk)

Dr Marc Tibber (m.tibber@ucl.ac.uk)

If you or your child feel you are in crisis, please call 999 or attend your local A&E
If you live in England, you can call a local NHS urgent mental health helpline for support during a mental health crisis. Anyone can call these helplines, at any time The NHS website has more information on urgent mental health helplines, including how to find your local helpline:
<http://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

Otherwise, other forms of support include:

- You can find your local NHS Psychological Therapy Service (IAPT) here: <https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/>
- The Samaritans: 116 123. A free 24/7 helpline for anybody experiencing distress.
- If you're experiencing a mental health problem or supporting someone else, you can call SANEline on 07984967708, leave a message, and a volunteer will call you back, You can also email: support@sane.org.uk
- You can call Campaign Against Living Miserably (CALM) on 0800 58 58 58 (5pm–midnight every day) if you are struggling and need to talk. Or if you prefer not to speak on the phone, you could try the CALM webchat service.
- If you're under 35 and struggling with suicidal feelings or concerned about a young person who might be struggling, you can call Papyrus HOPELINEUK on 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or text 07786 209 697.
- If you identify as gay, lesbian, bisexual or transgender, you can call Switchboard on 0300 330 0630 (10am–10pm every day), email chris@switchboard.lgbt or use their webchat service. Phone operators all identify as LGBT+
- Your General Practitioner (GP) can signpost you to additional services if you experience emotional distress.

Thank you for taking the time to read this information sheet and for considering taking part in this research study. If you decide to take part, please save this information sheet for your records.