

The impact of commissioning issues on phalloplasty and metoidioplasty patients

Context

Phalloplasty (otherwise known as phallo) is a type of surgery used to create a penis. This is a multi-stage surgical process, which typically consists of 3 stages when accessed via the NHS. It is most commonly sought by trans men and by some non-binary people assigned female at birth, but some cis (not trans) men might also access phalloplasty surgery if they have had a serious injury.

Metoidioplasty (otherwise known as meta) is a type of surgery which uses a person's existing genital tissue to create a penis. This is a multi-stage process and can consist of 3 stages. Meta is a surgical process specifically for trans men and non-binary people assigned female at birth.

More information about the processes involved in both types of surgery is available in the Gender Dysphoria National Referral Support Service's booklets on phalloplasty and metoidioplasty.

In March 2020, NHS Specialised Commissioning withdrew the contract from the only surgical team commissioned to provide NHS funded phalloplasty and metoidioplasty. 17 months later, NHS Specialised Commissioning announced that they had awarded a contract for the surgeries to a new provider (New Victoria Hospital). NHS phalloplasty and metoidioplasty surgeries have now



officially recommenced, with those classed as 'extremely urgent' being prioritised for treatment.

In October 2021, TransActual reported on the <u>results of a survey</u> of those on the waiting list for NHS phalloplasty or metoidioplasty surgeries. Based on an estimated waiting list size of 600, the report suggested that those waiting for Stage 1 surgeries may expect to wait 4 years for them to commence. Since obtaining further information about the waiting list, TransActual estimate that there are 1200 patients waiting for NHS phalloplasty and metoidioplasty related surgeries. According to our estimates, a patient referred in 2022 can expect to wait at least 8 years for stage 1 phalloplasty or metoidioplasty.

Patients waiting for stage 2, stage 3 or repair surgeries received a letter in December 2021 to inform them that their patient records had been transferred to New Victoria Hospital. Some, but not all, of these patients were given an indication of the time they could expect to wait for their next operation. Those waiting for extremely urgent repairs were given a short timeframe, as would be expected. Patients report having been told that they were one of more than 60 patients on a very urgent list. Other patients report being told that they were on an urgent list of approximately 100 people, but that they would be unlikely to receive surgery by the end of 2022.

A full timeline of events and additional context is available at www.transactual.org.uk/nhs-phallo-meta.



Scope and purpose

In February 2022, TransActual conducted a survey of individuals waiting for NHS phalloplasty or metoidioplasty surgeries, including those waiting for repairs. The intention was to gain insights into the impact of the commissioning issues on those on the waiting list. We also wished to gain insights into the experiences of those patients who were on the 'extremely urgent' list and who had recently had phalloplasty or metoidioplasty related surgery at New Victoria Hospital.

Survey participants were recruited via TransActual's social media channels, in a Facebook group for patients on the NHS phalloplasty and metoidioplasty waiting list, and via a newsletter for individuals on the waiting list. 79 people completed the survey, 4 of whom had recently undergone phalloplasty related surgery at New Victoria Hospital.

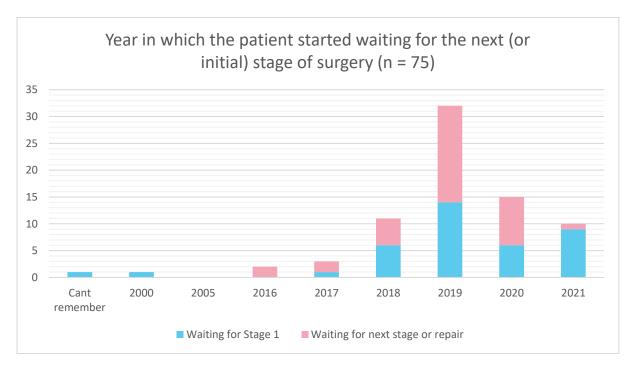
Length of wait

Just under half (48%, n = 38) of respondents are waiting for their first stage of surgery. Of those, 9 are waiting for metoidioplasty and the rest are waiting for phalloplasty. A small number of respondents have been waiting since before 2017 for their first operation, 16% (n = 6) had received their second signature for referral in 2018, 37% (n = 14) received their second signature in 2019, and the remaining 27% (n = 16) were referred in 2020 or later.

Another 46% of respondents (n = 37) are waiting for a subsequent stage of surgery. Of those, 4 are waiting for metoidioplasty related surgeries and the rest are waiting for phalloplasty related surgeries. Nearly half (49%, n = 18) of respondents in this group had their most recent phalloplasty or metoidioplasty related surgery in 2019, with 25% (n = 9) having had their most recent operation earlier than that. 27% (n = 10) of respondents had their most recent NHS



phalloplasty or metoidioplasty related surgery in 2020 or 2021 – this group includes individuals who had emergency repairs.



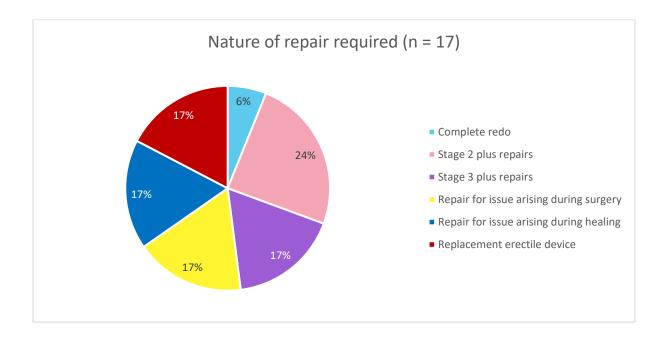
Based on our understanding of the waiting list size, we estimate that more than 700 people have already waited over 2 years for their next (or initial) stage of phalloplasty or metoidioplasty related surgery. An estimated 570 people are waiting for their first stage of surgery.

Type of surgery required

Of those respondents who have already had at least one phalloplasty or metoidioplasty related operation (including those who have had preparatory surgery), 47% (n = 17) are waiting for a repair surgery. This does not include the 4 respondents who recently underwent surgery at New Victoria Hospital but does include the 3 respondents waiting for a replacement erectile device. Some respondents report that they have been told that the repairs will be completed

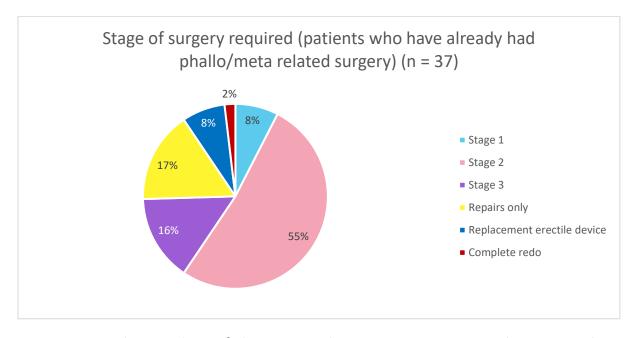


at stage 2 (24% of those waiting for repairs) or at stage 3 (17% of those waiting for repairs). One individual requires a complete re-do of his phalloplasty procedures, and the rest expect repairs to be completed during an operation which is separate to their other surgical stages (53% of those waiting for repairs).



As noted earlier, 48% (n = 38) of respondents are waiting for their first stage of surgery. An additional individual reported having had some phalloplasty or metoidioplasty related surgery, but reports being on the waiting list for stage 1. This could be because they are waiting for a complete re-do or because they required preparatory surgery. Of those patients that have already had phalloplasty or metoidioplasty related surgery, most respondents are waiting for stage 2 (55%, n = 18). 16% are waiting for stage 3 (n = 6), and 27% are waiting for repairs only or for a replacement erectile device (n = 10).





Using our understanding of the waiting list size, we estimate that more than 250 people are waiting for some form of repair surgery. An estimated 90 people are waiting for stage 3 surgery, which is the stage at which an erectile device is fitted.

We estimate that **at least 270 people are waiting for stage 2 surgery.** It is important to note that those individuals waiting for stage 2 of phalloplasty will be living with their natal genitalia in addition to a non-functioning penis. The majority of these patients are also likely to still have a uterus, cervix and ovaries, because hysterectomy as a stand-alone procedure is not included as part of the NHS care pathway for gender dysphoria. Individuals on the waiting list for stage 1 and 2 procedures have reported being refused hysterectomy, often despite painful medical issues such as endometriosis.



Additional waiting times

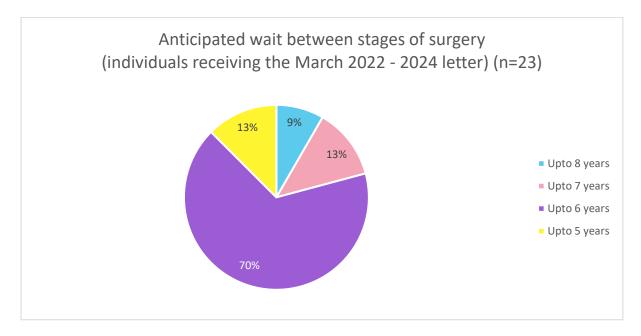
As we have already noted, those patients waiting for stage 2, stage 3 or repair surgeries received a letter in December 2021 to inform them that their patient records had been transferred to New Victoria Hospital.

3 of our survey respondents who had previously undergone phalloplasty or metoidioplasty surgery did not receive a letter. All of those individuals are awaiting surgical repair, rather than a replacement erectile device, which means they ought not to be treated as new referrals. This makes it unusual that they did not receive any correspondence to tell them that their records have been transferred.

Of those respondents that had received a letter (n = 34, not including the 4 individuals who were seen at New Victoria Hospital in December 2021 or January 2022), 68% reported being told that they could expect to have their next operation between March 2022 and March 2024. 26% reported that the letter didn't give a time frame, and 6% reported being given a different timeframe.

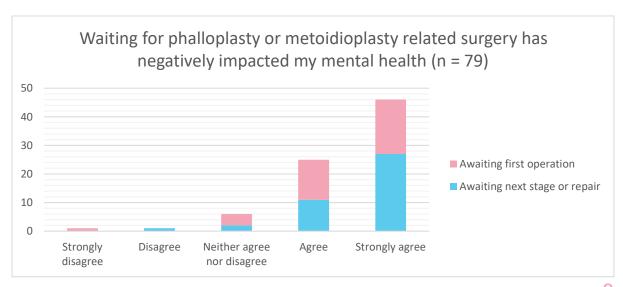
For those that were given the two-year time frame, 70% (n = 16) could potentially have waited 6 years between stages of surgery by the time they next access phalloplasty or metoidioplasty related surgery.



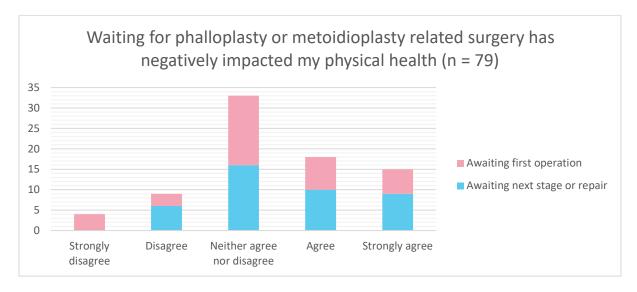


Impact of waiting

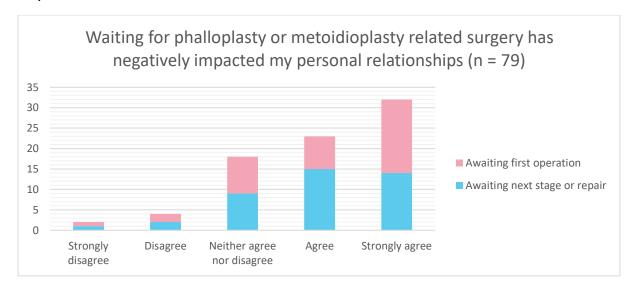
We asked respondents about the impact of the wait for phalloplasty, metoidioplasty or repair surgery on their mental and physical health. 90% of respondents agreed or strongly agreed that the wait had negatively impacted their mental health. 42% of respondents agreed or strongly agreed that the wait had negatively impacted their physical health.



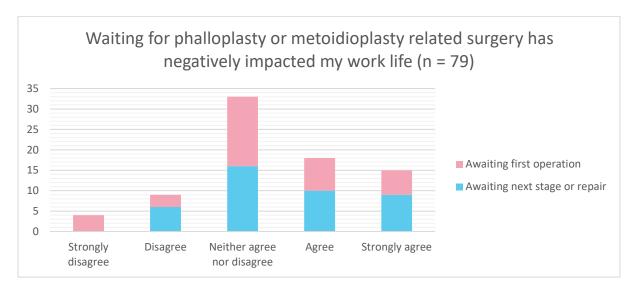




We also asked about the impact of the wait on respondents' personal relationships and careers, aspects which are often overlooked. 70% of respondents agreed or strongly agreed that waiting for phalloplasty, metoidioplasty or repair surgery has negatively impacted their personal relationships. 51% agreed or strongly agreed that the wait has negatively impacted their work life.







Please note that the remainder of this report contains references to surgical complications, suicidal ideation, eating disorders, poor mental health, media transphobia, experiences of dysphoria and relationship breakdowns.

We asked survey participants to tell us about the ways in which their life had been negatively impacted by their wait for phalloplasty, metoidioplasty or repairs.

Somebody waiting for stage 2 surgery said:

"The impact on my mental health has been huge and has had a knock-on effect on my relationships and confidence, and therefore on my work. I am now suffering from the worst anxiety and depression I've experienced in decades, my confidence is incredibly low due to feeling 'stuck in the middle' and wondering if I will ever get to achieve peace because I am already middle aged and I hoped all my surgery etc would be a memory by now, but now I'm constantly wondering if this is it for the rest of my life and if this will ever be over. It's proven pretty impossible to get a new job when my anxiety is so high, my confidence is so low, and I worry about going out in public."



One person awaiting repair surgery told us:

"It's been stressful since before the first surgery never knowing where you are on the list. I put many things on hold thinking I would be having surgery soon because expectations have never been managed properly. Because of the leak, I often pee over the seat If I forget to push my junk down when I'm using the toilet now, which is embarrassing / annoying. Not knowing how long I have to pee like this is stressful.

I lost a job previously because of some chaos around my surgery being cancelled and then rescheduled with short notice. I'm now in a job that I'd like to quit, but they've already offered paid time off for my corrective surgery when it happens (I raised it before signing the contract) and I am unsure about getting a new job and potentially having to take time off right away. If they could just say where in the two years between March 2022 and March 2024 I am, then it would be easier to plan for this."

A person waiting for stage 1 phalloplasty said:

"I want to join the army but cannot until all stages are complete. As I have yet to have stage 1, I estimate I'll be lucky to be able to join in 10 years."

Another person waiting for repair surgery explained the impact on their other health conditions:

"I had a broken implant put in and it ruptured my insides and shortened my phallus. I also have other issues arising from the implant surgery too. I had to have emergency surgery for these issues and as a result I inguinal hernia that needs fixing too. My arm graft need repair. I need lots. I can have my hernia done, but then that means I go to the back of the line and have to wait for my implant replacement. That could be 3 years wait, so I won't have my hernia fixed even though I'm in a lot of pain."



"My mental health is suffering too as my eating disorders are really bad, which is then impacting my diabetes and physical health. I feel so angry and frustrated all the time. I'm supposed to be having treatment for many health issues, but lower dysphoria is impacting all of them in many ways. I haven't been intimate with anyone since lower surgery started and it's making my mind crack. It's been 7 years since I started lower surgery."

A person waiting for stage 3 phalloplasty and repairs explained:

"I've been too distressed by my physical situation to engage in any physical relationship and my marriage broke down partially due to this. I had to leave my job due to problems caused by stress and time off work for recovery. I can no longer exercise as much I used to as it causes pains to start around my surgery sites. My arm donor site also feels tighter than ideal and painful in places if touched. I have to wear an arm brace if driving further afield or carrying heavy objects."

One of the people waiting for stage 1 surgery told us:

"It's knowing the length of time ahead without any hope or communication or support that is so detrimental. I lack motivation to do physical exercise, I drink because I'm in mental pain, I take my anger out on the one friend I have, there is no support from my gender clinic or GP. I'm alone with this and constantly seeing in the media the hatred against trans people....it destroys your soul and your will to live. I'm suicidal every day."

Additional qualitative responses can be found in the <u>appendix</u> of this report. We encourage everybody to read them in full in order to understand the detrimental impact that the commissioning issues have had on those affected by them.



Experiences of the new service

Of our survey respondents, 4 had undergone phalloplasty or metoidioplasty related surgery at New Victoria Hospital. All 4 patients were considered 'extremely urgent' and were therefore prioritised for treatment. We asked these individuals about their experiences at New Victoria Hospital. The 4 respondents reported feeling well cared for and stated that they were happy with the standard of care they received, although some noted that the hospital staff are new to working in a trans inclusive way and are currently on a journey of developing in that area. Only 1 of these respondents reported that the surgery had been successful in repairing any of the issues they'd experienced, and only 2 reported being happy with the aftercare provided. Issues with aftercare included not being given instructions on dressing their incisions and a refusal of care by their local district nursing team.

Discussion

This report highlights the profound impact that the commissioning issues, and resulting waiting times, have had on people waiting for metoidioplasty or phalloplasty related surgery. Most respondents to this survey reported that the wait for surgery has had a detrimental impact on their mental health. A number of respondents reported experiences of suicidal ideation, a return of eating disorders, or relapses relating to addition.

42% of respondents experienced a negative impact on their physical health. For many, this is a result of surgical complications that have been left for years without being repaired. TransActual are deeply concerned about the number of individuals who have approached us to tell us about bladder issues or the years they've spent reliant on pain medication because they are awaiting surgical repairs. These people are often report being refused treatment locally on the



basis of a perception that they are 'too specialist'. Some patients have been told 'we don't treat trans men'. One of the patients who was recently treated at New Victoria Hospital told TransActual that were refused post-surgical care by their local district nursing team because they were deemed 'too specialist'. They had been seeking the removal of a surgical drain, which is not an unusual or complex procedure.

We are glad that our respondents reported feeling well cared for during their stay at New Victoria Hospital but note that only 1 of them reported that the issues they had experienced have now been rectified. This would merit further investigation. It would be useful to know whether it is possible to fully rectify the issues that these individuals had experienced, and whether their surgical outcome would have been different without such a long delay to their repair surgery.

It is important to recognise that the impact of the commissioning issues extends beyond those of individual patients' health and into their personal relationships, work lives and social lives. A decline in these areas of life can, of course, further contribute to poor mental and physical health.

The majority of respondents reported that the wait for surgery has negatively impacted their personal relationships. For some people, this resulted in a breakdown of the relationship they had with their partner. Others have found themselves unable to consider pursuing romantic relationships due to their experiences of dysphoria. Some people reported having to delay starting a family so as not to place an undue burden on their partner during their surgical recovery.



More than half of respondents told us that their work life had negatively been impacted by the uncertainty around their wait for surgery. People reported being unable to work due to their declining mental health, others told us that they are unable to start their own business or move to a new job due to concerns about time off to recover for surgery. The uncertainty around timeframes makes this even more challenging.

The written responses to this survey paint a picture of people that want to get on in life, to contribute to society, and to play a full part in it. The ongoing issues surrounding NHS phalloplasty and metoidioplasty provision are preventing too many people from doing that.

The longer people have to wait for surgery, or between stages of surgery, the more likely there is to be a detrimental impact. Our data indicates that potentially hundreds of individuals can expect to have waited as long as 6 years between stages of surgery by the point at which they next access surgery. Many of those people have expressed a sense of being 'in limbo', particularly those awaiting stage 2. A number of the people waiting for stage 2 reported that they had been told that they would wait 6 months (not 6 years) living with both a non-functioning penis and their natal genitalia.

One man told us: "I consented to living like this for 3 to 6 months. I did not consent to being like this indefinitely. I don't know when I can expect the wait to end."

Those waiting for their first operation can expect to have waited 8 years before starting the multi-stage surgical process. However, the NHS have not given them an indication of how long they can wait and have only estimates based on



TransActual's previous work to go on. This uncertainty further contributes to the negative impacts on people's mental health, relationships and work lives.

Whilst it is positive that the surgical team have now started operating at New Victoria Hospital, three significant issues remain:

- 1. The poor mental health of those on the NHS waiting list for phalloplasty, metoidioplasty or repair surgeries.
- 2. The length of the waiting list for NHS phalloplasty and metoidioplasty related surgeries.
- 3. The lack of clear and honest communication about waiting times.

Recommendations

The situation caused by the commissioning issues with NHS phalloplasty and metoidioplasty cannot be allowed to continue.

TransActual recommend that:

- 1. NHS Specialised Commissioning apologise to the patients impacted.
- 2. Specialist mental health support is provided to patients on the NHS waiting list for phalloplasty and metoidioplasty.
- 3. The care pathway for gender dysphoria is amended to include hysterectomy as a stand-alone procedure.
- 4. Urgent steps are taken to increase the capacity of the NHS to provide phalloplasty and metoidioplasty.
- 5. And, whilst those urgent steps are being taken: Funding is made available for patients to access phalloplasty or metoidioplasty overseas.



Appendix: The impact of waiting

Participant responses to the question: "If your mental health, physical health, personal relationships, or work life has been negatively impacted by your wait for phallo, meta, or repair surgery, please tell us about it here."

"I want to join the army but cannot until all stages are complete. As I have yet to have stage 1, I estimate I'll be lucky to be able to join in 10 years."

Person waiting since 2020 for stage 1 phalloplasty

"My dysphoria is terrible, I'm not engaging in group hobbies/sports or intimate relationships because I don't feel able to until I feel whole."

Person waiting since 2018 for stage 1 phalloplasty

"I find it fills me with sadness/I feel desperate when I consider how long it looks like I will have to wait for phallo. It makes me feel different to everyone else or like an outsider, it makes me feel sad or depressed and like I am waiting for my life to start whereas most cis men my age are settled in their lives by now."

Person waiting since 2020 for stage 1 phalloplasty



"I haven't sought out any kind of relationship at all since 2018 due to not feeling I could been seen naked with a half finished phallo. I also haven't worked as I was never given a time frame to expect surgery within so always expected it could be any moment and I didn't want to start a new job and immediately need time off."

Person waiting since 2018 for stage 3 phalloplasty

"My life has been put on hold for the last 5 years since my first operation, I haven't wanted to start anything in case I have to take time out for surgery and recovery time. I feel like I've been left half-done for so long that it almost feels like it will never come. The uncertainty around when the surgery might happen is incredibly stressful, giving a 2 year timeframe that it could possibly happen in just adds to that stress.

My dysphoria has massively increased during this time and it affects my physical health and sexual relationships as I'm not where I would hope to be by this stage. My physical health has deteriorated in this 5 years and I don't want to get to the stage where I'm physically unable to have surgery and this is also stressing me out."

Person waiting since 2017 for stage 2 phalloplasty

"We are an older couple - phalloplasty was not available for the first 25 years that my wife and I were together. The surgery was difficult; 5 operations over several years, and we struggled at first with the changes, However, penetrative sex became an important and key aspect of our sex life together. When, after 15 years, the phalloplasty erectile device eventually failed as we were told it would, but the previously 'guaranteed' repair had not. That, alongside other matters, conspired to make intimacy extremely difficult. Both of us found it a real challenge, and our sex life almost vanished. We have worked hard together and gradually overcome this, but the inability to have penetrative



intercourse for what is now almost 5 years has been a real and profound loss for both of us."

Person waiting for a replacement erectile device

"My mental health has been affected as my dysphoria is still awful. Having had stage 1 helped but I still have waves of feeling really low. In terms of work life, I thought the waitlist would be shorter so it had thrown off my plans for the future and made it difficult to commit to things."

Person waiting since 2019 for stage 2 phalloplasty

"I feel more vulnerable generally about my gender, for example, highly dysphoric around clothing for exercise, using bathrooms, peeing outdoors when on long hikes. I have spent over two hundred pounds on STP devices but find them unsatisfactory.

The wait with, until recently, no letter explaining what is happening, adds to a feeling of being totally unimportant, invisible and 'discardable'. I have been in intensive psychotherapy during this period to address the many traumas I have suffered during my lifetime relating to my gender identity. Along with the current attacks on trans people from the anti-trans lobby I feel I am still being traumatised now, including by the NHS who have so grossly let me down through the whole process of transition. I have had intrusive suicidal thoughts.

I am retired and live on the state pension. Finding my own way through the lack of 'health' services for trans people from the very beginning of transition, including paying for hormones and top surgery, has cost me nearly seven thousand pounds which I could not afford and can never get back. This makes me depressed as I am never likely to earn again, and that money would have made a great difference to my security in retirement.

I realise that due to the pandemic many people have suffered a delay to medical treatment, have been in pain as a result, and perhaps felt forced to go



private. This situation for trans people is worse because it is part of a much bigger picture of neglect and marginalisation and is deeply, intensely personal to our sense of who we are. It is possible to be biologically alive and yet feel unable, as a human being with dignity, to meaningfully survive."

Person waiting since 2019 for metoidioplasty

"It's mostly what I think about when I'm around others, alone, I just feel incomplete all the time."

Person waiting since 2021 for stage 1 phalloplasty

"I experience a lot of dysphoria making me feel low and hating my body. I struggle to maintain any sexual relationships due to this as well, as I don't feel confident enough in them. Also struggling to use public toilets, making me anxious if going out for a long period of time as I worry I will need the toilet and will hold it instead of going, which has caused UTIs every so often."

Person waiting since 2019 for stage 1 phalloplasty

"I've been too distressed by my physical situation to engage in any physical relationship and my marriage broke down partially due to this. I had to leave my job due to problems caused by stress and time off work for recovery. I can no longer exercise as much I used to as it causes pains to start around my surgery sites. My arm donor site also feels tighter than ideal and painful in places if touched. I have to wear an arm brace if driving further afield or carrying heavy objects."

Person waiting since 2019 for stage 3 phalloplasty plus surgical repairs



"I lost my job and can't start a career out of fear of when I'll be called for surgery. I was promised it would he completed within a year and took a gap year at work but was fired as it took longer. I can't go into a job as I declare about the potential of long term sickness due to surgery and they aren't pleased. My relationship is struggled I wanted to experience sex and have intimate relations with my partner but both me and her are missing out and our time together is being robbed from us.

Promises are broken. My mental health is just shattered. I'm fed up, broken, and tired of empty words and being fobbed off. This is my life. I'm 26 this year. When I first has stage one I was in my early 20s looking forward to starting my life finally with the outside picture matching the inside. But I'm coming closer to 30, and I know some don't get surgery till they are in their 50s or 60s, but this means so much to me and I've put so much on hold given so much up just to feel compete in myself and they have let me down and robbed my life."

Person awaiting surgical repairs due to an issue arising during a previous surgery

"It's knowing the length of time ahead without any hope or communication or support that is so detrimental. I lack motivation to do physical exercise, I drink because I'm in mental pain, I take my anger out on the one friend I have, there is no support from gender clinic or GP. I'm alone with this and constantly seeing in the media the hatred against trans people....it destroys your soul and your will to live. I'm suicidal every day."

Person waiting since 2021 for metoidioplasty

"My dysphoria worsened after having my appointment cancelled, at no point have I really known when/if my meta will be done. I've had to put my life on hold, just waiting to get this done."

Person waiting since 2019 for metoidioplasty



"I have been on antidepressants, lost a relationship thru waiting so long, the pressure it put us both under was incredibly difficult. It's been very stressful waiting to hear even the smallest bit of information as to whether surgeries are going ahead or when they expect to be running again. There has been no communication. Working in the NHS during the pandemic has made an extra layer of stress and drained me emotionally. It has been difficult to concentrate on my job and I've taken time off for stress."

Person waiting since 2019 for stage 1 phalloplasty

"I had a broken implant put in and it ruptured my insides and shortened my phallus. I also have other issues arising from the implant surgery too. I had to have emergency surgery for these issues and as a result I inguinal hernia that needs fixing too. My arm graft need repair. I need lots. I can have my hernia done, but then that means I go to the back of the line and have to wait for my implant replacement. That could be 3 years wait, so I won't have my hernia fixed even though I'm in a lot of pain."

"My mental health is suffering too as my eating disorders are really bad, which is then impacting my diabetes and physical health. I feel so angry and frustrated all the time. I'm supposed to be having treatment for many health issues, but lower dysphoria is impacting all of them in many ways. I haven't been intimate with anyone since lower surgery started and it's making my mind crack. It's been 7 years since I started lower surgery."

Person waiting for surgical repairs and stage 3 phalloplasty

"I have severe barriers to physical intimacy as a direct result of gender dysphoria, which is why I am seeking this surgery. The longer I have to wait, the greater the negative impact not just on me but also my partner. The



process of going through all the stages and working to repair the damage of living with this situation of so long is already bad enough without an extra two years waiting to even start. It is galling to think that all this is due to an administrative error around recommissioning the service."

Person waiting since 2019 for stage 1 phalloplasty

"I lost my relationship as my dysphoria hit an all time low and I hate the way I look. I couldn't be intimate with my partner.

I had to take so much time off work after my stage 1 during my complications that I ended up having to change jobs. The extent and severity of my scarring and the position of it makes wearing trousers painful except tracksuit material which I cannot wear at work.

My phallus is tethered and looks permanently erect which I'm hugely self conscious about."

Person waiting since 2019 for stage 2 phalloplasty with surgical repairs

"It's been stressful since before the first surgery never knowing where you are on the list. I put many things on hold thinking I would be having surgery soon because expectations have never been managed properly. Because of the leak, I often pee over the seat If I forget to push my junk down when I'm using the toilet now, which is embarrassing / annoying. Not knowing how long I have to pee like this is stressful.

I lost a job previously because of some chaos around my surgery being cancelled and then rescheduled with short notice. I'm now in a job that I'd like to quit but they've already offered paid time off for my corrective surgery when it happens (I raised it before signing the contract) and I am unsure about getting a new job and potentially having to take time off right away. If they could just say where in the two years between March 2022 and March 2024 I am, then it would be easier to plan for this."

Person waiting since 2019 for repairs to their metoidioplasty



"Relationships have broken down due to the stress and dysphoria I have felt from not just waiting for surgery but the fact that there was no provision for surgeries after St. Peters lost the contract. I have sought therapy several times at private expense. It is on my mind every single day, affecting both my mental health and sex life. I also want to change careers but feel like I can't because I have no idea when surgery will take place so feel stuck in limbo in life."

Person waiting since 2020 for stage 2 metoidioplasty

"The impact on my mental health has been huge and has had a knock-on effect on my relationships and confidence, and therefore on my work. I am now suffering from the worst anxiety and depression I've experienced in decades, my confidence is incredibly low due to feeling 'stuck in the middle' and wondering if I will ever get to achieve peace because I am already middle aged and I hoped all my surgery etc would be a memory by now. But now I'm constantly wondering if this is it for the rest of my life and if this will ever be over. It's proven pretty impossible to get a new job when my anxiety is so high, my confidence is so low, and I worry about going out in public."

Person waiting since 2020 for stage 2 metoidioplasty

"The anxiety I have around having difficult urinating affects all aspects of life in terms of going out in public, work etc. I have had a large open hole in my penis almost half the time I've had my penis which massively impacts intimacy and mental health. Generally has led to poor control of diet due to mental health, and lack of desire and confidence to feel motivated to exercise etc so weight bounces all over the place"

Person waiting for surgical repairs to an issue that arose during healing.



"My mental health has completely crumbled waiting for phallo. I was told I would have stage 1 by October 2020 if not before - obviously with covid this understandably changed. My mental health has been worsened by the situation and uncertainty with St Peters and the loss of contract. My physical health declined due to my mental health decline. I have had to extend the majority of my assignments for my Postgrad degree due to my mental health."

Person waiting since 2019 for stage 1 phalloplasty

"I am stuck in limbo, unable to leave England for work due to funding. I was first put on the waiting list in 2015 and it will still be years before I'm finished. I find dating difficult due to the current state of my body."

Person waiting since 2018 for stage 3 phalloplasty