

Privacy Notice for project: “Exploring the experience of habits in co-occurring autism and eating disorders utilising social media content”

This information sheet explains how personal data will be used by project “Exploring the experience of habits in co-occurring autism and eating disorders utilising social media content” at the University of York.

For this project, the University of York is the [Data Controller](#). We are registered with the Information Commissioner’s Office. [Our registration number](#) is Z4855807.

What is the aim of this project?

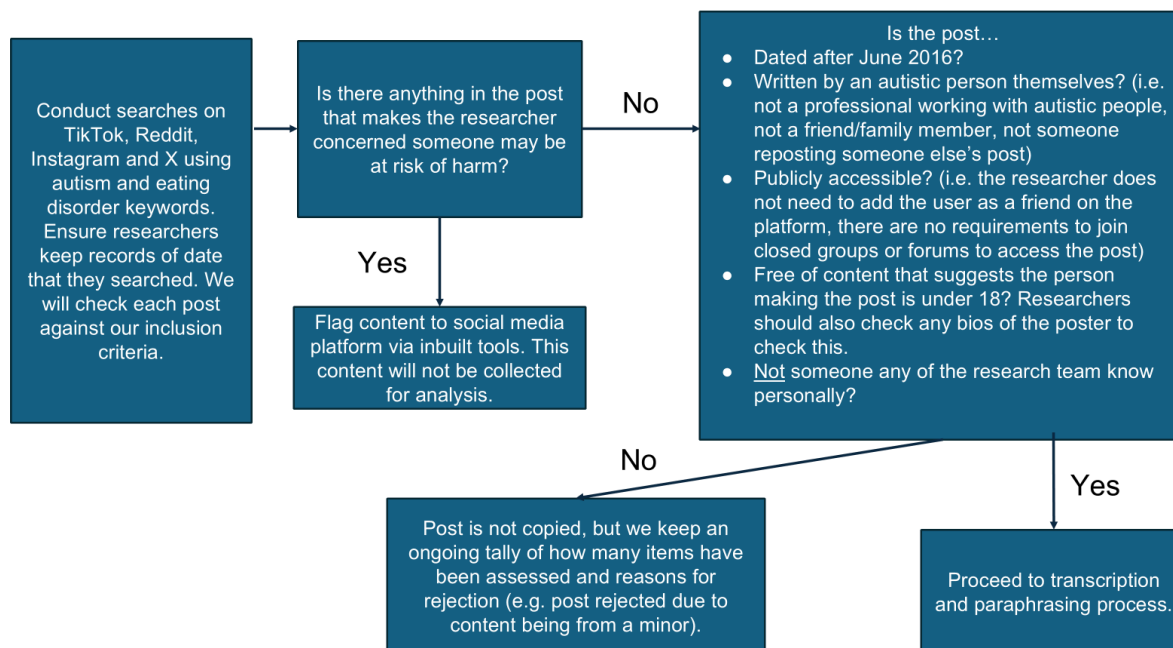
Dr Hannah Hobson, Dr Alex Pike, Lisa Woodley and Arianna Coraggio (at the University of York) are conducting a project into the experiences of autistic people with eating disorders. Arianna Coraggio will be running the searches and collating the data, with support from a British Association of Psychopharmacology summer internship. This project will form part of Lisa Woodley’s PhD: Lisa is planning to conduct a series of interviews with autistic people who also have anorexia about their experiences. However, the responses that people give in interviews are naturally shaped by the questions the researcher asks. Therefore, we also want to explore what autistic people have spontaneously said about eating disorders, especially habits and routines, on social media. This will help us notice specific patterns or sets of experiences that autistic people themselves have written about, without any researcher influence, which we can combine with responses in our interview project.

We hope that the findings from this project will help improve our understanding autistic people’s experiences with eating disorders, and the role that routines and habits play in both the recognition of eating disorders and their treatment for autistic people. We do not plan to develop any commercial products/make money from this project. It is conducted to understand the experiences of autistic people, and is for scientific research, not for profit.

What information do we have and where do we get data from?

We will search Instagram, Reddit, TikTok and X for a total of 200 posts that are made by autistic people, on the topic of eating disorders (which we will find by using keywords such as autism and anorexia, etc). Only posts that are able to be publicly accessed will be included. Researchers will not add individuals as friends, or join groups, in order to gain access to private accounts. If the information in the posts, or a person’s profile, suggests that they are under the age of 18 years, we will not include their posts. We will not collect any other details about posters (e.g. gender, ethnicity), but will note the year the post was made and what platform it was posted on. If anyone in the research team knows the poster personally, the post will not be used. We will only be including content where the poster is autistic (not content from friends/family/professionals who work with autistic people). We will not initiate any direct contact with the original posters of the social media posts.

How we find and decide what posts to include:



What is our legal basis for processing this data?

Privacy law (the UK General Data Protection Regulation (GDPR) and Data Protection Act 2018) requires us to have a legal reason to process your personal data. Our reason is we need it to perform a public task¹.

This is because the University has a [public function](#), which includes carrying out research projects². We need to use personal data in order to carry out this research project.

Information about your health, ethnicity, sexual identity and other sensitive information is called [“special category” data](#). We have to have an additional legal reason to use this data, because it is sensitive. Our reason is that it is needed for research purposes³. All research projects at the University follow our [research ethics policies](#).

How do we use the data and what happens to it?

Posts that meet our criteria will be converted into text (rather than images or videos), so that we can examine them for recurring themes, ideas or experiences. Any identifying content will be removed. For example, “While at York Hospital, the food was just not for me. My friend Hannah always brought me snacks she knew I could eat...” would become “While at CITY Hospital, the food was just not for me. My friend FRIEND always brought me snacks she knew I could eat...” . Light paraphrasing will also be employed to help prevent “backwards searching” (where people

¹This refers to [UK GDPR Article 6 \(1\) \(e\)](#): processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

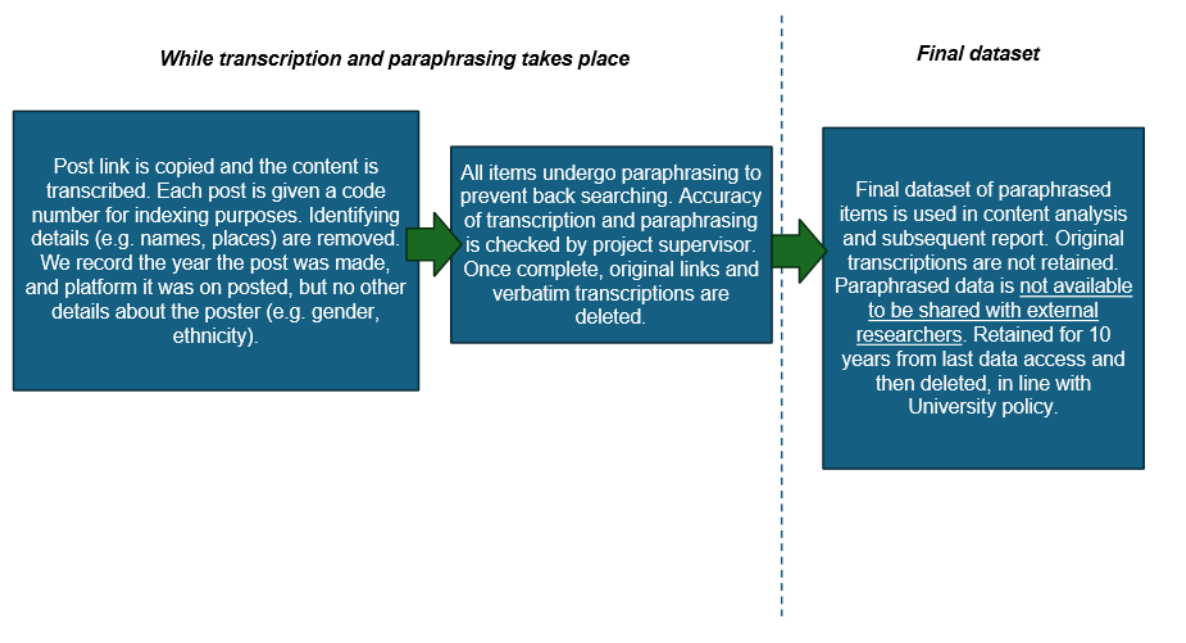
² [Our charter and statutes](#) states: 4.f. To provide instruction in such branches of learning as the University may think fit and to make provision for research and for the advancement and dissemination of knowledge in such manner as the University may determine.

³This refers to [UK GDPR Article 9 \(2\) \(j\)](#): processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

would be able to find the original posts by searching them). The previous example might become: “The food just wasn’t for me when I stayed in CITY hospital. My friend always brought me things to eat she knew I could have...” . The meaning of the posts will not be changed.

We will conduct a “content analysis” on the transcribed and paraphrased posts. This means we will look for themes, experiences or categories that come up again and again.

What happens to posts included in our analysis:



Who do we share your data with?

We will not be sharing data outside the research team (listed above).

The posts will be stored in a password protected file, accessible only to the research team. We will not include any direct quotes of original posts in any reports (as these could be searched and found). Therefore, it should not be possible for any specific social media content to be identified in our final reports.

While we think the paraphrasing process should prevent possible backwards searching, we will not share the dataset with other researchers. We will share the codebook that is developed from content analyses, but from this codebook it will be impossible for others to find the original posts. For the example mentioned above, the codebook might include things like “Food during treatment was not liked/not suitable”, or “Friends/family supplied alternative foods”.

We use computer software or systems to hold and manage data. Other companies only provide the software, system or storage. They are not allowed to use your data for their own reasons.

How do we keep your data secure?

The University maintains a high standard of information security. Access to information and systems for all users are restricted on a need-to-know basis, and security arrangements are reviewed to ensure their continued suitability. For further information see, [our IT security webpages](#).

How do we transfer your data safely internationally?

No data from this project will be transferred internationally, though for any transfers of data outside the UK, the University will always comply with UK GDPR obligations and use necessary safeguards to protect your data.

How long will we keep your data?

The handles and links to the original posts will only be kept temporarily, while we transcribe and paraphrase them. After one of the project supervisors (Hannah Hobson or Alex Pike) has checked the accuracy of the transcriptions and paraphrasing, the original links, posts, and original written transcriptions will be deleted, and we will only keep the 'lightly paraphrased' posts.

We will keep the paraphrased, transcribed data for 10 years from the last time someone asks to access it (this is in line with the University's Research Data Management policy).

What rights do you have in relation to your data?

Under the UK GDPR, you have a right of access to your data, a right to rectification, erasure (in certain circumstances), restriction of processing, objection or portability (in certain circumstances). You also have a right to withdraw consent, and rights relating to automated decision making. For more information see [Individuals' Rights](#). Please note that after posts have been transcribed and paraphrased the original links to posts will be deleted (approximately August 2026). After this point, the dataset will be considered anonymous and it will not be possible to identify whether your posts were included, and so deletion will not be possible.

Questions or concerns

If you have any questions or concerns about how your data is being processed, please contact Dr Hannah Hobson (hannah.hobson@york.ac.uk) or Dr Alex Pike (alex.pike@york.ac.uk) .

You can also contact the University's Information Governance Team at dataprotection@york.ac.uk

If you wish to make a data protection complaint, please contact the University's Data Protection Officer at dataprotection@york.ac.uk.

If you are unhappy with the way in which the University has handled your personal data, you also have a right to [complain to the Information Commissioner's Office \(ICO\)](#).

Changes to our privacy notice

This Privacy Notice is kept under regular review. It was last reviewed and updated on 11th June 2026.