



# Analysis of the NHS England Adult Gender Services Review Survey

Today NHS England have published a survey for people that have used NHS gender clinics in the past 5 years, current and former NHS gender clinic staff and (bizarrely) the family and friends that have used NHS gender clinics in the past 5 years. TransActual, and other trans and/or LGBTQ+ organisations, were asked to feed back on a draft of the survey.

This is what we responded and what happened as a result:

<b>Issue identified</b>	<b>Our feedback</b>	<b>What happened?</b>
The survey asks for a postcode, but does not make clear it is optional.	Emphasise that if they do provide this information, their responses are confidential and will not be shared with the gender clinic in an unanonymised form	This recommendation was followed by NHSE.
Use of the term GDCs (Gender Dysphoria Clinics).	Not many people in the community refer to GDCs, you'll be better off referring to gender clinics.	The survey now refers to gender clinics rather than GDCs.
When asking about which gender clinic people had attended/worked at, it did not mention that The Tavistock and Portman NHS Foundation Trust: Gender Dysphoria Clinic for Adults	It would be worth specifying that this the clinic formerly known as Charing Cross.	The survey now clarifies that The Tavistock and Portman NHS Foundation Trust: Gender Dysphoria Clinic for Adults is formerly known as Charing Cross.
Question 'While you were waiting for your first appointment, how would you rate the following: level of contact and information you received from your clinic?' asked for ratings on contact with the clinic and info provided by the clinic.	We suggested that because some clinics offer support for people waiting on the list, it might be useful to add that as another line on the table.	This suggestion was not taken on board, but this omission does not cause us any major concern.
One of the rating questions for 'Thinking about the time between your appointments, to what extent do you agree with the	We pointed out that people with language difficulties might find this reference to waiting	This suggestion was taken on board and the wording was amended.

following statements:' said 'The waiting time was about right'	times confusing. It could be 'The time gap between appointments' instead	
The question 'And [do/did] you have a named healthcare professional responsible for your care at the clinic?' had proposed answer questions of: Yes, No, Don't Know	We asked if there could be an option for 'I had a named professional for part of my care'?	This suggestion was not taken on board, which may result in a missed opportunity. However, people may well include info that might have been missed in the free text box at the bottom of the screen.
For the question 'Thinking about the care you have received, to what extent do you agree or disagree with the following statements', one of the things people were going to be asked to rate was 'Healthcare professionals made appropriate assumptions about my treatment goals'.	We asked why healthcare professionals would ever be making assumptions about a person's treatment goals.	'Healthcare professionals made appropriate assumptions about my treatment goals' was removed from the section of the survey.
For the choices under the question 'Were you offered any of the following interventions?' hair removal was not listed as an option.	We suggested adding hair removal as an intervention that might have been offered.	Hair removal was not added as an option, which seems a bit strange. However, people will be able to tick 'Other' and then specify hair removal in the box.
Originally the question 'How do you rate the information you were given around the following' was going to ask about weight loss advice, stopping smoking, fertility and sexual health.	We were pleased that all four were included so didn't feed back.	Sexual health was removed from the list of options. This is disappointing. However, the current service specification doesn't require the clinics to offer sexual health advice.
The question 'Thinking about your interactions with your GP in relation to your gender care, how satisfied are you with the following :' asked for ratings on 'Staff understanding of your needs and requirements' and 'The overall service you receive'.	We suggested that, given the increase in GPs refusing to prescribe HRT, it would be useful to also ask for a rating on GP's willingness to prescribe and willingness to order blood tests.	This suggestion was not taken on board, which may result in a missed opportunity. However, people may well include their experiences of that in the free text box at the bottom of the screen.

<p>There is a section asking about experiences of surgical referral.</p>	<p>We suggested that it would be useful to ask people how long it took the clinic to send the referral letter to the surgeon.</p>	<p>This question has been included in the prompt questions for the free text box in this section.</p>
<p>The original version of the survey asked in one question about experience of both referral and discharge.</p>	<p>We said would be useful to split this in two. Into discharge and into referral - that will help make sure people answer about their experience of referral and experience of discharge, not one or the other.</p>	<p>This question was split into two as we suggested.</p>
<p>The question ‘Which of the following statements best describes your views following your discharge?’ originally had the options:  a. I no longer require support from NHS adult GDCs  b. I would like to get support from NHS adult GDCs but don’t know how to go about getting it  c. I require support, but I don’t want to use the NHS adult GDCs</p>	<p>We suggested that it would be useful to add ‘I might need support in the future’ - this is particularly important for people who have had phalloplasty with an erection device, as they break and need replacing.</p>	<p>The options were amended and are now:</p> <ul style="list-style-type: none"> <li>• I no longer require support from NHS adult gender clinics</li> <li>• I would like to get support from NHS adult gender clinics but don’t know how to go about getting it</li> <li>• I would like to get support but I have been refused</li> <li>• I would like to get support but I am on a waiting list</li> <li>• I require support, but I don’t want to use the NHS adult gender clinics</li> <li>• I might need support in the future</li> </ul>
<p>The options for the question ‘Thinking about your journey and the process you went through, which of the following best describes you?’ were   a. I intend to fully transition  b. I have decided not to fully transition  c. I have decided to detransition   a. I have fully transitioned  b. I intend to fully transition</p>	<p>We told the team to avoid phrasing like ‘Fully transitioned’ - it doesn't mean anything. We explained that everyone's transition is different and different people access different aspects of care. We also mentioned that some people pause transition and wouldn't consider that they're detransitioning and that others detransition temporarily with the intention to transition later. We did of course acknowledge that a minority of people detransition permanently.</p>	<p>The options for this question were amended to:</p> <p>Thinking about your journey and the process you have been through so far which of the following best describes you? Please tick all that apply</p> <ul style="list-style-type: none"> <li>• I intend to pursue medical transition via the use of Hormone treatment</li> <li>• I intend to pursue medical transition via Surgery</li> </ul>

<p>c. I have decided not to fully transition d. I have decided to detransition</p>		<ul style="list-style-type: none"> <li>• I have completed my medical transition via hormone treatment</li> <li>• I have completed my medical transition via surgery</li> <li>• I have pursued medical transition, but have decided not to pursue some of the treatments that I thought I wanted</li> <li>• I have decided to detransition permanently</li> <li>• I have decided to detransition but might retransition in future</li> </ul>
<p>There had been a question ‘How has the NHS adult GDC supported you following your decision to not fully transition or detransition?’</p>	<p>We responded that ‘fully transition’ isn’t the right wording and it would be better to say ‘How has the NHS adult gender clinic supported you since your transition goals changed or since you decided to pause transition or to detransition?’</p>	<p>NHSE followed our advice and amended the question.</p>
<p>There was a proposed question ‘Are there any elements of care or the process you went through that you regret?’</p>	<p>We fed back that this question is too vague and would not answer what they were clearly to find out – did people have any regrets around hormones and surgery?</p>	<p>The question has been amended to ‘Have you had any hormones, surgery or treatments that in retrospect you decided you didn't want to have / you now regret?’</p>
<p>The question ‘What stopped you from sharing your concern, complaints or suggested improvement?’ did not have an option relating to fear that someone complaining might lose access to care.</p>	<p>We suggested that NHSE should add the options:</p> <ul style="list-style-type: none"> <li>• Fear that it would stop them being able to access care and therefore not have access to medical transition</li> <li>• Fear that they would be treated worse as a result</li> </ul>	<p>The option ‘I thought this may stop me from accessing care.’ was added to the survey, in line with our suggestion. There is an ‘other’ box, which would allow space for people to say if they were worried they would receive worse treatment as a result of complaining.</p>
<p>For the question ‘Thinking about the concerns, complaints or suggested improvement you raised, to what extent do you agree or disagree with the following statements:’, there wasn’t an option to allow</p>	<p>We suggested that NHSE add the line ‘I experienced the same level or a better level of care after the complaint’ in order to identify if there were people that did not experience</p>	<p>NHSE followed our advice and added the line to the rating matrix.</p>

<p>NHSE to find out if someone's standard of care hadn't been negatively impacted by complaining.</p>	<p>detrimental treatment (and thus vice versa) if they complained.</p>	
<p>The team expressed an intention not to collect full demographic data.</p>	<p>Demographic data - please ask the full set of demographic questions. It is important that you're able to identify inequalities - not least because our data suggests that trans people do experience racist and ableist discrimination within gender services. To maximise survey completion, you could put them at the end and give participants an option to say they'd prefer not to answer the demographic questions.</p>	<p>Our advice was followed – demographic data was collected at the end of the survey and was optional.</p>
<p>NHS England told us they planned to survey friends and family members of people that have accessed NHS gender clinics in the last 5 years.</p>	<p>We are not sure why friends and family are being asked at all.</p> <p>However it would be useful to also ask them if their family member would agree with their responses and if they've spoken to them about them. Many trans people have unsupportive family members who I'm sure are not pleased that they've had access to medical transition.</p>	<p>NHS England chose to survey friends and family and have not offered a reason for this. They did not follow our advice to ask respondents whether their family member or friend would agree with the responses they have given.</p> <p>This means that, for responses from family members and former friends that wish their family member or former friend had not accessed medical transition, it will not be possible to know whether or not the person who had accessed the clinic themselves was happy at having accessed the care or not.</p>