

Frequently Asked Questions

The lived experience of ‘Diabulimia:’ Individuals with Type 1 diabetes using insulin for weight control

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Supervisor: Dr Joel Vos

Thank you for expressing your interest in my research. Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Thank you.

What is the purpose of research?

The research aims to explore what it like for individuals with type 1 diabetes to omit and/or restrict their insulin for weight control. Research has established that eating disorders are more prevalent in individuals with type 1 diabetes, yet the omission or use of insulin for weight control is much less understood and researched. This practice can sometimes be known as diabulimia. By understanding this experience further, I hope that the findings of my research will help inform treatment pathways, diagnostic decisions, professional training and clinical practice for those working with your demographic. Furthermore, I would like my research to act as a platform where the unique issues faced by your demographic are validated and heard, not just by healthcare professionals but also by members of the public who may not know of your difficulties. In this way, my research stands to raise understanding and awareness.

Who can participate?

Take a look at the table below to see if you are able to participate:

You can participate if you....	Unfortunately, you are not able to participate if.....
Are over 18	You do not have a historic/current relationship with support services
Live in the UK	You are not able to independently manage your own insulin
Are fluent in English	You currently live in, or within the past 12 months have been in inpatient/residential treatment settings
Have a diagnosis of type 1 diabetes	
Have experience of omitting and/or restricting insulin for weight control	
Feel well established and stable in your insulin management for at least 6 months	
Have had previous or ongoing contact with a service that offers emotional and psychological support	

Do I have to take part?

No! Even if you meet the criteria in the table, it is up to you to decide whether to take part.

What is involved in taking part?

If you choose to participate, I will ask you to take part in the following parts of the research:

- A brief introductory telephone call. This gives us the opportunity to review the research process together and where I can answer any initial questions you may have. It also allows us to discuss the practicalities of your participation and arranging a meeting
- Review and sign a consent form
- Complete a short demographic questionnaire
- Meet me for an interview which will last approximately one hour and will be audio recorded. You can pause and/or terminate the interview at any stage. You can also skip questions you do not wish to answer.
- After the interview, we will have a short 'debrief' which gives you the opportunity to share your interview experience and ask any questions you may have. At this point, I will also provide details of support services that you can contact should you wish.
- After your interview, I may ask you to review the findings of my research once I have analysed the transcripts. If this is the case, we will meet again for approximately one hour and go through the data together.

What if I change my mind and want to leave the study?

Prior to or during the interview you can withdraw from the study at any point without giving a reason. After the interview, you will have 6 months from the date of our interview to withdraw from the research, or until I have included your data into the analysis section of my research depending on which event occurs first. If your data has already been included in the analysis it cannot be extracted from the research.

Will participation in the study be confidential?

Your anonymity in the research is guaranteed. Your name and contact details will be stored separately from research data. This research will comply with the legal requirements related to the storage and use of personal data as outlined in the Data Protection Act (1998), GDPR and other similar acts. All data will be stored in locked cabinets and/or password protected files.

All identifying information such as names, places, addresses and other individuals referred to in your interview will be altered as a means of securing your anonymity. During our meeting we will discuss the use of pseudonym's together. Please be aware that extracts from the interview may be included in the dissertation to help explain and contextualise findings. Furthermore, the research findings may be published and presented at conferences. A copy of the final dissertation will also be available for the public to read.

Although your confidentiality is critical there are circumstances where your confidentiality would be waived, for example if you disclose intent others, or if I feel you are at imminent risk and no longer safe. In such circumstances, I would share my concerns with you, and we would reach out to your emergency contact/GP. The consent form will ask you to provide details for an emergency contact and/or your GP.

What are the possible risks of taking part in the study?

It is not expected that the interview will cause distress, however you may find it difficult to reflect on your experience and notice that certain emotions are evoked. Please remember that you can skip questions and stop the interview at any time if you find it is more difficult than you anticipated. If you do experience any surprising or strong reactions, we will discuss options for you to explore these responses further. Our meeting is not a therapy session; however, I do have a list of organisations who can offer further support. We will revisit this point in our initial telephone conversation and after our interview during a debriefing.

What are the benefits of taking part in the study?

In taking part you are helping to give voice and raise awareness to a complex difficulty that has remained misunderstood and under-researched for some time. You may find the interview a positive experience as it allows you a space to share your story without judgement or expectation. Research has suggested that the process of saying something out loud in a welcoming space can have beneficial effects on our mood and way we make sense of an event.

Who has reviewed the study?

This research is being undertaken as part of my Doctorate in Counselling Psychology and Psychotherapy at the Metanoia Institute. The Metanoia Research Ethics Committee has reviewed and approved the research.

What if have more questions?

Please contact either the researcher or supervisor on the details below, we are happy to answer any questions you have.

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