



Effect of treatment delays to the psychological well being of transgender patients

Survey conducted by Transfigurations

<http://www.transfigurations.co.uk>

info@transfigurations.co.uk

This survey is online at:-

<http://eSurv.org?u=nhs-cuts>

	Name of GIC unit	How long have you been with GIC	How long have you been in RLE	Mental/Psychological well being after transition									Indication given for surgery	Have you been notified of any delays	Effect on mental/psychological after notification of any delay					Any other comments
				1	2	3	4	5	6	7	8	9			10	11	12	13	14	
1	Exeter	2 years	2 years	Yes	Yes			Yes		Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	No additional comments	
2	Charing X	1 year or less	3 years	Yes	Yes				Yes			No	Yes	Yes	Yes	Yes	Yes	Yes	No additional comments	
3	Nottingham	1 year or less	2 years	Yes	Yes							Yes	Yes						No additional comments	
4	Charing X	2 years	2 years	Yes	Yes							Yes	Yes	Yes	Yes	Yes	Yes	Yes	Recently it's really been getting me down. I am still a couple months away from my second surgical assessment but for the last few months I've been drinking a lot and doing a lot of drugs. Sometimes it gets to me worse than others. I've been speaking to a councilor but knowing how much this is holding me back really is so depressing.	
5	Charing X	4 years	4 years	Yes	Yes					Yes		Yes	Yes		Yes				I already have counselling once a fortnight which helps me cope to a certain extent.	
6	Charing X	2½ years	3 years	Yes	Yes			Yes	Yes	Yes		Yes	Yes		Yes	Yes	Yes	Yes	The fact they keep cancelling my appointments to the point i was told I should be having surgery around this time and I'm still waiting for a referral	
7	Exeter	2 years	3 years	Yes								No	Not applicable						No additional comments	
8	Charing X	3 years	5 years or more	Yes	Yes				Yes			Yes	No	No change as no delays					No additional comments	
9	Charing X	1 year or less	1 year or less	Yes	Yes							Not applicable	Not applicable	No change at the moment					I got referred in November 2013 and I'm still awaiting my first appointment. It is now July 2014	
10	Charing X	2 years	1 year or less	Yes	Yes			Yes				Not applicable	Not applicable	No change at the moment					No additional comments	
11	Charing X	2 years	2 years	Yes	Yes			Yes				Yes	Yes		Yes				No additional comments	
12	Exeter	2 years	2 years	Yes	Yes			Yes		Yes		Yes	Yes		Yes				I have just had my pre-op assessment today and the exact words were "you will not get a date until funding is there". I can fully assure you, that normally I am a very strong person emotionally, but I am in a very dark place at this moment in time. I have waited for this moment all my life, but at the moment it seems as far away as ever.	
13	Charing X	4 years	5 years or more	Yes								Yes	Yes	Yes	Yes		Yes		Firstly I waited much longer than the average patient at a GIC because my main psychologist refused to refer me for surgery because she thought I was too overweight. This psychologist has left and the one who I now see, put through the referral the first time I saw her. I got the letter through to say I had been referred, it was such a relief I finally felt like my life was moving forward. I rang up to make an appointment with my chosen surgeon only to be told there is a funding problem and that they will call me back when they know more. No time frame, no idea when my initial appointments or surgery will take place. After the euphoria of the referral letter I had the agony of being told I can't have surgery because there is no money available and they have left me with no idea when this situation will be rectified. In any other area of the NHS there would be outrage at such shoddy treatment. In relation to other areas of the NHS we are a small minority, there is no excuse as to why funding shouldn't be available, given what a small percentage we are and given the massive positive outcomes to the treatment and surgery for trans patients especially when again you compare them to other areas of the NHS! Every day I look down at a body I don't recognise, I have to struggle into a binder just to leave the house, surgery is the only way forward for me, the only way to make life better, it feels horrible being told that what I need to make my life not a constant struggle is not a priority and that there is no money available!	
14	Charing X	2 years	1 year or less	Yes	Yes							No	Not applicable	Not answered					Still waiting for a first assessment. Referral delayed for 14 months by NHS Wales	

	Name of GIC unit	How long have you been with GIC	How long have you been in RLE	Mental/Psychological well being after transition									Indication given for surgery	Have you been notified of any delays	Effect on mental/psychological after notification of any delay					Any other comments
				1	2	3	4	5	6	7	8	9			10	11	12	13	14	
15	Charing X	2 years	3 years	Yes	Yes								No	Not applicable	Not answered					No additional comments
16	Exeter	2 years	2 years		Yes								Yes	Yes	Yes	Yes		Yes		I am a normally very strong person and I have just been told by Brighton Nuffield Hospital that I will not be given a date due to the funding crisis. This was told to me during my pre-op appointment and ruined what was to be my special day. I have waited all my life to get to this point and I do not know how much more patient I can be. I was aware of the issues, but this has devastated me. I am told my my GIC not to worry or panic, but they aren't the ones going through this. I am worried sick for my emotional well being and I also care for my partner. This leads to more worry about whether I am capable of providing her care needs. I started living full time in July 2012, but it took me another 9 months to get to a GIC. I found full time life fulfilled and enjoyable. My journey through the GIC and now surgery has been awful. I never knew I could be despairing until after I started the assessment phase at my GIC. It has been one kick in the teeth after another and this situation is even worse for me.
17	Charing X	3 years	4 years		Yes								Yes	Yes	Yes	Yes		Yes		No additional comments
18	Charing X	2 years	3 years	Yes	Yes						Yes		No	No	Not answered					No additional comments
19	Charing X	1 year or less	1 year or less	Yes	Yes								No	No		Yes				I was referred in December, I'm waiting for my first appointment - an 8 month wait for a first appointment is completely unacceptable especially when it concerns mental health issues
20	Charing X	1 year or less ¹	1 year or less	Yes	Yes			Yes		Yes			Not applicable ²	Not applicable	Not answered ³					1. I was referred June 2013 and am waiting for first appointment, they say it will be Sept 2014. 2. I have been on Testosterone 10 months and had top surgery June 2014, privately funded. 3. If I had not instigated my own surgery I would be feeling pretty bad, having suffered anxiety & depression since adolescence (am now 42)
21	Nottingham	1 year or less	1 year or less	Yes						Yes			Not applicable	Not applicable	Not answered					No additional comments
22	Exeter	1 year or less ¹	1 year or less ²	Yes		Yes	Yes		Yes				Not applicable	Not applicable	Not answered					1. Referred at the end of January 2014, had initial appointment at the beginning of June. 2. Lived as male as possible despite name for many years before this.
23	Charing X	2 years	3 years		Yes		Yes				Yes		No	Yes	Yes	Yes	Yes	Yes		No additional comments
24	Charing X	3 years	3 years	Yes	Yes								Yes	Yes	Yes				Yes	The delays have only happened because of a surgeon leaving. As it happens even though waiting for the new arrangements to take affect with a new surgeon, this has left me with an opportunity to get thing in order. GRS is very important to me but i also feel like additional funding should be in place for other treatments we have to go through. and make the funding across the board not at GIC disgression. For example Leeds GIC helped patience claim the funding for Hair removal. but CHX didnt want anything to do with what the Interim Protocol presented.
25	Charing X	3 years	3 years	Yes						Yes			Yes	Yes		Yes				Cynical
26	Charing X	1 year or less	3 years	Yes		Yes							No	No	Not answered					No additional comments
27	Nottingham	2 years	4 years	Yes	Yes				Yes				Yes	Yes	Yes	Yes				No additional comments
28	Exeter	1 year or less	1 year or less	Yes								Yes	Not answered	Not answered	Not answered					1. On the waiting list (I suspect this might be a spam entry)

	Name of GIC unit	How long have you been with GIC	How long have you been in RLE	Mental/Psychological well being after transition									Indication given for surgery	Have you been notified of any delays	Effect on mental/psychological after notification of any delay					Any other comments
				1	2	3	4	5	6	7	8	9			10	11	12	13	14	
29	Charing X	2 years	4 years ¹	Yes	Yes								Yes ²	Yes	Yes	Yes	Yes	Yes	1. I was living full-time 14 months before I got to Charing Cross GIC so I saw Mr. Barrett for two years RLE I found my time at CX was trouble free. but I'm aware that many had a lot of issues. 2. I saw mr bellringer in dec 2nd 2013 and registered with admissions the same day after a number of attempts by myself and my gp. I still have no indication of a surgery date. This has completely made me feel if my whole life is on hold, i'm suffering from serve depression with suicidal thoughts, i lost my full-time job, i was doing really well up to the point of being referred to surgery i could see the light at the end of the tunnel. Now Charing Cross has stripped me of years of hard work of building self esteem and confidence.	
30	Nottingham	1 year or less	4 years	Yes							Yes		No	No answer	Not answered ¹					1. Seeing all the news about the cut backs has made me feel very despondent about what is happening and just when I will ever get my surgery
31	Nottingham	2 years	3 years ¹	Yes	Yes								Yes	No	Not answered					1. I was receiving private treatment before this I went to Nottingham GIC
32	Sheffield	1 year or less	4 years	Yes	Yes								No	No	Not answered					No additional comments
33	Charing X	4 years	1 year or less		Yes								Not applicable	Not applicable	Not answered					No additional comments
34	Charing X	4 years	5 years or more	Yes	Yes				Yes				Yes	No	Not answered					I am getting anxiety attacks on reading news about the delays to surgery at CX and wonder when they will catch up with all the backlog
35	Charing X	4 years	5 years or more	Yes	Yes				Yes				No	Yes	Yes				No additional comments	
36	Charing X	1 year or less ¹	2 years				Yes					Yes	No	No	Yes	Yes		Yes	Yes ²	1. I am not yet attending the GIC. Since my referral, I have been waiting over a year to be seen and there is still no indication when I will get my first appointment. 2. When I first started living in my proper gender (not new gender - I understand I was born this way, just in the wrong body), it was a huge relief and I began to feel happier. Now as the waiting drags on and on, I feel more and more miserable. It feels like the NHS is trying to save money by delaying and delaying in the hope that as many patients as possible will kill themselves and go away, saving the NHS money as they no longer have to deal with them.
37	Charing X	3 years	3 years	Yes	Yes								Yes	Yes	Yes	Yes			No additional comments	
38	Nottingham	4 years	5 years or more		Yes				Yes	Yes			Yes	No	Not answered					No additional comments
39	Exeter	1 year or less ¹	2 years ²	Yes	Yes				Yes				Yes	No ³	Not answered					1. I waited 7 months after my initial referral for an appointment. I had to complain to PALS. I was then told that they would make up for this. Now my Dr is refusing to budge on 2 years. The NHS pathway is 12 - 24 months. I have presented f/t for ages and have no idea why they have now decided on the maximum possible period. I've lost the plot but know as a certainly I cannot survive without treatment. I class these delays as refusing treatment. 2. Previously did a 4 year spell between 1986 -90 3. Found out about the delays through friends and felt very depressed. For me it's femininity or death there is no alternative. This is a life or death question. I don't want to die but I will take my own life if they continue to refuse me meaningful medical support as a result of delays.
40	Charing X	2 years	3 years	Yes	Yes								No	Yes	Yes	Yes	Yes	Yes	I have heard about the delays due to Mr. Bellringer leaving and the backlog of patients building up and also shortfalls in funding for these operations which is making me feel really bad and sometimes suicidal	

	Name of GIC unit	How long have you been with GIC	How long have you been in RLE	Mental/Psychological well being after transition									Indication given for surgery	Have you been notified of any delays	Effect on mental/psychological after notification of any delay					Any other comments
				1	2	3	4	5	6	7	8	9			10	11	12	13	14	
41	Charing X	2 years	3 years		Yes								Yes	Yes		Yes		Yes		No additional comments
42	Charing X	1 year or less ¹	3 years		Yes								No	Yes	Yes ²	Yes	Yes	Yes		1. Got my referral in July 2013, was offered my first appointment in July 2014, which was then cancelled (doctor ill) and rearranged for August 2. It took me a long time to be sure that this was what I wanted, and it's incredibly hard to find once I have made this decision that I will have to wait so long for any kind of treatment. After my referral in July 2013 I didn't even hear from the GIC until May 2014. It's been a very tough year. I know the NHS are struggling and I don't blame them, but it's hard to bear.
43	Charing X	3 years ^{1,2}	3 years	Yes	Yes			Yes					Yes	Yes	Yes					1. I attended for the two years RLE then they dropped me. That was a year ago. 2. I spent a year of writing letter, writing emails and making phone calls, none of which were acknowledged. The phone calls were transferred to an answering machine. Extremely frustrating
44	Charing X	2 years	2 years	Yes	Yes								Yes	Yes		Yes		Yes		No additional comments
45	Charing X	2 years	5 years or more	Yes	Yes								Yes	Yes	Yes	Yes		Yes	Yes	No additional comments
46	Charing X	3 years	2 years	Yes	Yes								Yes	Yes		Yes				No additional comments
47	Leeds	4 years	3 years	Yes	Yes			Yes					No	Yes	Yes	Yes			Yes	No additional comments
48	Charing X	2 years ¹	2 years		Yes								No	No	Not answered					1. Though I have been on their books it took until half way after my first year to actually be seen and then the usual delays/waiting until my 2nd and 3rd
49	Charing X	1 year or less	1 year or less	Yes	Yes								No	Yes	Yes	Yes	Yes	Yes	Yes	No additional comments
50	Exeter	1 year or less	5 years or more		Yes			Yes	Yes	Yes			No	No	Not answered					No additional comments
51	Charing X	3 years	3 years	Yes	Yes			Yes	Yes	Yes			Yes	Yes			Yes			Waiting for surgery is making me very anxious about my future as I hope to attend full time education, had I already had the surgery prior to starting education then I would feel no anxiety knowing it would not impact my future plans at all.
52	Charing X	3 years	2 years	Yes	Yes			Yes		Yes			No	No	Not answered					No additional comments
53	Charing X	2 years ¹	1 year or less	Yes	Yes								Not applicable	Not applicable	Not answered					1. I've only had two appointments in two years.
54	Charing X	1 year or less	2 years	Yes	Yes			Yes		Yes			Not applicable	Not applicable	Not answered					No additional comments
55	Nottingham	3 years ¹	3 years	Yes	Yes			Yes	Yes	Yes			Yes	Yes			Yes			1. First attended in 2004, but then stopped attending until 3 years ago.
56	Charing X	2 years	1 year or less	Yes				Yes		Yes			Not applicable	Not applicable	Not answered					
57	Charing X	1 year or less ¹	1 year or less	Yes	Yes				Yes				Not applicable	Not applicable	Not answered					1. Only been referred not had initial appointment, problem with referral
58	Leeds	1 year or less ¹	2 years	Yes	Yes								Yes	Yes	Yes	Yes				1. I started my transition before my referral worked it's way to the top of the waiting list at the GIC 2. I was possibly one of the first people to be in the unfortunate position of seeing the surgeon for pre surgery consultation(1st July 2014) and then being told (At the Consultation) that although I personally had funding allocated to me (25th April 2014) I was not able to get a surgical appointment, Apparently, I may get surgery after April 2015
59	Charing X	5 years or more	5 years or more	Yes	Yes								Yes	Yes	Yes			Yes		Went on Monday to be told 12 months been on list for years and they want me to go back to the psychologist just to make sure
60	Charing X	4 years	3 years ¹	Yes	Yes				Yes				Yes	Yes	Yes	Yes		Yes	Yes ¹	1. Feel suicidal sometimes

	Name of GIC unit	How long have you been with GIC	How long have you been in RLE	Mental/Psychological well being after transition									Indication given for surgery	Have you been notified of any delays	Effect on mental/psychological after notification of any delay					Any other comments
				1	2	3	4	5	6	7	8	9			10	11	12	13	14	
61	Charing X	2 years	3 years	Yes	Yes								Yes	Yes		Yes				I feel lost. The lack of information does not help to me figure out where I stand and what my options are, so I have to second guess everything and hope I get it right.
62	Charing X	1 year or less ¹	1 year or less	Yes	Yes			Yes					Not applicable	Not applicable	Not answered					1. Extremely poorly managed expectations to date with promises made and then subsequently retracted
63	Nottingham	2 years	3 years		Yes								No	No		Yes				No additional comments
64	Leeds	2 years ¹	1 year or less	Yes									Yes	No		Yes ²				1. I have a list of complaints about how I have been treated during my dealings with LEEDS and even after requesting to see another clinical nurse, it seems that there is and always be a norm of bad communication and I really feel that there is a need to totally change the whole TG process within the NHS. To much money is spent on staff in the GIC's to administrate and do not do perform modern articulate person centered work with individuals. They treat the users like sheep applying antiquated processes whilst using all the excuses of Victorian psychology to worm out of making decisions. I really think it is time that something else needs to transition and it is not us it is the NHS! 2. i had to tell my LEEDS GIC contact about the issues.
65	Charing X	2 years	3 years	Yes	Yes			Yes		Yes			Not applicable	Not applicable	Not answered					No additional comments
66	Exeter	2 years	2 years	Yes	Yes					Yes			Yes	No	Not answered at this time but please see comment 1.					1. I am anticipating hearing of a delay and feel I am becoming increasingly anxious and not sure how I will deal with the news. I have organised the next several months around surgery and this will be an enormous blow in all respects
67	Charing X	3 years	3 years	Yes ¹	Yes								Yes	Yes	Yes	Yes	Yes	Yes		1. Intrinsic well being +++++ Extrinsic well being -----
68	Charing X	2 years	2 years ¹	Yes	Yes								No	Yes	Yes	Yes		Yes	Yes ²	1. 2 yrs 9 months 2. I want to end it all
69	Northampton	1 year or less	1 year or less	Yes ¹									No	Not applicable	Not answered					1. Sometimes I get really depressed, and think of suicide. But far less often then before living as myself.
70	Charing X	2 years	3 years	Yes	Yes			Yes	Yes	Yes			Not applicable	Not applicable	Not answered					No additional comments
71	Exeter	3 years	2 years ¹								Yes		Yes	Yes						1. Actually 18 months now
72	Charing X	3 years	2 years	Yes	Yes			Yes	Yes	Yes			Yes	Yes						No additional comments
73	Exeter	2 years	3 years							Yes			Yes	Yes			Yes			No additional comments
74	Charing X	0 years ^{1,3}	0 years ²		Yes								No	Not applicable	Not answered					1. I have been waiting to hear back from a GIC which I presume to be Charring Cross, because of being in the Birmingham area, for nearly three years now. Despite continually asking my GP what's happening, my mental health has suffered due to my prolonged wait and I actually feel I've been treated unfairly without consideration. 2. I felt it was important to make sure my personal and family life were as healthy and positive before making permanent changes. Though I have taken long than most to begin my Transition I have a good level of family support and understanding. 3. I'm still waiting to Transition fully, though I am now quite level headed and ready to move forward with my new identity. I long for a relationship, but my existing genitalia is a massive issue and a huge barrier in forming a relationship for me. I also don't engage in sports activities because of changing facilities.
75	Charing X	2 years	3 years	Yes	Yes			Yes		Yes			Yes	No	Not answered					No additional comments

Table and Analysis of Results

Results will be updated every 10 participants	Mental/Psychological well being after transition									Total number of eligible participants who have been affected by this	Effect on mental/psychological after notification of any delay				
	1	2	3	4	5	6	7	8	9		10	11	12	13	14
	I feel much more relaxed	I feel much happier	I feel about the same	I am finding it just as hard as it was before transition	I no longer suffer from periods of depression	I no longer self harm	I no longer have thoughts about taking my own life	I am self harming more	I think more often about taking my own life		Are you feeling depressed about the delays	Are you feeling anxious about the increase in the waiting time	Are you feeling any need to self harm	Are you feeling lethargic and miserable	Are you feeling suicidal
Total number of participants	65	64	2	3	22	14	25	1	4	Total number of eligible participants	34	32	9	26	15
81	81%	81%	2%	4%	28%	20%	31%	1%	5%	49	73%	80%	18%	55%	33%

Conclusions:

Of the participants who have actually transitioned a total of 6% are finding life to be pretty much the same or more difficult after transition than it was before and 6% are actually self harming and/or considering suicide more frequently. Transition for the majority of people has brought about a much greater feeling of being relaxed about their new role in life (81%), feeling much happier with themselves (81%). Many have stopped self harm altogether and many who had suicidal thoughts prior to transition no longer consider this (20% and 31% respectively).

Unfortunately, of those who have been told of delays (caused by various factors such as the funding shortfalls at many GIC's or the resignation of one of the surgeons performing gender reassignment surgeries at Charing Cross Hospital causing a massive backlog which will take a considerable time to work through) this has led to a large increase in those reporting increased depression (73%), anxiety (80%) and lethargic/miserable (55%) - of those some are resorting to self harming as a means of coping (18%) and a large increase (33%) in those considering suicide they feel so abandoned by the NHS.

Gender Identity Clinic	Number of Participants	%age of Total
Exeter (The Laurels GIC)	13	16.3%
Leeds (Newsome Centre GIC)	3	3.8%
London (Charing Cross GIC)	54	67.5%
Newcastle GIC	0	0%
Northampton GIC	1	1.2%
Nottingham GIC	8	10.0%
Sheffield (Porterbrook Clinic GIC)	1	1.2%
Tavistock & Portman Institute	0	0%
Total	80	100%