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# Counseling patients in the predictive genetics clinic for Huntington's disease: A qualitative analysis of ethnographic observations

Shane Doheny[1] | Rebecca Dimond[2] | Lisa Ballard[3] | Anneke Lucassen[4] | Peter Turnpenny[5] | Angus Clarke[1]

[1]Division of Cancer & Genetics, School of Medicine, Cardiff University Institute of Medical Genetics, Cardiff University, Cardiff, UK

[2]School of Social Sciences, Cardiff University, Cardiff, Wales, UK

[3]Applied Genomics and Public Health Research Group, University of Southampton, Southampton, UK

[4]Nuffield Department of Medicine, University of Oxford, Oxford, UK

[5]Royal Devon University Healthcare NHS Foundation Trust, Exeter, UK

**Correspondence**
Shane Doheny, Division of Cancer & Genetics, School of Medicine, Cardiff University Institute of Medical Genetics, Cardiff University,Heath Park, Cardiff, Wales CF14 4XN, UK.
Email: dohenys1@cardiff.ac.uk

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## Abstract

Little research has been conducted on patients' experiences inside the predictive genetics clinic. In this clinic, a person with a familial risk of inheriting a rare disease seeks a test that will provide them with information about their future health. Counselors combine gentle challenges with neutral approaches to educate and counsel patients wanting to take the predictive test. We conducted ethnographic observations of predictive genetics clinics for Huntington's Disease in England and Wales. Four content categories were prominent throughout the analysis, which we present in this paper: connecting, deciding, coping, and supporting. (1) Connecting describes how discussions began with an exploration of the idiosyncrasies of the patient's connection with Huntington's Disease. (2) Deciding describes how counselors asked patients about their decision to seek referral to the predictive genetics clinic; (3) Coping describes how counselors explored whether and how the patient was likely to cope, especially with a positive (bad news) test result; and (4) Supporting describes the support patients may need if they receive such news. This article contributes to a deeper understanding of patient experience in predictive genetics clinics, which is invaluable for genetics professionals and others who support patient care. Based on this analysis, the paper underlines the importance of the elongated counseling process and the need to ensure counselors receive the training and support they require to manage such complex medical encounters.

**KEYWORDS**
content analysis, Huntington's disease, non-directive counselling, Predictive genetic test

## 1 | INTRODUCTION

The offer of a predictive test for Huntington's Disease (HD) puts those eligible in a difficult position. They must decide whether they want to know their future and consider whether this is also right for those close to them. The role of the predictive genetics clinic is to help patients understand the implications of going ahead with the test and to support patients in preparing themselves in case of a positive ('bad news') or negative ('good news') result for themselves and those around them.

In this paper, we present an analysis of ethnographic observations of predictive genetics clinics for HD in England and Wales. We

begin by outlining the context of the predictive genetic test and how patients and families access 'counselling and testing' as a package. We outline our methodological approach before exploring four content categories identified in our data: connections (to the condition), decisions (to proceed with testing), approaches to coping, and anticipated support needs.

### 1.1 | Background

Genetic services offer predictive tests for a small (but increasing) number of conditions. Predictive genetic tests are mostly offered to asymptomatic patients *at risk of becoming* affected by an autosomal dominant disorder. Onset for these disorders is age-dependent, and those affected are sometimes unaware of this when they are considering having a family (Clarke, 2020: 137). This group includes serious but often manageable diseases like polycystic kidney disease and also serious but less manageable conditions like HD and motor neuron disease; conditions associated with malignancy, such as von Hippel–Lindau syndrome and BRCA1/2, may be seen as intermediate. In this paper, we focus on predictive testing for HD. The child(ren) of a parent diagnosed with HD have a 50% risk of developing the disease. The predictive genetic test for HD will (with certain caveats) diagnose that a patient will develop HD before symptoms appear. As an illness, HD is a disorder of the central nervous system characterized by choreiform movements, cognitive deterioration, and dementia. The mean onset of symptoms is between 30 and 50 years of age, but in some cases may appear before the age of 20 (Roos, 2010). HD is (currently) incurable, but scientists have begun to identify promising therapies (see Gulzar et al., 2025).

From the beginnings of predictive testing, concerns that knowing one's genetic status could negatively impact patients have occupied genetic counselors (see Quaid, 2017). Knowledge that someone will develop HD (if they do not die for some other reason first) may lead to significant challenges, including depression, suicide, or negative impacts on the individual's work, education, or family life (Crozier et al., 2015). The choice to undertake testing may be affected by factors including "the absence of disease-modifying treatments, anxiety about an abnormal result, the financial implications of an abnormal result, personal experiences of caring for relatives with HD, or perceived stigma associated with the condition" (Baig et al., 2016: 1398). Recognizing and responding to these concerns, protocols were developed to manage how patients access testing. The result in the UK is that the predictive test for HD is available to all adults (usually over the age of 18) based on recommendations (MacLeod et al., 2013) that have been implemented pragmatically (see Crook et al., 2022). The process of accessing a predictive genetic test begins with a pre-clinic counseling session focused on gathering information, assessing, and setting expectations. The clinic involves at least one pre-test counseling session, a session where a blood sample is collected, and a results session; follow-up consultations are also offered. An interval of a month is built in between the pre-test and the test session to ensure patients have the opportunity to reflect before proceeding (Clarke & Wallgren-Pettersson, 2019).

**What is known about this topic**

We have some insight into the use of neutral counseling in the predictive genetics clinic from retrospective accounts, but there is little direct knowledge of what actually happens in these clinics.

**What this paper adds to the topic**

This paper clarifies the complex range of responses to topics discussed in the predictive genetics clinic for HD. This paper also adds some insight on how counselors use neutral techniques to probe and challenge patients on these topics.

There has been extensive research on motivations to take a predictive test (Ibisler et al., 2017; Tillerås et al., 2020), the process of becoming ready to take the test (Cox & McKellin, 1999; Taylor, 2005; Tillerås et al., 2020), and how patients respond to results (Tibben, 2007; Almqvist et al., 2003), which has addressed the experiences of patients before and after their engagement with the predictive genetics clinic. However, little research has focused on what happens inside the predictive genetics clinic when the patient is asked to explore their reasons for seeking the test and its implications with a counselor (genetic counselor and/or clinical geneticist) (see Clarke, 2020: 140–142). Drawing on Goffman, Sarangi et al. (2004) explore how genetic counselors use reflective frames to encourage patients to think through their position, while supporting the counselor's 'non-directive' or neutral stance. Underscoring just how difficult these conversations can become, Sarangi et al. (2005) examine the structure of misunderstandings or 'misalignments'. Their point was that patients and counselors engage in a kind of negotiation. By analyzing misalignments, Sarangi et al. (2005) reveal that, while counselors seek to ensure patients have the opportunity to reflect and make autonomous decisions, patients respond to what they perceive as good reasons in the clinic "are thus likely to engineer their responses in ways that match these criteria" (2005: 40).

In a later paper, Sarangi (2013: 3) provides a structural map of a genetic counseling session that identifies two counseling topic areas. Phase I of the typical session is controlled by the counselor and involves information-giving, focusing on the disease and inheritance patterns. Phase II shifts to the client's engagement with the information. In a discussion of talk in the predictive HD clinic, Clarke and Wallgren-Pettersson (2019) point to three main topic areas. First, there is an introductory phase in which the counselor and the patient negotiate the basis for valid consent to the test. This involves a discussion of the medical basis of the test while addressing the patient's attitude. Second is counseling, where they

"would usually discuss how they [the patient] became aware of their risk of HD and how long ago" and "what has triggered the request for testing *now*". This is followed with a third topic on "how they feel they would cope with an adverse result" (2018: 8). Additional topics may be raised, for instance, on family support and the communication of results (2018: 8). This paper contributes to this literature by adding ethnographic observations of the topics discussed in these clinics.

Ethnography provides a methodological route to study the interaction between the medical system and the personal lifeworld in the predictive genetic clinic. Sarangi et al. (2004, 2005) drew on Goffman (1981) to focus on the use of frames as cognitive devices, analyzing how language is used to frame and interpret what is said in the clinic. In the analysis that follows, we build on Sarangi et al. (2004, 2005) by addressing what Goffman (1981) terms 'footing', 'alignment' or 'code switching' in everyday talk. Goffman (1981) describes how talk is used in multifaceted and shifting ways. Those engaged in talk shift registers, codes, or footing for a variety of purposes. Within the predictive genetic clinic, counselors and patients switch footing as they move between topics of conversation. Our analysis focuses on how patients align their responses with the shifts introduced by counselor-initiated shifts of topic.

## 2 | METHODS

The data presented here were collected as part of a project on how patients decide to take tests with limited clinical utility. Recruitment was led by genetics specialists. Potential participants were identified by clinicians who sent an information sheet to patients with their clinic invitation letter. Upon arrival at the clinic, patients were reminded of the research project, and provisional verbal consent to record their consultation was sought. Because they sent letters and information sheets to eligible patients before the clinic, and then raised the possibility of participating at the beginning of their first clinic, clinicians were not pre-selecting patients based on previous knowledge. After the consultation, the patient met with a researcher and was asked about continuing to participate in the study. This ensured that the patients were pre-warned of the project and had already taken part in genetic counseling before deciding to participate. All who agreed to the initial recording continued with the research and completed the consent form. For patients, ongoing participation in this study involved the observation and recording of their clinics, participating in a post-decision interview, and keeping a reflective diary on the process of making a decision. The diary enabled patients to contribute their own views on aspects they felt were important (see Clarke et al., 2024). Approval for the project was obtained from an NHS Research Ethics Committee (Wales REC 1) and the Research & Development Office of each NHS trust involved. Data gathering and analysis were conducted in collaboration with our study advisory and PPI (patient and public involvement) team. Initial coding and analysis were developed through consultation with this project advisory team and the PPI team through both internal team meetings and at a project meeting that was used as a key opportunity to reflect on developing analyses.

Our analysis focuses on the experiences of 15 patients at risk of HD, over the course of 20 clinic consultations conducted between 2018 and 2020 across four genetics services in South/South-West England and Wales. The participants included seven females and eight males (aged 16 to 69), three clinical geneticists (CG1–CG3), and two genetic counselors (GC1 and GC2). In addition, 13 patients brought a friend or family member to the clinic. One patient ceased attendance at clinics. Four participants had previously attended a clinic but had chosen not to take the test at that time. The clinics observed included three pre-clinic sessions, ten pre-test, six 'talk and test' (blood draw), and one results clinic. The team refrained from observing results clinics as acutely private spaces; however, one patient requested our presence. Half (10/20) of the observed clinics were led by one geneticist (CG2) due to the workload pattern. Observed dialogue included extensive and varied discussion of topics that recurred across the clinics. This combination of specificity of experience and high-quality dialogue contributes to the power of the analysis that follows (Malterud et al., 2015).

NVivo12 was used to manage data analysis. Transcripts were anonymized to replace person and place names with pseudonyms. With this being ethnographic research, the researchers did not define conversation topics. By identifying and collecting responses to topics raised by the counselors, we conducted what is termed inductive (Kyngäs, 2020; Vears & Gillam, 2022) content analysis. This method is used to reduce and summarize text to identify meaningful patterns. Whereas thematic analysis uses reflexive and interpretive approaches to reveal latent meaning, content analysis focuses on the meaning of data. The data were first coded for content by the lead author (SD). These codes described the data in manageable segments. Coding continued iteratively until the entire data set was coded. SD grouped and sub-divided the codes into content categories. These content categories followed the form of the topics raised by counselors in the clinics. The analysis presented below focuses on these content categories. Thematic analyses are presented elsewhere (Dimond et al., 2022, Ballard et al., 2025, Doheny et al. 2026). The main content categories raised in counseling sessions, which are explored here, are patients' connections with HD, their decisions about the test, how patients anticipate coping with a positive test, and the support systems they expect to be available.

### 2.1 | Positionality statement

The research team comprised sociologists, a health psychologist, and clinical geneticists with clinical and academic commitments. SD is primarily responsible for this paper. This author is a middle-aged, middle-class, cisgender, white male, Irish immigrant working as a professional sociologist in the UK. This author took on the role of an interested observer, able to question aspects of clinical

practice which might be taken for granted by 'insiders'. Moreover, as a professional sociologist, his role is to contribute to knowledge in ways that are sensitive to the data and of use for practitioners and researchers. The clinical geneticists are practitioners interested in the social dimensions of genetics who have made significant contributions to ethical counseling practice. As a multidisciplinary team, we regularly reflected on the challenging nature of the decision to take the predictive genetic test, identifying and discussing our own personal and professional perspectives. Our purpose has been to document how patients do this in situations where they are supported by counseling to make this decision for themselves.

## 3 | FINDINGS

### 3.1 | Category 1: Understanding patient connections with HD

The first topic addressed the patient's experience of HD. Raising this topic, counselors requested information about the patient's knowledge and experience of HD. In all the consultations, counselors asked the patient to describe their knowledge and experience of HD.

For some, HD was a taken-for-granted background of their life. For instance, Gareth described being aware of HD as a teenager:

**Gareth:** So been aware of the Huntington's in the family since around about 14 years of age. It's never really shaped or defined my life. … it's [illness appearance] always tended to be the mid-40s, my dad's diagnosis and displaying of the first symptoms in the early 50s. So I suppose me being 46 now I wanted to understand, because if, again depending on where the test results would come out, is making certain plans [patient plans to retire early if he receives a positive test result]. (Gareth, pre-test clinic)

Here, Gareth claims HD has not "really shaped or defined" his life. His expectation that symptoms appear in midlife allowed him freedom to live his life. He has had no biological children, and we do not know if HD had any role in that. He explains he is considering retiring early if he receives a positive test result, potentially because of reflections on his father's experience of symptoms from a similar age and of diagnosis. Contrary to his earlier assertion, the risk of HD clearly had had some impact on his life.

Another patient takes a different route to a 'taken for granted' acceptance. David responds to the request for information about his experience by situating HD alongside other illnesses that cause death in his family:

**David:** Cancer, but on my mum's side it's cancer anyway. And like I say they all go early, so if this [HD] is another thing it's just another thing.

**CG2:** Yeah, it's almost not the only thing that's a possibility.

**David:** Like I say, my grampy, my mum's dad, he got dementia as well before he went as well. So like I say, with the old man now, it's sort of like we had to care for my grampy and what have you, so we're used to it now. These things happen; you get ready for them, don't you? (David, pre-test clinic)

David put HD into the background by locating it alongside cancer and dementia as illnesses causing difficulties and an early death in his family. He asserted a general assumption that members of his family become ill and die 'early' without marking out HD as different. Here, it is the experience of illness that is highlighted; risk is present but normalized.

Some patients took a distant view of HD. These linked their risk of HD with perceptions of age of onset in their family, placing their risk at something of a distance from themselves:

**Jonathan:** So my, my mum's father, err, my pap, was, um, he had a stroke, or a, is it a TA?

**CG3:** TIA [a Transient Ischemic Attack or 'mini stroke'].

[Omitting eight turns]

**Jonathan:** um but it's now come up that he has some symptoms, but it seems as though the stroke triggered it or made it worse or something, cos before that he was fine. Um, my mum's, as I said, is in her late fifties, early sixties, … I think she was initially quizzed by someone, I cannot, can't, can't remember who um but she, yeah didn't feel the need to do it [take presymptomatic test] or however. So then when mum first said that he [grandfather] had it, obviously I did a bit of research … and so it was my understanding that you can pass it to your children, err like a fifty-fifty chance. (Jonathan, pre-clinic)

Jonathan observes the emergence of symptoms in his grandfather and their absence in his mother. He speaks of how his grandfather's symptoms were 'triggered' by a TIA and notes how his mother (who is in her 60s) is so far unaffected. Much of Jonathan's consultation focused on his mother and how she had not had a diagnosis but was at 50% risk of developing the condition. Jonathan has a 25% prior risk of developing the disease (50% multiplied by 50%–calculated as his mum's risk multiplied by his risk of inheriting from his mum). Crucially, a positive test result for Jonathan will mean his mother has the gene change. However, a negative test for Jonathan does not mean his mother does not have the change: she could carry the expansion without having passed it to Jonathan. For Jonathan, the idea that the disease emerged in his grandfather following a stroke, and that his mother is not affected, combine to create distance between himself and the disease. Later, he speaks of how he may pass on the gene change: "I mean I'm not too bothered, but apart from if I have kids, if I have kids, there's a chance I can eradicate it, I'd like to". So despite expressing a low level of concern, he considered HD serious enough for him to want to ensure that his future children would not inherit it.

Donna's position parallels that of Jonathan's mother. Donna is a woman in her 60s whose father developed HD in his 80s and who

has adult children who want to start families. She faces the possibility of replicating her dad's experience. Here, she describes observing him in a care home:

**Donna:** Um, but I dunno, I just … I went to visit my dad last time and had a really nice time with him And I was just thinking: "He's at a good age. He's 88" He's in a home now being looked after…
[Seven turns on the condition of Donna's father omitted]
**Donna:** … so, he just made me sort of like think, mm, mm, you know, you can get to 88 and have all sorts of things wrong, can't you.
**CG2:** Yeah
**Donna:** Do you know what I mean, so he could have dementia, Alzheimer's, Parkinson's, all sorts? So, it just sort of like put it in perspective, just looking at him and thinking … (Donna, pre-test clinic)

This patient describes her thoughts on seeing her affected father in a care home. Reflecting that he is 'a good age', and being 'looked after'—although with frustrations—suggests Donna thinks this might be an acceptable outcome for her, considering that other diseases also cause cognitive decline. The path to aging and decline mapped by her father seems acceptable—at least for him, and perhaps for herself too.

Counselors sometimes requested information on how patients felt about their risk of developing HD. Raising the topic of connection through risk perception allowed patients to align based on their own approach to the world. Some patients focused on the riskiness of the 50% chance. Being a person with a one in two (i.e., 50%) chance of developing HD made some feel it was more likely that they would become affected:

**CG2:** What do you think's the, I know it's a 50/50 chance but […] do you have a gut feeling?
**Richard:** I'm quite pessimistic as, er, normally cause then I'm pleasantly surprised when something goes right so I'm, I'm leaning more toward having it [laughing], but also I think it's, it's better to be mentally prepared to have it because it's going to be, it's a much bigger thing to deal with. (Richard, pre-test clinic)
**CG2:** But you don't feel that you're lucky, you don't have, that's what you're sort of saying.
**David:** Like I say I'm not unlucky, but if there's something like this I don't think, like I say I've got three brothers and a sister, and let's be honest with you I think at least maybe three of us probably have it. (David, pre-test clinic)

Weighing the implications of a 50/50 chance of disease manifestation left patients seeking to accommodate themselves to developing the illness. This meant assuming their chance result would be positive, and they would develop the condition. Hence, it seemed sensible to "choose to think that the, the bad outcome is the reality and then it's nice to find out when it's not" (Hannah, pre-test clinic).

Counselors also addressed patients' connection with HD by requesting information on symptoms the patient may be identifying in themselves. Living at risk of developing this condition left many people trying to identify symptoms in themselves, which meant that the risk of disease was a constant presence in their lives:

**GC1:** Do you have any concerns about any symptoms or anything at all?
**David:** I'm getting myself a little bit forgetful again. … Like I say for instance [describes confusing similar items based on color] and every single day I try and put the wrong top on the wrong thing. And I tell myself "don't do it today David". (David, pre-test clinic)

David describes buying coffee as part of his daily commute and how he always mixes up container tops. It's not just that he mixes the container tops: he anticipates that he will do this, reminds himself not to do it, and finds himself repeating the mistake daily. This sense that his reflection about action is not followed through into action creates worry. In the following, Susan refers to a character trait of forgetfulness and suggests this trait has worsened, leading her to worry that this is a symptom of cognitive decline:

**CG2:** And you forget someone's 12-digit phone number or something
**Susan:** Yes, I forget names in seconds and stuff.
**CG2:** Is that different, or have you always done that?
**Susan:** No, in the last few years I've got, my short term memory for names in particular is dreadful. It's got really bad, which is quite worrying, and just various things. Stuff like that, and you're like "Is this aging, what is it?" It could be any number of things, but having HD looming does hover around. It's always there, even if you go "I'm not really thinking about it", it pops up quite often. And it's a tough thing to live with. (Susan, pre-test clinic)

In both cases, the patients observe something about themselves and connect this observation with knowledge of symptoms. This surveillance of the self was both based on and nurtured by worry that the condition may be beginning to take hold.

To summarize, patients connected with HD in different ways. Some viewed HD as a background concern, an ever-present assumption in their lives. Others saw developing HD as a distant possibility, especially those with affected relatives who showed symptoms later in life. A third way of connecting with HD was to focus on the risk of developing HD: having a 50:50 risk of developing such a disease as HD meant that the outcome of a test had significant meaning. Lastly, some patients experienced cognitive burdens, constantly monitoring for signs of the illness.

### 3.2 | Category 2: Decision-making about testing

Many patients discussed the process of making the decision whether to take a predictive genetic test. Here, we consider how the topic was introduced within the consultation and how testing was used as an aid to understanding, as a motivator, and as a tool to manage anxiety.

Counselors often initiate the discussion, introducing this topic using neutral language. For example:

**CG2:** And what are your own thoughts about getting tested now? (Susan, pre-test clinic)
**CG2:** 'Cause some people are very clear straight away … and other people need a bit more time to think about it. (Rebecca, pre-test clinic)
**CG3:** Grandfather has been diagnosed with Huntington's.
**Jonathan:** Yes, yeah.
**CG3:** Um and that you're sort of wanting to find out a bit more? (Jonathan, pre-clinic)

In raising the topic of the decision, counselors used open-ended language that allowed patients to respond by selecting the information they felt relevant. This took the form of a general invitation to outline thoughts (Susan, pre-test clinic), indicating the array of positions people may take on the decision (Rebecca, pre-test clinic) or the use of hedging terms ("sort of wanting") while addressing motivation (Jonathan, pre-clinic).

### 3.2.1 | Testing as an aid to understanding

For some patients, the predictive test offered information about their future. They wanted the predictive information, but had no plans on how they would use this information:

**CG2:** … […] Yeah so, yeah so you've decided you'd like to go ahead with the testing?
**Emelia:** Yeah.
**CG2:** And you, you're saying it will change nothing and that, that sounds like a funny reason …
**Emelia:** Yeah I mean I, I just …
**CG2:** … to, to test
**Emelia:** … I just want to get tested and I want to know what's going to happen in the future, just to be ready
**CG2:** Okay.
**Emelia:** And that's all. (Emelia, pre-test clinic)
**John:** I'm always slightly prepared for it, you know, I know I've got it, I can't even think about it, there's no cure, I'm gonna continue with my life, I'm gonna probably continue having kids and I'll work until I die, I'm gonna do what I need to do to be able to support my family. (John, pre-clinic)

Emelia indicates a general desire to be ready but does not say what she would do if she had a positive result. This alignment prompts the counselor to initiate a gentle challenge. Pointing to the idea that knowing will "change nothing", the counselor observes that "that sounds like a funny reason", thereby questioning the basis for Emelia's decision. Emelia responds by further explaining her thinking. The extract involving John is taken from a pre-clinic discussion, where the counselor is gathering information that may be helpful for the predictive clinic. With no cure for HD, John expresses his desire to "continue" with his life, as he has been doing, and not make accommodations. Here, he indicates a keenness not just to do what he needs to do to support his family, but also to make reproductive decisions that may have implications for the health of his future children, contrasting with many others' accounts.

Other patients paid attention to their need to understand their situation to make adequate preparations:

**CG2:** What would you change, do you think?
**Hannah:** About?
**CG2:** In the future if you've found out that you definitely got it?
**Hannah:** Um so obviously if I wasn't gonna be diagnosed for a while then initially it wouldn't really make much difference, other than an awareness of yeah, how my life might pan out. But I think when diagnosed, then obviously the first thing I'd be thinking about is work and making adjustments [lists further plans in the event she receives a positive test result]. (Hannah, pre-test clinic)

Hannah felt that if she knew what to expect, and then became symptomatic, she would start to adjust her life. Other patients described not only wanting this information for their own planning but also to enable their children to plan their futures:

**David:** "if he [speaking of his 10 year old son] finds a partner they'll need to know before they have any children […]" (David, pre-test clinic).

### 3.2.2 | Testing as a motivator

Patients used the test as a motivator, where the new knowledge would prompt them to live a more active, purposeful life. As the following patient articulates it, this approach is contrasted with 'just sitting':

**GC2:** […] is it gonna change, what, what do you think it would change for you knowing?
**Kate:** Well I've always said that if the test came back positive, then I think that's even more reason to live my life while I still can, before like anything, the symptoms come.
**GC2:** Okay.
**Kate:** Because what, what's the point in just sitting, doing nothing. (Kate, pre-clinic)

Here, it is suggested that a positive result would counter any drift into inaction. A similar perspective is expressed by another patient:

**CG2:** What I mean is could it spoil the here and now knowing that it is there?
**David:** No, I think it would probably make me stop putting so much stuff off and what have you, because if I have got it then

obviously I can see what's going to happen in the future, and I'm not going to be able to do some of the stuff I want to do later on in retirement, so I'll get it done now. (David, pre-test clinic)

David is emphasizing how a positive result would motivate him to bring forward plans to make the most of his remaining healthy years.

An interesting counterpoint to this was articulated by Hannah. For her, the mere thought that she was at risk was sufficient motivation to become more active. Hence, a positive test result would not prompt her to increase her activity:

**Hannah:** [...] so um yeah I get that that's ["to do the things in life"] quite a common way of thinking and I probably did it early on, because I was thinking so pessimistically anyway

**CG2:** Yeah, yeah, so that, so in terms of your general lifestyle, there might not be that much of a change right?

**Hannah:** No I can't be arsed now I've done too many, too many things going on (chuckling). (Hannah, pre-test clinic)

For Hannah, the motivation to take a more active approach to life was triggered earlier in her experience. Just being at risk was sufficient motivation to take a more active approach to her life, and so Hannah had already done many of the things she would want to. Hannah is an example of a patient who did not need a positive test result to become active. But while she claims proactivity, her choice of language punctuates pessimism, and she suggests she would adopt a blasé attitude to a bad news test result she could no longer "be arsed" making further efforts to live a more active life, having already done so.

### 3.2.3 | Testing to manage anxiety

During the consultation, patients would be encouraged to consider how genetic insight might help them resolve worries about their own health. For example, the following patient considers the activities that he will not be able to engage in if he has HD, and notes how this worries him:

**Richard:** ... but, seeing, seeing what my dad used to do, ... it makes me a bit worried for myself really. I won't be able,
'cause I do all the repairs for everyone and fixing and making stuff and... Erm, I'm worried I won't be able to do that anymore. (Richard, pre-test clinic)

Not only does Richard worry about the things he will not be able to do, but also the implication that a positive result might threaten his valued social role of handyman.

The following patient reflects in a very different way. This patient finds herself worried about her current risk status and wondering whether she is showing early signs of being affected. For her, being at risk of HD is a cause of anxiety:

**CG2:** And what are your own thoughts about getting tested now?

**Susan:** When I first found out [about my risk] I wanted to know. I was like it's the kind of thing I'd like to know to be able to organize. ... I would rather be worrying for a reason than every time you drop something, forget something, trip over, do something. "Am I getting old, is there something else wrong with me" ... And it becomes a constant worry in that sense, in the back of your mind all the time, and I'd rather it be there for good reason. (Susan, pre-test clinic)

For these patients, the presymptomatic genetic test provides an opportunity to confirm the presence of the genetic change and to transform their anxiety. They would no longer need to worry about developing the condition. One element of this subcategory is the idea that the patient prefers to have this information rather than not to have it:

**Hugh:** Yeah, I'd rather get the information sooner so I can digest it, whichever way. I think the whole process I, I feel like I've exhausted the whole, the thought of it. ... So, instead of stressing about what that result could be, I'd rather know it's that and coping with it whichever way it is really. (Hugh, pre-test clinic)

In summary, this section explores how counselors make a topic of the decision to undergo predictive genetic testing. Within this category, three sub-categories are identified: understanding, motivating an active life, and managing anxiety. The sub-category of understanding was used by patients who discussed pursuing testing to gain clarity about their future and make informed life plans. In contrast, the motivating active life sub-category refers to something like the spirit with which one approaches activities. The managing anxiety sub-category encompasses a desire to alleviate anxiety, preferring to confront a known risk rather than continuing the stress of not knowing.

## 3.3 | Category 3: Coping with test results

Counselors raised coping as a topic to explore how the patient is likely to respond if they discover they carry the gene change. In turn, patients framed their responses around their capacity for resilience, making this content central to their narrative.

### 3.3.1 | Being resilient

Some patients sought to emphasize their resilience. For example, in the following, the counselor introduces coping using a combination of neutral and directive language. The patient responds by suggesting he simply managed:

**CG2:** Yeah, in terms of yourself dealing with the result, have you, when you've had difficult information in the past, [counselor suggests possible information from the patient's history] has it

impacted you quite badly, or have you managed when you've found out?

**David:** I just seem to have just managed. As I say, I lost my mum's mum, my grampy, my mum's dad, and my mum all probably within five years of each other, all from cancer. It's just the hand you're dealt.

**CG2:** It's just what, yeah?

**David:** It's something, we can't change what's happened or anything, there's no point, you grieve and move past it. (David, pre-test clinic)

Here, the counselor raises coping by pointing to "difficult information" that may have "impacted you quite badly", and requests information on how the patient "managed". This invites David both to select relevant information and to detail his response along a continuum between badly impacted to managed alright. David chooses 'managed' and points to the deaths of family members as relevant events to illustrate his resilience – "just the hand you're dealt", "you grieve and move past it" and "there's no point dwelling on things". Thus, David presents himself as someone who manages difficult information in an emotionally appropriate way. A similar approach is used by the following patient:

**CG2:** I suppose the immediate reason I was just asking about coping with things is if in another, after one or two appointments, if I'm sitting there and telling you, "Yes, it is there, I'm sorry", then …

**Gareth:** If I had to self-assess myself, and again it's not being big-headed, but if I had to self-assess myself on a scale of one to 10, 10 being I cope with things like that really well, I'm going to be a nine at least. … it's almost like with that type of diagnosis I'd [describes bringing forward his retirement plans]. Terrible stress in work. So in a way it's like even with a positive test it's like I'll make the best of that. (Gareth, pre-test clinic)

Here, the counselor raises the topic of coping by asking Gareth to imagine how he will feel if the counselor soon reports a positive test result. Gareth responds with an assessment of his own capacity to cope. He considers himself particularly well-equipped to cope with bad news and explains how he can respond to a positive test result by making a series of positive changes in his life.

### 3.3.2 | Securing resilience

Some patients presented their resilience as something of an achievement. The following patient brings up her own history of using suppressive coping styles to deal with adverse situations as she explains how she has learned from this experience and intends to use a more rational and reflective coping style if she receives an unfavorable predictive result:

**Hannah:** I think the time after the assault, I definitely was depressed and um did all those mad, active mechanisms, like taking drugs and just not really taking much control of my life, um, but I think because I so badly don't want to experience that again, I try really hard to work on my sense of self-esteem and all the components that make up and I think before the assault, I already had low self-esteem so something like that kind of dragged me under even more … So I suppose that's the thing I'm trying to do to prepare um … (Hannah, pre-test clinic)

In this exchange, Hannah points to her experience of sexual assault as an example of adversity that prompted her to use reactive coping mechanisms. Dealing with this assault by "taking drugs" and "not … taking control of [her] life" indicate that she avoided addressing these problems. Wanting to take a more constructive approach to coping on this occasion, Hannah speaks of focusing on her sense of self-esteem as both the cause of her previous tendency to avoid her problems and the route to a more reflective form of coping.

A second example involves Donna, who is unsure how, given the pressures she is under, she will cope knowing she does have HD:

**CG2:** So, you've got a lot going on at the moment with focusing on other people, it sounds like. How do you think that will affect your ability to cope with a bad news result if we have to give you?

**Donna:** Um, I'm not sure … I'm hoping it's gonna be okay. Um, but then I was thinking the other day, my dad's got to 88 … he's got that far in life without having [Omitting reflections on patient's father's illness]

**Donna:** So, I sort of think to myself, "well if I can get to his age …

**CG2:** Mm, mm.

**Donna:** … that'll be great", if you know what I mean [door slam]. "If I can get to his age, without any problems that would be great". (laughs). (Donna, pre-test clinic)

Here, the counselor points to pressures and encourages Donna to consider how she will cope if she does have a positive HD diagnosis. Donna responds that she is hoping she does not have the condition and then describes her observations of her father as a man in his eighties. Donna is not suggesting she has shown resilience in the past and expects to be equally resilient in the future. Instead, she suggests that she expects she would follow a similar path to her father and would find resources to cope.

In contrast to many of the other patients, Richard provides an example of one who suggests he may not show resilience in his response to a bad news result:

**Richard:** Erm, I think I'm going to need help with it to be honest with you, yeah. Yes. I think I'll end up probably drinking a lot to, er, to forget about it then, … but I'm not sure how I would [pull himself together] in fact, just assume that it will fade and just get my stuff, and just get my, get my shit together, you know… (Richard, pre-test clinic)

Richard has described a potentially problematic alcohol dependency. Asked how he expects to cope with a positive test result,

Richard asserts he is likely to drink "to forget about it". Richard thinks the unhelpful qualities of this information will, over time, 'fade', allowing him to reassert his self-control. During the rest of the consultation, the counselors move to explore support for Richard. The point here is that Richard exhibited characteristics that meant a resilient response would require work.

### 3.4 | Category 4: Support systems

A fourth topic prominent in these clinics examines support available to patients. Like category 1, the range of responses in this category reflected the variability of the patients' lives. In addressing this category, counselors frequently requested information on where the patient would find 'support' if they found themselves 'struggling' with a result or going through a 'bad patch'. For instance:

**CG3:** You know and if, so if we're doing the test and we're giving you a result that is bad and we're saying it's there, a lot of people will go through quite a bad patch afterwards.
**Jonathan:** Yeah.
**CG3:** You know, often for quite a few months, for quite a… (Jonathan, pre-clinic)

Here, the counselor constructs the situation as broadly normal. This invites the patient to discuss how he might find support while vulnerable. In addition, counselors would ask for details of individuals who were aware of the patient's situation:

**CG2:** I was wondering who, obviously your parents know you're coming through this, who else is aware that you're not just vaguely interested in testing but you're coming today and have a, a trajectory to get a result fairly soon? (Hannah, pre-test clinic)

In what follows, we explore the two main systems of support identified by patients: family and friends.

#### 3.4.1 | Family

Exploring support, counselors typically requested information on the patient's networks: specifically, the sources of support in case of bad news. Some patients cited their partner as an important source of support ("I've got quite a good family thankfully and Sarah's [his partner] very, very good" (Jonathan, pre-clinic)).

Other patients felt they had access to support from across their family network:

**Rebecca:** I got like my, my cousin found out about two years ago as well and she, she said that, I've got, we've got, I've got a big family, I've got amazing support there anyway. We've always had that, so that's one thing that I'm grateful for. (Rebecca, pre-test clinic)

Some patients' immediate family were dealing with challenges of their own. For instance, Peter's partner struggled with depression. Jennifer had little support from her own family but did have support from her partner and the option to access support from his family. But this created the challenge of needing to repeatedly explain the condition:

**Jennifer:** Yeah. I don't know; I think … I don't know, we haven't got a great support network anyway, would you say though [indicating her partner]?
**Harry:** Yeah, there's support there, haven't you, more my family would support you wouldn't they?
**Jennifer:** Yeah, but I suppose it would be for them like because it's a bit strange. Because like my side of the family would know a lot more about it, … We're going to have to always explain to your family about it and have them conversations with them then, isn't it then so. (Jennifer, pre-test clinic)

Absence of knowledge of the condition within a family meant having to repeatedly inform and educate. For a different patient, Kate, her family presented further complications. Kate was under 18 years of age at her first pre-clinic appointment. She was the youngest child of an affected man, had minimal contact with her siblings, and was living with her mother's sister. So, while Kate had contact with her family, her ties appeared weak. Kate attended the pre-clinic alone, while the protocol for HD testing includes the recommendation that patients receive support during the counseling process:

**GC2:** Um so you've not told anyone in the family that you're here, have you discussed anything with friends or anyone else around you, just yourself okay?
**Kate:** No (chuckling).
[Counselor requests information about friendship support]
**GC2:** Uh huh. Um, okay the reason I ask about people around um is that for anybody that's going through this process
**Kate:** Yeah I know.
**GC2:** We feel quite strongly to have um, a support person with them.
**Kate:** Yeah, I know.
**GC2:** Um whether that's a relative or a friend or um, you know, somebody else who is able to support you through that process, [introduces idea of receiving support from the Huntington's Disease Association] (Kate: pre-clinic)

In this situation, the counselor explores family and friendship networks before creating the groundwork for the use of a support group to help Kate through the counseling process. The counselor achieves this by adding enquiries, then explaining the reason for enquiries, before offering a solution. The point here though is that support is not simply something counselors check in conversation but is also constructed and acted upon.

To summarize, many patients felt able to access support within their families. However, for others, family members were not suitable sources of support for various reasons.

### 3.4.2 | Friends

Many patients cited their friends as an important, if not their primary, source of support. The following patient primarily relied on friends and brought two different friends to observe clinics:

**CG2:** And what sort of network around you have you at the moment in terms of friends? [Two turns omitted as patient describes wider friendship network]

**Susan:** I've told a select few people what's going on, and we've had chats about it. Because I was going to say if there are any questions you [Susan indicates her friend in attendance] wanted to ask … if there's anything about the disease you wanted to know. (Susan, pre-test clinic)

Accessing friendship networks involved revealing health information, not only for the patient, but also for their affected parent. For some patients, the reluctance of their affected parent to share this health information prevented them from accessing their friends, particularly where these networks overlapped:

**GC1:** Because have you told any friends or anyone about the family history?

**Jennifer:** Nothing at all. No I think, you know any of us … but dad hasn't said anything to anybody since his diagnosis either then. I think he's still coming to terms with a lot of it then really. So erm I think you know … I think if he didn't want me to say anything because obviously he's not at the point where he wants to tell anybody yet either then, you know.

[…] (Jennifer, pre-test clinic)

Patients were not always receptive to the patient's predicament:

**Hannah:** […] Um I have told other friends, but the one, closest friend, Claire, I just feel like she just didn't really understand […] because it's like "Oh well it hasn't affected you and you'll probably be fine and it's in the future" I just didn't really find those conversations very satisfying and so I stopped.

[…] (Hannah, pre-test clinic)

In summary, friends were clearly important in many cases, but access to friendship networks was sometimes restricted and friends themselves may not absorb this information.

## 4 | DISCUSSION

This ethnographic study shows how talk in predictive genetics clinics involves a plethora of patient alignments to topics raised by counselors. Nevertheless, patients responded constructively to these topics. This is clearly illustrated in the first content category which was on *understanding patient connections with HD*. Here, patients aligned with the topic of their knowledge of HD and the predictive clinic process by discussing their connection with HD. Reflecting on complex personal histories, Cox and McKellin (1999) described attitudes toward the materialization of risk in a family, noting a shift in attitudes to risk as risk moves from something diffuse and background to become proximate. This sense of family history as an important modality of assessment is highlighted in the data as patients situate their sense of risk through stories about family. What is also clear here is that patients articulate different ways in which apprehensions about the condition are present in their lives. This reflects Cooper et al.'s (2025) finding on the complex interaction of personal risk and family narrative on time of onset. These issues reappear in the clinic as patients' alignments with the topic of knowledge through personal connection cause counselors to have to deal with the patient's sense of risk, vulnerability and HD related anxieties.

In the second content category, *decision-making about testing*, counselors ask patients to explain their reasoning for seeking the test. Inside the predictive genetic clinic, patients gave responses to questions about their decision in their experience of themselves or in the needs of children. The data presented above indicate how patients align their responses in ways that cast their decision as largely settled. Sarangi et al. (2004) show how counselors challenge these decisions to initiate reflective frames. As the conversation proceeds, counselors work with patients to ensure that the patient wants this information and will be willing to live with the consequences regardless of the outcome (Doheny et al., 2026). The data here show how patients can choose from a variety of groundings to align with the decision-making topic, requiring counselors to respond with dexterity if they are gentle in probing these alignments.

Also notable is how patients justify accessing the predictive test by suggesting it will motivate them to live a more active life. Confirmed carriers of the gene change can feel a sense of regret and distress considering the meaning of the result and the limitation to their life, but also an increased sense of urgency about achieving milestones, and it can positively influence career choices and family planning (Duncan et al., 2008; Gong et al., 2016). Non-carriers can feel a sense of survivor's guilt. In either case, after testing, patients can feel a pressure to live an extraordinary life, which can prompt them to introduce significant life changes (Winnberg et al., 2018).

The third content category focused on *coping with test results*. Self-perceptions of patient capacity to cope help explain variations in decisions to take the predictive test (Decruyenaere et al., 1997; Taylor, 2005; Tibben, 2007). One benefit of having the predictive test is that counselors can make patients aware of available supports (Duncan et al., 2008) and so enhance the capacity to cope. Responses to testing are complex, with a potential for fluctuating distress in those with favorable and unfavorable results, somewhat greater in carriers than non-carriers, including feelings of hopelessness in carriers and survivor's guilt in non-carriers. In the medium to longer term (> 2 years after testing), the psychological impact does not depend on the test result so much

as the development of symptoms (Crozier et al., 2015). Of course, it is also possible that the act of seeking a predictive genetic test can be understood as a coping strategy, as it provides patients with a way of controlling the situation by providing certainty. The patients in this study presented themselves to counselors as resilient, emphasizing the strength of their coping capacities. The patients either already had the disposition to cope or saw coping as something that they would achieve through determination or based on their expectations.

Patients aligned with the topic of *support systems* by footing conversation in descriptions of support networks. This article extends current knowledge about their essential role in providing a safe space for discussing concerns about testing and its implications (see Dimond et al., 2022 for an overview). In contrast to much of this literature, here we specifically highlight the importance of friends, as well as family, within a support network. We also highlight the limitations in this role, where a lack of knowledge about HD and where a relative's diagnosis remains a secret can be experienced as a barrier to providing the support needed. Overall, it highlights the need for practitioners to be aware of the different support systems available to patients and the unique part each source of support plays in helping them make sense of their situation.

## 5 | LIMITATIONS

This paper is based on data collected before the COVID-19 pandemic. We acknowledge that the fact that this data is six to eight years old as a weakness and that some practices may have changed with more clinics conducted online. However, given the paucity of observational studies of this hard-to-research clinic, we believe that the present analysis still has value. The data analyzed here reflect practices adopted in a small number of clinics. The data were generated before recent reports of benefit from gene-based therapy for HD; further study of HD predictive genetic counseling will be important to see how such reports are incorporated into genetic counseling clinic discussions. At what point will such detailed genetic counseling be seen as irrelevant, with at-risk patients requesting testing to gain access to therapies?

## 6 | CONCLUSION

The predictive genetic test clinic is a space of pressure and complexity. Patients arrive at this clinic having decided to arrange a test, while genetic counselors and clinical geneticists retain control of patient access to these tests. Counseling in these clinics involves the use of open questioning formats unusual in medicine, which elicit complex responses from patients. This study reveals the degree of complexity in the talk taking place in these clinics. In doing so, this paper underlines the uniqueness of these clinics and the importance of properly supporting counselors in their efforts to manage such complexity.

### 6.1 | Clinical implications

Our findings suggest clinicians and counselors need to anticipate a great variety of responses to questioning in the predictive genetic clinic. Whereas most clinical encounters that involve clinicians asking questions of patients involve a narrowing of the range of potential responses, the predictive genetic counseling clinic opens the clinician to responses that can encompass the full breadth of the patients' lifeworld. These encounters can raise complex questions that call on counselors to deal with complex practical, social, ethical, and medical issues. One clinical implication is the need to defend the elongated counseling process. A second is the need to ensure counselors receive the training and support they require to manage such complex medical encounters.

### AUTHOR CONTRIBUTIONS

**Shane Doheny:** Conceptualization; formal analysis; funding acquisition; methodology; project administration; writing – original draft; writing – review and editing. **Rebecca Dimond:** Writing – review and editing. **Lisa Ballard:** Methodology; writing – review and editing. **Anneke Lucassen:** Writing – review and editing; funding acquisition; investigation. **Peter Turnpenny:** Funding acquisition; investigation. **Angus Clarke:** Conceptualization; funding acquisition; supervision; writing – review and editing.

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The authors have no conflict of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Cardiff University Research Data Repository at https://doi.org/10.17035/cardiff.31109563.

### ETHICS STATEMENT

All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Wales Research Ethics Committee 1 (REC reference 18/WA/0127).

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### CONSENT

All participants provided informed consent, and their confidentiality was maintained by using pseudonyms chosen by the lead author and storing data in password-protected files accessible only to the research team.

## ORCID

*Shane Doheny* https://orcid.org/0000-0003-0529-7301
*Rebecca Dimond* https://orcid.org/0000-0003-1974-7289
*Lisa Ballard* https://orcid.org/0000-0003-1017-4322
*Anneke Lucassen* https://orcid.org/0000-0003-3324-4338
*Peter Turnpenny* https://orcid.org/0000-0002-5947-0897
*Angus Clarke* https://orcid.org/0000-0002-1200-9286


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