

Trans Health Research at a Gender Identity Clinic

Transcript of an oral presentation for the Mini-Symposium on
Ethical Considerations in Transgender Health Research Practice

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Chair:

Now I have the great pleasure to introduce somebody in three dimensions: we have Dr Ruth Pearce, who will be presenting with her co-author Michael Toze, about trans health research at a gender identity clinic.

Ruth Pearce:

Hello, so I'm Ruth Pearce, I'm a sociologist based at the University of Leeds. I'm presenting this talk in collaboration with my [absent] colleague Michael Toze, who is a researcher based at the University of Lincoln, also a sociologist.

In this talk, we're arguing that both ethical and methodological issues can arise when research data on trans populations is derived from clinical assessments. I should not that we're not clinicians, we're social researchers specialising in trans health, so what we're offering here is an external perspective on issues we've identified in existing research. We're using a case study of research undertaken at a Gender Identity Clinic in the UK, and occasionally will use the abbreviation "GIC", which in this case refers to "Gender Identity Clinic", and not "Gender Incongruence in Childhood". We're going to focus specifically on an example of published research on video gaming among trans populations.

So there's three primary arguments that run through this presentation.

1. Firstly, we're arguing that care must be taken in obtaining informed consent, particularly if there's a possibility of potential coercion, unintentional or otherwise.
2. There are methodological issues that arise as patients may attempt to guess preferred responses to questions in clinical research.
3. Finally, we encourage clinical researchers to recognise this as a very sensitive area: to understand that there is a troubled history of trans health research that may lead to a lack of trust, to be transparent in their aims and intentions, and to take care with language in designing research.

I've got some content notes on this presentation. We are going to be talking about patient experiences of self-harm and dysphoria, and what patients may regard as coercion. I've also given out handouts, there should be two or three per table, and this is the actual research questionnaire which we're looking at. This handout includes – as well as self-harm and dysphoria – questionnaires and questions about eating disorders, bullying, suicide and mental health.

Before I move onto the content, I should also state that I wish to apologise on behalf of the research team that this presentation is only in English and not Spanish. I've talked about this with my colleagues and we feel this is unacceptable given the amount of money available to WPATH, but we also feel that we could have prepared better, for instance by preparing bilingual slides. So this is something we'll consider in the future and we encourage you to take away too.

I first came across the issues we're going to talk about today when reading a report published by the UK Parliament's Women and Equalities Committee. They had conducted a Transgender Inquiry, and this is a quote from the report.

“Assessment procedures in clinics are not transparent and not consistent. Patients are aware of this through informal discussion. For instance, Nottingham GIC recently sent patients a new form asking them what video games they play. It is not clear why this is relevant to their assessment for care, and if it is relevant, why other clinics are not asking”.

This was based on some feedback given to the Women and Equalities Committee by Michael Toze, which is how I ended up collaborating with him on this project. And Toze, following this, undertook a Freedom of Information request in March 2016, to find out more about the patient information form. In doing so, we found out that the form was indeed about more than assessment. And why was Nottingham asking specifically? Nottingham is a pioneer in trans clinical research in the UK, where very few clinics are doing this work.

So, here's a couple of pages from the questionnaire, and you've also got copies you can look at yourself. This presentation is focusing particularly on the copy you have with you, which is a 27-page version of the form, however this was available and sent to patients over a roughly two-year period. There have been other versions of this form, as there are periodic changes made, for instance the introduction of new questionnaires as part of the battery, or the removal of questionnaires.

The questionnaire battery is sent to all new patients at the clinic, some time after their referral is made, and they are required to fill it out. As we found out through our Freedom of Information request and through our surveying of clinical literatures, it's used for assessment and for research.

So, Toze's informal observations are of patient confusion, and he talked further in his submission to the Women and Equality Inquiry about patients sitting around and trying to interpret what the questions meant, what they were about, and what answers were most likely to guarantee access to care upon their eventual arrival at the clinic. This is echoed in Ben Vincent's 2016 PhD thesis, in which a participant – a Jamie, whose quote I've got here – reports responding to an earlier version of the form. And Jamie says:

“So this [clinic] form. It's 19 pages long”.

I note here that it's an earlier version of the form, than the one we saw through the Freedom of Information request.

“Includes a section where you label almost every body part with a rating of how you feel about it, including ‘beard’ (is that ‘not satisfied’, ‘I want one’, or [not applicable]?) and ears (literally this has made me feel dysphoric about my ears, [for fuck's sake]). A section on anxiety/depression, where you mark how often in the past week you've had a variety of anxious thoughts, which of course triggers all of said anxious thoughts. A section that seems designed to see if you have an eating disorder, with three slightly differently worded questions asking whether you think your buttocks are too big (if I say yes, will they think I just have an eating disorder and am not really trans?)”

Bearing in mind again, this is a questionnaire which is [reportedly] used for assessment as well as for research.

Jamie continues:

“And a section that maybe designed to test if you're autistic, I dunno – you have to rate the extent to which you agree with statements like “I would rather go to a library than a party” (is it a nice library? Who will be at the party? Did I get enough sleep the night before?) and most bizarrely “I find it easy to remember long strings of numbers, such as car number plates”. That one caused a lot of anxiety at [a trans group] because it sounds gender related inadvertently or not: ‘masculine’ brains are stereotypically supposed to remember numbers better”.

Jamie summarises this in a way that sums up a lot of the problems:

“That's the problem with asking seemingly irrelevant questions in a context where there's so little trust between practitioners and patients: we start wondering why the questions are being asked, how they're relevant to the issue at hand, and what the “right answer” [is] that will result in us getting access to treatment.”

Here's one of the surveys that Jamie was referring to; again, you can see it in the handout, because this was continued from the 19-page form into the 27-page version. And here's the example of the assessment and research questionnaire where they're asked to rate body parts.

HBDS

How satisfied are you at this moment with the following body characteristics?
Please give each body part one of the following scores:
1 = Very satisfied, 2 = Satisfied, 3 = Average, 4 = Dissatisfied, 5 = Very dissatisfied, NA = Not Applicable

If your birth gender was MALE, please complete this questionnaire.

	Agree Completely	Agree Somewhat	Neutral	Disagree Somewhat	Disagree Completely
1. My life would be meaningless if I would have to live as a boy/man	5	4	3	2	1
2. Every time someone treats me like a boy/man it hurts	5	4	3	2	1
3. I feel unhappy if someone calls me a boy/man	5	4	3	2	1
4. I feel unhappy because I have a male body	5	4	3	2	1
5. The idea that I will always be a boy/man gives me a sinking feeling	5	4	3	2	1
6. I hate myself because I am a boy/man	5	4	3	2	1
7. I feel uncomfortable behaving like a boy/man, always and everywhere	5	4	3	2	1
8. Only as a girl/woman my life would be worth living	5	4	3	2	1
9. I dislike urinating in a standing position	5	4	3	2	1
10. I am dissatisfied with my beard growth because it makes me look like a boy/man	5	4	3	2	1
11. I dislike having erections	5	4	3	2	1
12. It would be better not to live than to live as a boy/man	5	4	3	2	1

Slide 7: Hamburg Body Drawing Scale (HBDS)

There's also several questions about self-harm asked in addition to questions about anxiety and depression. What's really worth noting at this junction is that this form is often sent out months before a first appointment at a clinic, so there is no associated therapeutic support for patients who are filling in this form. In my own research, participants at the Nottingham gender clinic described feeling that they had to demonstrate that they were appropriately trans in clinical appointments, managing their stories accordingly. So where patients are sharing stories in advance of appointments you can see how this might affect clinical research also.

SELF-INJURY QUESTIONNAIRE
Treatment Related (SIQ-TR)

Self-harming behaviour refers to various kinds of deliberate self-inflicted damage to one's own body (e.g., cutting oneself, burning oneself) but without suicidal intent. In this questionnaire, you will be asked whether you have engaged in any cutting or any other behaviour and if so, to state how often and to which parts of the body.

Section A: How often?
(please circle the appropriate number)

When did you last...	A week ago	A month ago	Several months ago	More than a year ago	Never
Cut yourself	4	3	2	1	0
Hurt yourself such as Bum, Scratch, Bruise, Bite...	4	3	2	1	0

*Please specify how you hurt yourself.....

Section B: Which parts of the body?
(please tick the appropriate box)

Which part of your body did you hurt when you...	Head, neck	Arms, hands, fingers, nails	Torso, belly, buttocks	Legs, feet, toes	Breasts, genitals
Cut					
Hurt yourself such as Bum, Scratch, Bruise, Bite...					

Thank you for taking the time to complete these questionnaires

Signature:

Date: ___/___/___ (DD/MM/YY)

THE QUESTIONNAIRES YOU HAVE JUST COMPLETED ARE AN IMPORTANT PART OF YOUR ASSESSMENT

BUT

WE WOULD LIKE TO ASK YOUR PERMISSION TO USE THE INFORMATION FROM THOSE QUESTIONNAIRES ANONIMOUSLY ALSO FOR A RESEARCH PROJECT.

THIS RESEARCH AIMS TO INVESTIGATE HOW THE TREATMENT FOR GENDER DYSPHORIA HELPS (OR NOT) PEOPLE.

Please read the information sheet at the end of this package. If you are happy for us to use the information from the questionnaires anonymously for this project, please sign the consent form and send it back to us with all the questionnaires

Thank you

Slide 8: Self-Injury Questionnaire and research permission request

You can also see on the right-hand side of this slide a page which is at the end of the questionnaire. So you've got the questionnaire [battery], and you have all of the questionnaires, and at the end there is this page, which states explicitly that the questions form "*an important part of your assessment*". However there is no information here on how they are being used or why they are being asked. Some of that information follows in an incomplete manner in a participant information sheet which is included at the end of the document, after the consent form.

So, to dig deeper into the question of how and why these questions were being asked, I focus now on the specific example of the video gaming questionnaire, which is one aspect of this, which you may recall was also mentioned by Toze in the Women and Equalities Committee report. Toze is not the author of the report, I should add, he is a contributor who they cited.

Video Gaming Questionnaire

This questionnaire asks about both **previous AND current** gaming activity.

1. Do you **CURRENTLY** play any type of gaming activity? Yes No

2. Have you, **IN THE PAST**, played any type of gaming activity? Yes No

IF YES, CONTINUE

3. What is/was your preferred game / type of game?

4. What is/was your preferred way of playing?

- Computer / laptop
- Games console
- Smart phone / tablet
- Other (please specify)

5. How many times (on average) do you / did you play **each day**?

6. How many times (on average) do you / did you play **per week**?

7. Do you / did you play every day of the week? Yes No

8. How long (approx.) does / did each gaming session last?

9. At what time of day / night do you / did you prefer to play? Tick all that apply

- Mornings
- Afternoon
- Evenings
- During the night

10. If you **previously gamed but now do not**, why did you stop gaming?

The following questions will ask you about your gaming activity **during the past year** (i.e., last 12 months). By gaming activity we understand any gaming-related activity that has been played either from a computer/laptop or from a gaming console or any other kind of device (e.g., mobile phone, tablet, etc.) both online and/or offline.

	N	R	S	O	V
	e	a	o	f	t
	v	r	m	e	r
	e	e	e	n	y
	r	l	t	O	f
	y	i	m	t	e
		e	s	e	n
1. Do you feel preoccupied with your gaming behaviour? (Some examples: Do you think about previous gaming activity or anticipate the next gaming session? Do you think gaming has become the dominant activity in your daily life?)	1	2	3	4	5
2. Do you feel more irritability, anxiety, or even sadness when you try to either reduce or stop your gaming activity?	0	1	2	3	4
3. Do you feel the need to spend increasing amount of time engaged in gaming in order to achieve satisfaction or pleasure?	0	1	2	3	4
4. Do you systematically fail when trying to control or cease your gaming activity?	0	1	2	3	4
5. Have you lost interests in previous hobbies and other entertainment activities as a result of your engagement with the game?	0	1	2	3	4
6. Have you continued your gaming activity despite knowing it was causing problems between you and other people?	0	1	2	3	4
7. Have you deceived any of your family members, therapists or others because the amount of your gaming activity?	0	1	2	3	4
8. Do you play in order to temporarily escape or relieve a negative mood (e.g., helplessness, guilt, anxiety)?	0	1	2	3	4
9. Have you jeopardised or lost an important relationship, job or an educational or career opportunity because of your gaming activity?	0	1	2	3	4

Slide 9: Video Gaming Questionnaire

We looked at the reported research on this topic from the Nottingham Centre for Transgender Health, which included conference presentations such as a poster at the WPATH 2016 Symposium in Amsterdam, as well as peer-reviewed publications.

The first peer-reviewed publication from the clinic on this topic was entitled: Video Gaming and Gender Dysphoria: Some Case Study Evidence, [published] in 2016. This paper used clinical [case] studies rather than quantitative data taken from the new patient form, but as I will show in a moment, it is relevant. They used four case studies derived from clinical notes, and the findings are entirely speculative. The case studies were selected because: *“they were in no way atypical”* and [they] *“demonstrate the different ways video gaming may help people with gender dysphoria”*.

There is no indication in the article that informed consent was obtained from patients; in fact there are no comments on informed consent at all. There is no indication that patients knew they were taking part in research about video gaming. *“The original case notes taken by therapists were not specifically concerned with gaming but were rather a general case assessment. Consequently, only one of the individuals specifically described their motives and relationship with online gaming and/or their avatars”*.

So let’s look in a bit more detail at how consent might have been obtained for the research reported in this article. Towards the end of the questionnaire is an informed consent sheet, but again it’s very vague and open-ended in terms of wording. The relevant tick box is: *“I understand that relevant sections of my medical notes and*

data collected during the study may be used by individuals from the Nottingham Centre for Gender Dysphoria”, the old name of the clinic, “where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records”.

Clinical correlates and outcomes of treatment for trans people
INFORMED CONSENT
(to be completed after Participant Information Sheet has been read)

Please read the following carefully. Please initial each box and sign at the bottom to show you have read and understood what is expected of you.

I hereby give my consent to participate in the questionnaire study clinical correlates and outcomes of treatment at the Nottingham Centre for Gender Dysphoria. I confirm that:

The purpose and details of the study have been explained to me in the attached information sheet. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the regional Ethics Committee.

I have read and understood the Patient Information Sheet

I have been informed that my participation in the study will involve completing a set of questionnaires and that my responses will be kept anonymous and confidential.

I understand that relevant sections of my medical notes and data collected during this study may be looked at by individuals from the Nottingham Centre for Gender Dysphoria, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I understand that I am under no obligation to take part in the study; I have the right to withdraw at any stage for any reason; and that I will not be required to explain my reasons for withdrawing.

Your name _____

Your Signature _____

Date _____

Slide 11: Informed Consent form

The consent form therefore provides permission for clinical notes [to be used in research], in theory. There's a patient information form that follows the consent form which states: "If you wish to receive a summary of findings upon completion of the project, you may request this from a researcher via email". However, there is no way for participants to know whether their own case notes have been used, as these were chosen by clinicians picking cases from a large collection. There is also no indication whether patient permission for that particular study was asked beyond this initial consent form. I'm going to return to this topic shortly.

A second peer-reviewed paper followed in 2017. This one is entitled: Video gaming and gaming addiction in transgender people: An exploratory study. This article does clearly use quantitative data collected in the patient survey. It also cites the Griffiths et al 2016 article, making unsupported claims about what the first paper showed. I've got an example of this highlighted in yellow here. "Case studies exploring gaming activity in the transgender population have found that the use of video gaming among this population is not unusual". This claim is being made about an entire population, citing an article which doesn't have a particularly strong literature review. The article itself cited only four case studies, where no questions specifically about video gaming were asked of patients. In the 2016 paper, Griffiths and colleagues

explicitly claim that the case studies are “*unlikely to be representative of those with gender dysphoria more generally*”. So there’s one claim in the 2016 paper, and a different claim that’s being made about the 2016 paper in the 2017 paper. This is an issue with empirical claims that are being made across a research programme.

In the Arcelus et al 2017 article we can also see some ethical issues arising. Most pertinent is that the article provides a misleading description of the consent process. “*Prior to the clinical assessment at the service, patients were invited to participate in the study. If they agreed, they completed a series of self-reporting psychometric measures [...] and signed a consent form*”. This is inaccurate. Patients were sent a form, they were required to fill in the questions, and [were] then asked if they wanted to participate in the study. This is an important distinction, because there’s a question here of how patients move through the research journey. If patients sent the questionnaire work through it in order, they will fill out all the information first, then read that it is all important for their clinical assessment, including the video game questionnaire. We can see on this page, prior to the consent form which I showed you earlier, that “*the questionnaires you have just completed are an important part of your assessment*”. This implies that if patients withdraw from the study, all questions, including those about video gaming, are still relevant to their accessing care at the clinic.

SELF-INJURY QUESTIONNAIRE
Treatment Related (SIQ-TR)

Self-injuring behaviour refers to various kinds of deliberate self-inflicted damage to one's own body (e.g. cutting oneself, burning oneself) but without suicidal intent. In this questionnaire, you will be asked whether you have engaged in any cutting or any other behaviour and if so, to state how often and to which parts of the body.

Section A: How often?
(please circle the appropriate number)

When did you last...	A week ago	A month ago	Several months ago	More than a year ago	Never
Cut yourself	4	3	2	1	0
Hurt yourself such as Burn, Scratch, Bruise, Bite...	4	3	2	1	0

*Please specify how you hurt yourself.....

Section B: Which parts of the body?
(please tick the appropriate box)

Which part of your body did you hurt when you...	Head, neck	Arms, hands, fingers, nails	Torso, belly, buttocks	Legs, feet, toes	Breasts, genitals
Cut					
Hurt yourself such as Burn, Scratch, Bruise, Bite...					

Thank you for taking the time to complete these questionnaires

Signature:

Date: ____/____/____ (DD/MM/YY)

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Thank you

Slide 14: Research permission request, with relevance to assessment highlighted

Now it’s worth pointing out also at this point that there’s been numerous studies over the years, as well as theoretical papers, which draw attention to the culture that

exists between trans healthcare providers and the trans population. Consequently, many trans people feel unable *not* to consent, because they might fear this will negatively affect their chances of a quick and positive experience at the gender clinic. This is evidenced in the data quoted earlier, from Ben Vincent's PhD thesis, as well as in my own PhD work and my book *Understanding Trans Health*. An element of coercion would explain an unusually high response rate reported in the 2017 paper: 95.3%. Anyone who's done quantitative research will know how unusual it is to ask people if they want to participate in research and have such a high response rate.

We wondered how this compared to the ethical procedure the researchers were required to undertake for the UK's National Health Service, prior to commencing the research. In his Freedom of Information request, Toze asked about the intended purpose of the questionnaires. Were they sent to patients for the purpose of individual clinical assessment, for research, or for both? He was informed by a representative of the healthcare foundation trust that the questionnaires were intended for both assessment and research. However, this does not necessarily align with the stated aim of the research in the published ethics application made to an NHS research authority prior to the commencement of the research.

Trans Health Research at the Gender Identity Clinic

FOI to Nottingham GIC, Question B

"for each questionnaire, is it sent to patients for the purposes of individual clinical assessment, or for the purposes of research, or both?"

Response:

"The questionnaire for new patients is for the purpose of both individual clinical assessment and for research"

– Vicky Lee, Assistant Company Secretary, Nottinghamshire Healthcare, NHS Foundation Trust (21/3/2016)

Ethics application to NHS health research authority (142544):

"this study will investigate treatment outcome (sic) of gender dysphoria [...] the main aim of the study is to identify which factors are significantly associated with treatment outcome among a sample of patients attending a national gender identity clinic for gender dysphoria".

Slide 15: Purpose of study (Freedom of Information request and ethics application)

In the ethics application, the researchers claim that they would be studying treatment outcomes, as you can see here: "*the main aim of the study is to identify which factors are significantly associated with treatment outcome*". Nothing about the research produced about gaming using the questionnaires is relevant to post-

transition patients, at least not in a way that's stated in the study. Is it anything to do with treatment outcomes? Well, there's also a contradiction in that sense with what the patients are told in the participant information sheet which follows from the ethics form. This states [that] *"this study will help researchers and clinicians better understand the role hormone treatment plays in the overall treatment pathway for people with gender dysphoria"*. There is no mention explicitly of how video gaming addiction might necessarily connect to hormone treatment in the paper. The publications focus primarily on the relationship between video gaming and possible dysphoria, as well as video gaming addiction. Therefore what is being published does not seem to clearly align with either the ethics application or the information sheet for prospective patients.

Trans Health Research at the Gender Identity Clinic

What is the purpose of this study?

The purpose of this research study is to identify what influence treatment has on the overall quality of life, mental health, self-esteem, body image, social support and interpersonal function of people with gender dysphoria. People who have gender dysphoria face a number of difficulties unique to their gender identity or gender presentation. These difficulties can be alleviated through treatment, including hormone therapy and gender surgery. This study will help researchers and clinicians better understand the role hormone treatment plays in the overall treatment pathway of people with gender dysphoria.

Slide 16: Purpose of study (participant information sheet)

So, to summarise: the gender clinic sent out a number of questionnaire packs, including a 19-page version mentioned in Vincent's PhD, and a 27-page version that you have in front of you. The consent form and information sheet were at the end of the questionnaire, asking to use some of assessment questions and clinical notes in research as well. However, in applying for NHS ethics approval, the researchers claim they would look at treatment outcomes only. Various papers have been produced from this data, including a presentation at WPATH 2016 and two peer-reviewed publications. The wording of the research summary submitted [for] ethical permission implies that research questions are included in a separate pack to the assessment questions but we can see that in actual fact they're all in one. And the latter paper, in 2017, uses the former to make ungrounded assertions.

So there are some important methodological and ethical issues created as a consequence.

- There are some clear inconsistencies in how the questionnaires relate to assessment. Information provided to participants claim that they will be used for assessment but this is not at all clear in the ethics application for the research.
- The only available research contacts are the senior Nottingham clinicians: prospective patients who fear alienation, which I've observed extensively in my own research, would not necessarily want to jeopardise their access to treatment by challenging this, or for that matter refusing to participate.
- There is no indication the questionnaires themselves are voluntary: even if patients don't consent to research, it's strongly implied they have to fill in all the forms, without any kind of mental health support.
- Informed consent for multiple research projects is sought with one ethics form.
- This ethics form does not clearly describe some of the research conducted, such as that into video gaming, or describe why it is being undertaken.
- There are no mechanisms for information participants about findings: again, they are expected to contact researchers who are senior clinicians who might be responsible for their care.
- There are poor referencing practices that overstate the claims of previous papers: I gave one example, there are several others.
- There's a complete lack of reflexivity: there's no reflection on how the clinical context might affect the power relation between patient and practitioner and hence affect the answers given to the questions.

The most important methodological issue, therefore, is that it is difficult to say that researchers are capable of making any real empirical claims from their data given the above issues. This is not just relevant to the video gaming research, but [is] also relevant to many other papers published from the research programme by the authors, including in the International Journal of Transgenderism. Patients waiting to present themselves as meeting assessment criteria are also likely to conform to normative gender roles through their answers, to fulfil perceived expectations. The charged context of this research potentially invalidates the research findings.

From an ethical point of view, the most important issue is that participants are exhibiting documented distress as a result of the questions asked.

So I'm going to finish this paper by contextualising this in terms of the present. As far as I'm aware, the research is still ongoing, however a new version of the questionnaire was introduced either in late 2017 or early 2018, when I got a copy. In the new version, the participant information form for the more recent battery of questionnaires has been updated, and this is really good news. It now explicitly clarifies that patients are [not] required to sign the consent form, and this will not

affect the treatment they receive. This is an important takeaway lesson: if you're doing clinical research and you want to avoid some of these issues, this is a way forward. This should also have an important impact on the value of the empirical claims going forward. However, existing publications produced by the clinic are still highly questionable.

Moreover, patients continue to report informal pressure to participate in research. I've been approached by a number of such individuals over the past year who want to talk about their experiences, and I've started conducting some qualitative interviews. I interviewed one of these individuals just two weeks ago, and here is what they had to say.

So this person – I'm using the pseudonym Avery – provided an explanation of their experiences which I think both summarises some of the issues [discussed] in this paper, and also I hope will be useful to people in considering how to conduct their own clinical research in a more ethical manner. Avery states:

"I asked specifically that my records not be used for academic research. I don't feel confident that this has happened, and I'm not sure that the clinician really understood that research ethics were being violated, as I hadn't signed any consent form. The clinician did express regret that [they] then wouldn't be able to use my notes to prove the success of [the procedure] which made me feel slightly guilty about causing a fuss."

Elsewhere in the interview Avery describes their experiences at Nottingham's Centre for Transgender Health as *"disrespectful, infantilising"*, and with a stark power dynamic.

I'm going to close this talk with a quote from them which again I feel summarises a lot of these issues.

"The GIC have so many keen and willing research partners, if only they'd stop seeing us as objects of research and treating us with respect and start thinking of us as participants in a joint-venture. The GIC has a totally outdated, Victorian model of research practice. At best it's laughable - do they not realise that when we write our 'narratives' we are writing in order to get treatment and pass through their gatekeeping? All that analysis of those narratives can tell a researcher is how trans people represent themselves to the GIC in order to get treatment, it's not going to reveal anything about trans people's subjective experiences. At worst, their research practices is a complete violation of our agency and personhood as trans people."

References

- Arcelus, J., Bouman, W.P., Jones, B.A., Richards, C., Jimenez-Murcia, S., & Griffiths, M.D. (2017). [Video gaming and gaming addiction in transgender people: An exploratory study](#). *Journal of behavioral addictions*, 6(1), 21-29.
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- Vincent, B.W. (2016) [Non-Binary Gender Identity Negotiations: Interactions with Queer Communities and Medical Practice](#). PhD thesis, University of Leeds.

Further reading

- Adams, N., Pearce, R., Veale, J., Radix, A., Castro, D., Sarkar, A., & Thom, K. C. (2017). [Guidance and ethical considerations for undertaking transgender health research and institutional review boards adjudicating this research](#). *Transgender health*, 2(1), 165-175.
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- Stone, S. (2006). [The Empire Strikes Back: A Posttranssexual Manifesto](#). In Stryker, S. & Whittle, S. *The Transgender Studies Reader*. London: Routledge.
- Vincent, B.W. (2018). [Studying trans: recommendations for ethical recruitment and collaboration with transgender participants in academic research](#). *Psychology & Sexuality*, 9(2), 102-116.

Presentation slides

<https://transactivist.files.wordpress.com/2018/12/Presentation-Ethical-Considerations-in-Transgender-Health-Research-Practice-3.pptx>

Audio recording of talk

<https://soundcloud.com/ruthpearce/trans-health-research-at-a-gender-identity-clinic>

Freedom of Information request: Gender Identity Questionnaires

https://www.whatdotheyknow.com/request/gender_identity_clinic_questionn?unfold=1