

Living with a Controversial Disorder: a qualitative exploration of experiences in individuals who have a formal diagnosis of Dissociative Identity Disorder

You are being asked to take part in a research project. Before you decide whether you wish to take part, it is important that you understand why the project is being done and what it would involve for you. Please take time to read the following information carefully and decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

This study is interested in individual experiences of navigating the health system and encountering different professionals with different views and the importance of obtaining a formal diagnosis. Mental health professionals have a range of views about all diagnoses but there is probably more diversity of views about Dissociative Identity Disorder (DID) than about most diagnoses.

Why have I been invited?

We are inviting individuals to participate that have had a formal assessment of DID by a multidisciplinary team of mental health professionals at the Clinic for Dissociative Studies or Pottergate Centre in the last two years and who are over 18 years old.

Do I have to take part?

You do not have to take part. Taking part in the study is entirely voluntary and you will be asked to complete a consent form if you choose to participate. If you agree to take part and later change your mind, you are free to withdraw from the study at any time. Your data will no longer be used in the study and withdrawal from the study will **not** affect your healthcare. Participation in the study will not affect decisions made regarding your current or future healthcare.

What will I have to do if I take part?

After you have consented I will agree a convenient time to meet with you at the Clinic for Dissociative Studies in London. Your travel expenses to attend the interview will be reimbursed so please make sure you get a receipt for any public transport fares and bring them to the interview with you. The meeting will last between one to two hours. I will ask you some questions about your experiences of mental health services, professionals and what it means to you to have a formal diagnosis of DID.

What are the possible disadvantages and risks of taking part?

It is possible that you could find talking about this topic upsetting, particularly if you have had upsetting experiences of healthcare. If this happens, I will stop the interview and you will be offered appropriate emotional support. If concerns arise about risks to your well-being, experienced clinicians will be available to offer you some emotional support in order for you to be able to return home safely. This would be a 'one-off' meeting and would not entitle you to ongoing care from the clinic if you are not already in receipt of a service from the clinic.

What are the possible benefits of taking part?

Although this study will **not** help individual participants get help, the findings may inform future service provision by helping to understand the meaning and importance of formal diagnoses to individuals in instances where professionals disagree about the existence of a condition.

What if there is a problem?

If you have a concern about any aspect of this study, you should discuss this with me and I will do my best to answer your questions [see contact details below].

Alternatively, you may contact my supervisor, Dr Susan McPherson (smcpher@essex.ac.uk), at the same address as myself if you wish to ask any questions about me or the research.

If you wish to discuss a concern with someone outside of the research team, you may contact Sarah Manning-Press via email (sarahm@essex.ac.uk) or at the following address:

Research Governance and Planning Manager
Research & Enterprise Office
University of Essex
Wivenhoe Park
Colchester
CO4 3SQ

Will my taking part in this study be kept confidential?

Your contact details and responses to the interview questions will be dealt with in confidence. The interviews will be recorded on a digital recorder which will then be uploaded via a password-protected computer into a password protected file on the secure drive at the University of Essex and the digital recording will be deleted from the recording device. Your contact details will be kept in a research file at the University of Essex, which is only accessed by myself and my supervisor. Your file will be kept in a locked cabinet on secure premises in accordance with the Data Protection Act. All data will be kept for up to 12 months after completion of the thesis relating to this research after which it will be destroyed securely.

Confidentiality will only be breached if you disclose that either yourself or another individual (including children) is at risk of harm. Risk of harm could include injury, death, disclosure of abuse etc. In this instance, the Clinic director will be notified who will follow the Clinic's safeguarding procedures and notify the relevant authorities.

Who has reviewed the study?

The study has been approved by the National Research Ethics Service Hertfordshire Research Ethics Committee to ensure that the study meets ethical standards.

What will happen to the results of the study?

The research will also be written up for submission as a thesis by the researcher to the University of Essex as part of the Doctoral degree in Clinical Psychology. Results may be summarised for publication and conferences to inform clinicians and others interested in this area. Such summaries would be fully anonymised, i.e. written so

no-one would know if you took part and any quotes from the interviews would be chosen very carefully not to identify you or any other participant.

Feedback of the findings of the study will be made available to you and other participants should you wish to receive them. In all these reports your name or any other personally identifiable details will not be mentioned.

Further information and contact details

If you wish to get more information about the study at any point please contact me:

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Trainee Clinical Psychologist
C/o Claire Wicks (course administrator, dept of Clinical Psychology)
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Thank you for your time!