



University of Brighton

SC.DTP South Coast
Doctoral Training
Partnership



Economic
and Social
Research Council

PARTICIPANT INFORMATION SHEET

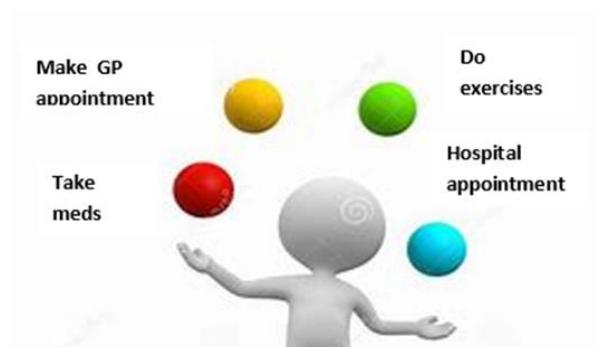
Please let me know if you would prefer this sheet as an audio recording



Title of study: Living well with multiple LTCs? Young people's care experiences

1. Invitation

I would like to invite you to take part in a study to explore how young people's experiences of health and social care services and their relationships with others support them to make the changes to live well. Before you decide whether to take part it is important for you to understand what I am trying to do and what it will involve. Please take time to read the following information carefully. Do talk to family and friends and do ask any questions you may have about any part of the study.



2. Why am I doing this research?

Very little is known about the experiences of young people living with multiple long-term conditions (LTCs) as they navigate many adult care services. How I have chosen to collect information and the questions I will ask, have been selected so that the findings can inform the future planning and delivery of health and social care services for young people living with multiple long-term conditions.

A long-term condition is a health condition that cannot be cured but the symptoms are managed with medication and other treatments.

3. Why have you been asked?

You have been invited as you meet my research requirements. You are aged between 18-24 years. You are living with two or more long-term conditions and you may have a moderate frailty score. Importantly, you will have experiences of being diagnosed and supported to manage living with your health conditions.

4. Do you have to take part?

No. It is entirely up to you whether you take part. You will be asked to agree to take part and for interviews to be digitally audio recorded. You are free to stop taking part at any time during the research without giving a reason and your information (data) can be withdrawn up to the point that I start to analyse it. I will remind you of this at the time of the interview. Your care or treatment will not be affected if you do not want to take part or stop taking part in the study.

5. What will happen to you if you decide to take part?

This study involves being interviewed by me - a post graduate researcher. I will have two interviews with you over the phone. It is important that you have a private space to take the calls so you can talk freely. If you don't, let me know and I'll organise a private space for you either on the university campus or in the community and pay back your travel costs.



The first interview will last about 15 – 30 minutes and will involve me asking you about your key life and health experiences. After the interview, I will plot this information as a life grid diagram which will help our discussion at the second interview.

The second interview which will take place a week later will last about 30 – 45 minutes. I will start by sharing with you (sent to you by email at this point in the interview) the life grid diagram and we can check it for accuracy. The interview will involve me asking some questions about your experiences and what they meant to you. There are no right or wrong answers.

I will write up the interviews and you can check them for accuracy. With your permission, some anonymised quotes may be used in publications I write. These quotes will not refer to you by name at any point. Before the first interview you will be asked some personal questions such as your age and where you live and to give verbal consent. I will ask you for your permission again before the second interview.

Once you let me know you would like to take part, I will contact you to arrange the interviews at times that are convenient to you.

6. What are the benefits of taking part?



Your responses will be used to influence the design and delivery of health and social care services for younger people living with multiple long-term conditions. However, I cannot guarantee that services will be improved as a result of your participation and/or the findings from the study. I will offer you a £20 “thank you” Amazon e voucher for your time in taking part in this study.

7. Points to think about

There are no foreseeable risks to taking part in this study. However, if the interview raises issues for you that cause you to become upset, I will talk with you to agree what to do. We could skip parts of the interview or stop it. If you want, I will contact someone to support you. I will also provide you with a list of services that could help and support you.

8. What if something goes wrong?

If you do not feel happy with the interviews you can stop at any time without giving a reason. If you have any complaint or concern about any part of the study, you can contact my lead supervisor or the Head of the School of Applied Social Sciences.

Supervisor: Professor Nigel Sherriff, Email: N.S.Sherriff@brighton.ac.uk or phone: 01273 644539

Supervisor: Professor Jorg Huber, Email: J.Huber@brighton.ac.uk or phone: 01273 644078

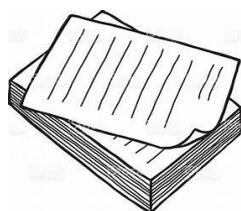
9. Will anyone else know I'm doing this?

The research team which includes me, and my three supervisors will know that you are taking part. Any information you provide will be kept confidential. The only exception to this is if something you say means that criminal acts have been or will take place, or you, a child or vulnerable adult has been, or is at significant risk of harm. In these cases, I have a responsibility to report these to my supervisors and the relevant authorities. However, I will privately tell you first if I feel this may be necessary.

Recordings of interviews will not be marked with your name but will have a unique code. Your personal details will be stored separately from the data and any potential identifying details will be removed when your interview records are written up and stored on computer.

All data information will be stored securely using locked filing cabinets and password and network protected computers. Personal data is securely destroyed at the end of your involvement in the project whilst the research data is stored securely for 10 years.

10. What will happen to the results?



The findings will be reported in my doctoral thesis. I will also aim to present the results at conferences and publish in academic journals. I would like to hear your ideas for presenting and publishing the findings.

Reports may include direct quotes from interviews. However, any names or other identifying information will be removed. A summary of the results can be sent to you if you wish to see them. You will not be personally identified in any reports or publications of the research.

11. Who has checked this research?

The University of Brighton's External REC Review Panel and the Cambridge South Research Ethics Committee have approved this study.

12. Who has funded this study?

This study is funded for three years by the Economic and Social Research Council which is managed by the South Coast Doctoral Training Partnership (SCDTP) (grant reference number ES/P000673/1).

13. Contact for further information

If you would like further information about this study, please contact:



- Name: Tracy Whittle
- Role: PhD Researcher (University of Brighton)
- Email: T.Whittle2@brighton.ac.uk
- Phone/text: 07533 867972

Thank you for taking the time to read this. If you would like to take part, I look forward to hearing from you.

