

APPLICATION FOR ETHICAL APPROVAL

RESEARCH STUDENTS

This form is to be completed by the student within **SIX** months for full-time students and **TWELVE** months for part time students, after the commencement of the research degree or following progression to Part Two of your course.

Once complete, submit this form via the **MyTSD Doctoral College Portal** at (<https://mytsd.uwtsd.ac.uk>).

This document is also available in Welsh.

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk, with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

In order for research to result in benefit and minimise risk of harm, it must be conducted ethically. A researcher may not be covered by the University's insurance if ethical approval has not been obtained prior to commencement.

The University follows the OECD Frascati manual definition of **research activity**: "creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man, culture and society, and the use of this stock of knowledge to devise new applications". As such this covers activities undertaken by members of staff, postgraduate research students, and both taught postgraduate and undergraduate students working on dissertations/projects.

The individual undertaking the research activity is known as the "principal researcher".

Ethical approval is not required for routine audits, performance reviews, quality assurance studies, testing within normal educational requirements, and literary or artistic criticism.

Please read the notes for guidance before completing ALL sections of the form.

This form must be completed and approved prior to undertaking any research activity. Please see Checklist for details of process for different categories of application.

SECTION A: About You (Principal Researcher)

1	Full Name:	Carly Evans			
2	Tick all boxes that apply:	Member of staff:	☐	Honorary research fellow:	☐
	Undergraduate Student	☐	Taught Postgraduate Student	☒	Postgraduate Research Student
3	Institute/Academic Discipline/Centre:	Education and Humanities/Centre for Psychology and Counselling			
4	Campus:	SA1 Campus			
5	E-mail address:	1301958@student.uwtsd.ac.uk			
6	Contact Telephone Number:	07669278374			

For students:		
7	Student Number:	1301958
8	Programme of Study:	MA Psychotherapeutic Practice
9	Director of Studies/Supervisor:	Dr Ceri Phelps

SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)	YES	☒	NO	☐
					Date
2	If Yes, please indicate source of approval (and date where known): Approval in principle must be obtained from the relevant source prior to seeking ethical approval	Research Degrees Committee	☐		
Institute Research Committee		☐			
Other (write in) Academic Supervisor		☒	Dr Ceri Phelps – 01-09-2025		

SECTION C: Internal and External Ethical Guidance Materials

Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, location-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines. You may add rows to this table if needed.	
1	UWTSD Research Ethics & Integrity Code of Practice ☒
2	UWTSD Research Data Management Policy ☒
3	The BACP Ethical Framework for Counselling Professions (2018) ☒

SECTION D: External Collaborative Research Activity N/A

If there are external collaborators then you should gain consent from the contact persons to share their personal data with the university. If there are no external collaborators then leave this section blank and continue to section E.

1	Institution	
2	Contact person name	
3	Contact person e-mail address	
4	Is your research externally funded?	YES ☐ NO ☒
5	Are you in receipt of a KESS scholarship?	YES ☐ NO ☒
6	Are you specifically employed to undertake this research in either a	Voluntary YES ☐ NO ☒
7	paid or voluntary capacity?	Employed YES ☐ NO ☒
8	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)?	If YES then the permission question below does not need to be answered. YES ☐ NO ☒

9	Has permission to undertake the research has been provided by the partner organisation?	(If YES attach copy) If NO the application cannot continue	YES	☐	NO	☐
---	---	---	-----	--------------------------	----	--------------------------

Where research activity is carried out in collaboration with an external organisation N/A

10	Does this organisation have its own ethics approval system?	YES	☐	NO	☐
	If Yes, please attach a copy of any final approval (or interim approval) from the organisation (this may be a copy of an email if appropriate).				

SECTION E: Details of Research Activity

1	Indicative title:	Genetically informed, Psychologically Ignored? An interpretative phenomenological analysis of the lived experience of life after genetic testing for Huntington's Disease			
2	Proposed start date:	01-11-2025	Proposed end date:	01-07-2026	
	Introduction to the Research (maximum 300 words per section) Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the points below: <i>Purpose of Research Activity</i> <i>Proposed Research Question</i> <i>Aims of Research Activity</i> <i>Objectives of Research Activity</i> Demonstrate, briefly, how <u>Existing Research</u> has informed the proposed activity and explain <i>What the research activity will add to the body of knowledge</i> <i>How it addresses an area of importance.</i>				
3	Purpose of Research Activity The purpose of this Dissertation study for the MA Psychotherapeutic Practice programme is to explore the experience and unmet therapeutic needs of individuals who have undergone genetic testing for Huntington's Disease. Huntington's Disease (HD) is a rare incurable neurodegenerative genetic disorder that causes the gradual breakdown of nerve cells within the brain. Consequently, it leads to significant functional decline where there are changes to one's mind, memory, and movements (Paulson, 2011). Given the genetic complexion of HD, symptoms arise within a family. It is inherited in an autosomal dominant pattern which means each biological child is at 50% risk of inheriting the disease (Rivera-Navarro et al., 2015). Being at risk for HD is said to have profound psychological effects on an individual. As such, some individuals who are aged 18 and above can take a predictive genetic test to determine if they have inherited the incurable disease (Cooper et al., 2024). Being impacted by HD is a daunting experience for everyone, and whilst individuals undergoing				

	genetic testing for HD are supported by genetic counselling prior to and during the genetic testing process, the pathways and experience of psychological support after testing is less clear. This study will explore the lived experience of undergoing genetic testing and the need for follow-up psychological support in a small number of individuals who are actively involved with the Huntington's Disease Association and are familiar and comfortable with sharing their HD stories.
4	Research Question What is the lived experience of individuals going through genetic testing for Huntington's Disease and their ongoing support needs following testing? (this box should expand as you type)
5	Aims of Research Activity 1. To understand the lived experiences and therapeutic needs of individuals following genetic counselling and genetic testing for HD in the UK 2. To identify how the counselling profession can best support individuals following genetic counselling and genetic testing for HD. (this box should expand as you type)
6	Objectives of Research Activity The primary objective of this research study is to attain a profound insight and awareness into the psychological support that is needed for individuals following their experience of genetic testing for Huntington's Disease. This will be achieved through carrying out a small number of online in-depth qualitative interviews. The study has the support of the Huntington's Disease Association (HDA) who will be supporting recruitment to the study (please see appendix).
	Proposed methods (maximum 600 words) Provide a brief summary of all the methods that may be used in the research activity, making it clear what specific techniques may be used. If methods other than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed. You do not need to justify the methods here, but should instead describe how you intend to collect the data necessary for you to complete your project.
7	A qualitative research approach will be used for this study applying Interpretative Phenomenological Analysis (IPA) (Smith & Shinebourne, 2012). IPA methodology will permit an exploration of each participant's personal lived experiences and identify common themes and patterns that appear. This will provide further understanding of not only the genetic testing process but the therapeutic support that is needed for these individuals following the genetic testing process. Semi-structured interviews through the online platform Microsoft teams will provide an exploration into the participants personal experiences of the genetic testing process and what support they feel they did or did not receive throughout (Mashuri et al. 2022). These interviews will take place online to be able to interview participants who are located across other parts of the UK. The study will aim to recruit a maximum number of 6 participants. The

	target group for this study will be ambassadors from the Huntington's Disease Association who have been through the genetic testing process. There is no exclusion criteria in terms of genetic test result, the participants may have tested either positive or negative for Huntington's Disease. However, the only exclusion criteria would be the participants did not receive this test result within the last year as the researcher would not be able to ask the questions related to support and this is also a very emotionally raw time for the participants. Each interview will be recorded through Microsoft teams where the participants will be able to join the meeting at the specified interview time sent to them via the researcher. The interviews are expected to last no longer than 45 minutes to 1 hour. The researcher will greet each participant and although they will already have provided consent at this stage, provide them with some background information regarding what the interview will entail so they have that opportunity to withdraw if they do not feel comfortable. The same questions will be presented to all participants however, they will be semi-structured questions so it allows each participant to share their unique perspective into the genetic testing process, and some may wish to share more than others. The questions will be carefully considered and piloted to ensure they are not too intrusive or overly sensitive although this is a sensitive topic area. The researcher will explore participants experience of genetic counselling prior to having their result and how prepared they felt. In addition to this, if the counselling process prior helped them prepare for their genetic test result and how they felt emotionally once they found out – did they feel they had sufficient mental health support? Following each interview, participants will be thanked for their time and fully de briefed to ensure they leave the interview without any distress. If any participants do however require any support or further information this can be given (dependent on the issue or question) by the researcher, the researcher's supervisor, or the Huntington's Disease Association who have already stated they are available during this process. Data will be transcribed and analysed using the steps of IPA, with pseudonyms and contextually identifiable information removed from any published quotes. Due to her own role as a HD advocate/ambassador, the researcher is aware of the challenges of her own dual positionality. The practice of bracketing throughout the research process will enable the researcher to navigate both her subjective personal involvement whilst maintaining objectivity and neutrality, focusing solely on the research phenomenon. This is explored further in Section H4. (this box should expand as you type)
	Location of research activity Identify all locations where research activity will take place.
8	As the ambassadors are from different locations within the UK, data collection will be carried out online through the Microsoft team's platform. Each interview will be recorded so the data can be used for transcription. Every participant will be informed of this to ensure full consent is provided (this box should expand as you type)
	Research activity outside of the UK If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised

	by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants. If you live in the country where you will do the research then please state this.
9	N/A <i>(this box should expand as you type)</i>

10	Use of documentation not in the public domain: Are any documents NOT publicly available?	NO	☒
		YES	☐
11	If Yes, please provide details here of how you will gain access to specific documentation that is not in the public domain and that this is in accordance with the current data protection law of the country in question and that of England and Wales. N/A <i>(this box should expand as you type)</i>		

	Does your research relate to one or more of the seven aims of the Well-being of Future Generations (Wales) Act 2015?	YES	NO
12	A prosperous Wales	☐	☒
13	A resilient Wales	☐	☒
14	A healthier Wales	☒	☐
15	A more equal Wales	☒	☐
16	A Wales of cohesive communities	☐	☒
17	A Wales of vibrant culture and thriving Welsh language	☐	☒
18	A globally responsible Wales	☐	☒
19	If YES to any of the above, please give details:		
	Whilst this study does not include all welsh participants, the findings from the study are of interest to medical genetics services within Wales, and a summary of the study findings may be shared with them. <i>(this box should expand as you type)</i>		

SECTION F: Scope of Research Activity

	Will the research activity include:	YES	NO
1	Use of a questionnaire or similar research instrument?	☐	☒
2	Use of interviews?	☒	☐
3	Use of focus groups?	☐	☒
4	Use of participant diaries?	☐	☒
5	Use of video or audio recording?	☒	☐

6	Use of computer-generated log files?	☐	☒
7	Participant observation with their knowledge?	☐	☒
8	Participant observation without their knowledge?	☐	☒
9	Access to personal or confidential information without the participants' specific consent?	☐	☒
10	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	☒	☐
11	Performance of any acts which may cause embarrassment or affect self-esteem?	☐	☒
12	Investigation of participants involved in illegal activities?	☐	☒
13	Use of procedures that involve deception?	☐	☒
14	Administration of any substance, agent or placebo?	☐	☒
15	Working with live vertebrate animals?	☐	☒
16	Procedures that may have a negative impact on the environment?	☐	☒
17	Other primary data collection methods. Please indicate the type of data collection method(s) below.	☐	☒
	Details of any other primary data collection method: (this box should expand as you type)		

If NO to every question, then the research activity is (ethically) low risk and **may** be exempt from **some** of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

If there are no participants then do not complete this section, but go directly to section H.

	Who are the intended participants:	YES	NO
1	Students or staff at the University?	☐	☒
2	Adults (over the age of 18 and competent to give consent)?	☒	☐
3	Vulnerable adults?	☐	☒
4	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	☐	☒
5	Prisoners?	☐	☒
6	Young offenders?	☐	☒
7	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper?	☐	☒
8	People engaged in illegal activities?	☐	☒
9	Others. Please indicate the participants below, and specifically any group who may be unable to give consent.	☐	☒
	Details of any other participant groups:		

	(this box should expand as you type)		
--	--------------------------------------	--	--

Participant numbers and source Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?		
10	How many participants are expected?	5 to 6 ambassadors will take part in this study. <i>(this box should expand as you type)</i>
11	Who will the participants be?	The participants are ambassadors (18 years or over) from the Huntington's Disease Association within the UK. They are impacted by Huntington's Disease and have made the decision to go through the genetic testing process. The participants have already expressed interest in this study through informal conversations.
12	How will you identify the participants?	Information will be disseminated through the HDA to existing ambassadors for the association. The association have already provided an email to confirm their involvement (see appendix at end of this form).

Information for participants:		YES	NO	N/A
13	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	☒	☐	☐
14	Will you tell participants that their participation is voluntary?	☒	☐	☐
15	Will you obtain written consent for participation?	☒	☐	☐
16	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	☐	☐	☒
17	If the research is observational, will you ask participants for their consent to being observed?	☐	☐	☒
18	Will you tell participants that they may withdraw from the research at any time and for any reason?	☒	☐	☐
19	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	☐	☐	☒
20	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	☐	☒	☐
21	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	☒	☐	☐
22	If NO to any of above questions, please give an explanation			
Participants will be informed that although pseudonyms will be used during the interview process, as they are actively involved in the HD community with their own blogs through social media, the HDA website and talk through media platforms, there is potential they could be identifiable. All participants will have the opportunity to view and approve any quotes used from them prior to completing the dissertation. The information sheet and consent form will be provided in electronic format with online consent captured through the online survey system Qualtrics. This means we will use an electronic tickbox format which asks participants to indicate that they give consent, a method deemed acceptable for collection of online consent according to the BPS Ethics Guidelines for Internet-Mediated Research (2021). Consent will also be captured verbally at the start of the online interview to ensure that participants remain happy to take part.				

	Information for participants:	YES	NO	N/A
24	Will participants be paid?	☐	☒	☐
25	Is specialist electrical or other equipment to be used with participants?	☐	☒	☐
26	Are there any financial or other interests to the investigator or University arising from this study?	☐	☒	☐
27	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	☐	☒	☐
28	If YES to any question, please provide full details			
	<i>(this box should expand as you type)</i>			

SECTION H: Anticipated Risks

	Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them. If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.					
1	Full risk assessment completed and appended?	<table border="1"> <tr> <td>Yes</td> <td>☐</td> </tr> <tr> <td>No</td> <td>☒</td> </tr> </table>	Yes	☐	No	☒
Yes	☐					
No	☒					
2	Risks to participants For example: sector-specific health & safety, emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information					
	Risk to participants: Risk to participants: 1. Participants may raise concerns over their anonymity as each interview in this study will be recorded for the researcher to later transcribe.	How you will mitigate the risk to participants: 1. Prior to any interviews commencing, each participant will be informed that all personal information and data will be confidential and stored securely in line with GDPR. Participants will also be informed that their data will be anonymised as far as possible and that they will be identified by their unique pseudonym. The participants will be given the opportunity to record audio only, without the camera being on. The researcher will inform participants that they can stop the interview at any time without penalty and withdraw their information. All participants will be informed that only myself and my supervisor will have access to the interview recordings. In addition to this, the final report will be anonymised using pseudonyms. However, there is potential they will be identifiable to those who know them and their stories as they openly talk about these. The study information sheet will outline that this maybe a possibility and if they are uncomfortable with this, they can				

	2. (The topic of Huntington's Disease particularly the participants experience of genetic testing is of a sensitive nature which could be emotionally triggering to participants. Therefore, this may cause emotional distress. <i>this box should expand as you type</i>	withdraw from the study. Contact details for the researcher will be provided to participants if they have any issues or concerns that they wish to discuss at any time. 2. Participants are ambassadors for the HDA who already actively talk about their HD stories through social media platforms and/or have openly spoken about their story at HD conferences and through media platforms (TV/Radio). The interview questions will be carefully selected to respect sensitivity and consideration will be given to the wording of each question to avoid being overly intrusive. In addition to this, so the researcher can gain feedback on the appropriateness of each question, one ambassador who is not taking part in the study will have access to the questions prior to the interview schedule being finalised. The questions will then be reviewed and piloted prior to the final data collection process. The researcher has ensured that all questions specifically relate to the participants experience of genetic counselling, the genetic testing process and the follow up support they may or may not have received. Full support will be provided by myself, and my supervisor if any participant were to become distressed as a consequence of any interview question. Jordan Barbrooke who is from the HDA and runs the ambassador programme will also be a source of support. She has a close relationship with the ambassadors, providing support outside of this research study. Participants will be able to decline answering a question or exploring a topic area if they do not wish to and given the opportunity to withdraw at any point from the study. <i>(this box should expand as you type)</i>
3	If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities	
	Full information will be provided to each participant prior to any interviews commencing to ensure nothing is kept from them. If any participants were to become distressed as a consequence of any of the interview questions, they will be given the opportunity to pause, take a break, or to withdraw at any point. In addition to this, following each interview full support will be provided if needed and	

April 2022` 11 PG2 Ethical Approval Form

		with support via the HDA if they feel they need this. The researcher will ensure the BACP code of ethics is adhered to at all times.
5	University/institutional risks For example: adverse publicity, financial loss, data protection	
	Risk to the University: 1. Risks related to the reputational damage of the university <i>(this box should expand as you type)</i>	<i>How you will mitigate the risk to the University:</i> 1. The researcher will ensure they are following the BACP code of ethics and UWTSD Code of Research Ethics & Integrity (2022) at all times. 2. The researcher will work closely alongside their supervisor as they have experience conducting research with vulnerable groups. The researcher will ensure they behave appropriately and with the upmost integrity. In the event of any unexpected serious issue occurring, the study will stop and advice will be sought from the supervisor immediately.
6	Environmental risks For example: accidental spillage of pollutants, damage to local ecosystems	
	Risk to the environment: N/A – online interviews only <i>(this box should expand as you type)</i>	<i>How you will mitigate the risk to environment:</i> <i>(this box should expand as you type)</i>

Disclosure and Barring Service				
	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	YES	NO	N/A
7	Does your research require you to hold a current DBS Certificate?	☐	☒	☐
8	If YES, please give the certificate number. If the certificate number is not available please write "Pending"; in this case any ethical approval will be subject to providing the appropriate certificate number.			

SECTION I: Feedback, Consent and Confidentiality

1	Feedback What de-briefing and feedback will be provided to participants, how will this be done and when?
	Following the completion of each interview, the participants will be verbally debriefed, and the researcher will check if the participants have any concerns or would like to ask any questions in relation to the study. Additionally, participants will be presented with a written debrief form which will be emailed without delay as soon as each interview is complete. This will include contact details of the researcher and supervisor. The researcher will inform participants of their right to remove their data from this study, with clear information and

	guidance, and links to our HDA contact for support. Finally, all participants will have the opportunity to view and approve any quotes used prior to the final submission of the dissertation.
2	Informed consent Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	Participants will be required to provide informed consent prior to taking part in this study. Initial information about the study disseminated via the HDA will include an online link/QR code to access the online information sheet and consent form. The researcher will also be able to email an electronic information sheet to interested participants which will outline full information of what the study entails ensuring they are aware of exactly what is expected of them should they decide to participate. Participants will be asked to complete electronic consent via the online Qualtrics survey software. Verbal consent will also be obtained at the beginning of each interview to ensure the remain happy to consent.
3	Confidentiality / Anonymity Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.
	All participants will be reassured that confidentiality will be protected. They will also be given unique pseudonyms to protect their anonymity, but they will also be aware that as they openly talk about their stories through their HDA ambassador role, it is possible they may still be identifiable. As participants are reflecting on their personal experiences of genetic testing, it is likely that each participant will open up about being impacted by Huntington's Disease, so participants will be given the opportunity to stop and withdraw at any time. Once each interview has ended, participants will be signposted to where they can get support if they require it. All interview questions will be pre-approved by the researcher's supervisor and piloted with other ambassadors who are not taking part for feedback on the appropriateness. All primary data i.e., video recordings will be stored on the University one drive where only the researcher and supervisor will have access. Secondary data i.e., the interview transcripts will be anonymised as much as possible through the use of pseudonyms to protect participants confidentiality and anonymity.

SECTION J: Data Protection and Storage

	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 "GDPR" and the Data Protection Act 2018 "DPA")?	YES	NO
1	"Personal data" means any information relating to an identified or identifiable natural person ('data subject'). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Any video or audio recordings of participants is considered to be personal data.	☒	☐
	If YES, provide a description of the data and explain why this data needs to be collected:		
2	Email addresses are required for the purposes of arranging interviews. Participant age, gender, and genetic status will be recorded for the purposes of analysis (describing the sample) Video/audio recordings of interviews are required for the purposes of analysis.		
	Does it involve special category data (as defined by the GDPR)?	YES	NO

3	“Special category data” means sensitive personal data consisting of information as to the data subjects’ – (a) racial or ethnic origin, (b) political opinions, (c) religious beliefs or other beliefs of a similar nature, (d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992), (e) physical or mental health or condition, (f) sexual life, (g) genetics, (h) biometric data (as used for ID purposes),	☒	☐
	If YES, provide a description of the special category data and explain why this data needs to be collected:		
4	Physical Health Condition. Participants are taking part in this study as they are impacted by a genetic condition and are either diagnosed as gene positive or gene negative for Huntington’s Disease. As ambassadors for the HDA they are already open about living with this condition and regularly share their stories through social media and other channels such as conferences.		

	Will data from the research activity (collected data, drafts of the thesis, or materials for publication) be stored in any of the following ways?	YES	NO
5	Manual files (i.e. in paper form)?	☐	☒
6	University computers?	☐	☒
7	Private company computers?	☐	☒
8	Home or other personal computers?	☒	☐
9	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	☒	☐
10	“Cloud” storage or websites?	☐	☒
11	Other – specify:	☐	☒
12	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of backup procedures, password protection, encryption, anonymisation and pseudonymisation:		
	All recordings and transcriptions will be stored on the researcher’s laptop in the University OneDrive and will be password protected. To protect the anonymity of participants, any identifiable information will be anonymised when the recordings are transcribed within 72 hours of each interview. Once transcribed, the video/audio recordings will be deleted from the one-drive. The transcriptions will be used for the final report write up. Hard copy drafts of interview transcripts used for the purposes of analysis and/or hard copies drafts of the dissertation will only contain already anonymised data.		

Data Protection			
		YES	NO
	Will the research activity involve any of the following activities:		
13	Electronic transfer of data in any form?	☒	☐
14	Sharing of data with others at the University outside of the immediate research team?	☐	☒
15	Sharing of data with other organisations?	☐	☒
16	Export of data outside the UK or importing of data from outside the UK?	☐	☒
17	Use of personal addresses, postcodes, faxes, emails or telephone numbers?	☒	☐

18	Publication of data that might allow identification of individuals?	☒	☐
19	Use of data management system?	☐	☒
20	Data archiving?	☒	☐
21	If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and Data Protection Act (2018) (and any international equivalents, where appropriate):		
	Only the student and supervisor will have access to the recorded material and raw interview data, and this will be stored on a secure UWTSD one drive folder with password protection. No interview transcripts will be shared with the HDA only potentially the final study report. Email addresses are required for the purposes of study consent and interview arrangements only and these will be stored in a separate password protected one drive folder with the electronic consent forms. Whilst every effort will be made to ensure the final report and any publications do not contain identifiable data, the participants will be aware that due to their role as a HDA ambassadors that some aspects of their story may be identifiable.		
22	List all who will have access to the data generated by the research activity:		
	The Researcher: Carly Evans Supervisor: Dr Ceri Phelps <i>(this box should expand as you type)</i>		
23	List who will have control of, and act as custodian(s) for, data generated by the research activity:		
	The Researcher: Carly Evans <i>(this box should expand as you type)</i>		
24	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.		
	The data which includes, recordings and transcripts will be stored in the University OneDrive, which can only be accessed with a password. Data storage will comply with the UWTSD Data Protection and Storage Protocol and the UWTSD Data Management Policy. Copies of the electronic consent will be stored in a separate folder in OneDrive, which is secured by two-step verification. Once transcribed, the video/audio recordings will be deleted.		
25	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtsd.ac.uk/). If so please explain. <i>(Most relevant to academic staff)</i>		
	The data may be stored in the repository if there is the possibility of publishing the data following completion of the study.		
26	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtsd.ac.uk/library/research-data-management/)	YES	☒
27	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	YES	☒

SECTION K: Declaration

The information which I have provided is correct and complete to the best of my knowledge. I have attempted to identify any risks and issues related to the research activity and acknowledge my obligations and the rights of the participants. In submitting this application I hereby confirm that I undertake to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice which is published on the website: https://www.uwtsd.ac.uk/research/research-ethics/		
1	Signature of applicant: C Evans	Date: 22-09-2025

For STUDENT Submissions:

2	Director of Studies/Supervisor:	Dr Ceri Phelps	Date: 29/09/25
3	Signature:		

For STAFF Submissions:

4	Academic Director/ Assistant Dean:		Date:
5	Signature:		

Checklist: Please complete the checklist below to ensure that you have completed the form according to the guidelines and attached any required documentation:

☒	I have read the guidance notes supplied before completing the form.
☒	I have completed ALL RELEVANT sections of the form in full.
☒	I confirm that the research activity has received approval in principle
☐	I have attached a copy of final/interim approval from external organisation (where appropriate)
☐	I have attached a full risk assessment (where appropriate) ONLY TICK IF YOU HAVE ATTACHED A FULL RISK ASSESSMENT
☒	I understand that it is my responsibility to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice.
☒	I understand that before commencing data collection all documents aimed at respondents (including information sheets, consent forms, questionnaires, interview schedules etc.) must be confirmed by the DoS/Supervisor, module tutor or Academic Director.

RESEARCH STUDENTS ONLY

Once complete, submit this form via the **MyTSD Doctoral College Portal** at (<https://mytsd.uwtsd.ac.uk>).

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk, with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

Appendix: Letter of support from Huntington's Disease Association

Begin forwarded message:

From: HDA Comms <comms@hda.org.uk>

Date: 18 September 2025 at 15:10:53 BST

To: Carly Evans <carlyevans29@yahoo.co.uk>

Subject: Huntington's Disease Association Support

Hi Carly

I am emailing on behalf of the Huntington's Disease Association to state that we will support your mental health after genetic testing study and we will also be a form of support for those participating in the study.

We wish you luck in organising your ethical approval and will assist you in recruiting participants once the study opens.

Best wishes,
Jordan Barbrooke,
Communications Officer,
Communications Team
Huntington's Disease Association



Join us for our Huntington's Community Conference

Each year, we host an in-person Annual General Meeting and community conference. It is an opportunity to meet other families, hear updates from the charity, research developments from Huntington's experts, and personal stories from three speakers in the Huntington's community.

Register to attend

Registered Charity No. 296453

The poster features a man speaking at a podium with a microphone, holding a small object. The background is a large circular graphic with the Huntington's Disease Association logo and the text 'Inspire community'.

Tel - 0151 331 5444 **Email** - info@hda.org.uk **Website** - www.hda.org.uk

Address - Huntington's Disease Association, Liverpool Science Park, IC1, 131 Mount Pleasant, Liverpool, L3 5TF

Follow us on - [Facebook](#) | [X](#) | [Instagram](#) | [Linked In](#) | [Message board](#)

The Huntington's Disease Association takes your privacy very seriously. If you would like to learn more about how we manage your personal data please read our Privacy Policy which is available on our website www.hda.org.uk/privacy-policy

Registered Charity no. 296453. A company limited by guarantee. Registered in England no. 2021975

This email, together with any attachment(s), is for the exclusive and confidential information of the addressee(s). Any other distribution, use or reproduction without the sender's prior consent is unauthorised and strictly prohibited. If you receive this message in error, please notify the sender immediately and delete the message without making any copies.



Any views or opinions expressed are the author's and do not necessarily represent those of the Huntington's Disease Association. You should not rely on the content of this message unless satisfied it is from an authorised source. The Huntington's Disease Association reserves the right to monitor all email communications.