



# Insights into the NHS phalloplasty/metoidioplasty waiting list

## 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.

In March 2020, NHS Central Commissioning withdrew the contract from the only surgical team commissioned to provide NHS funded phalloplasty and metoidioplasty. It was not until 17 months later that NHS Central Commissioning announced that they had awarded a contract for the surgeries to a new provider (New Victoria Hospital). At the time of writing (12<sup>th</sup> October 2021), timescales for the re-commencement of surgeries are yet to be confirmed. No suitable



mental health support has been made available to help those on the waiting list cope with the situation, and no steps have been taken to reduce the length of the waiting list. It is not clear how many people have been impacted, but we can confidently estimate that there are at least 600 people waiting for NHS phalloplasty or metoidioplasty surgeries.

Full details and background information can be found at [www.transactual.org.uk/nhs-phallo-meta](http://www.transactual.org.uk/nhs-phallo-meta)

## Scope and purpose

In September 2021, TransActual conducted a survey of individuals waiting for NHS phalloplasty or phalloplasty surgeries, including those waiting for repairs. The intention was to gain insights into the proportion of people waiting for each stage of surgery, lengths of time spent waiting, and the nature of surgical complications.

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. The survey was completed by 193 people. We estimate that this completion rate equates to one third of people on the NHS waiting list.



## Status for stage 1 patients

In the UK, stage 1 phalloplasty involves surgeons creating a phallus, using a skin graft from the person's arm, leg, or abdomen. At this stage, the surgeon also creates a urethra, but does not yet attach the neo-urethra to the person's natal urethra.

Stage 1 metoidioplasty typically involves 'clitoral release' surgery and a skin graft from the mouth which is used to form a urethra. Similar to phalloplasty, the neo-urethra is not attached to the person's natal urethra at this point.

### Waiting list size

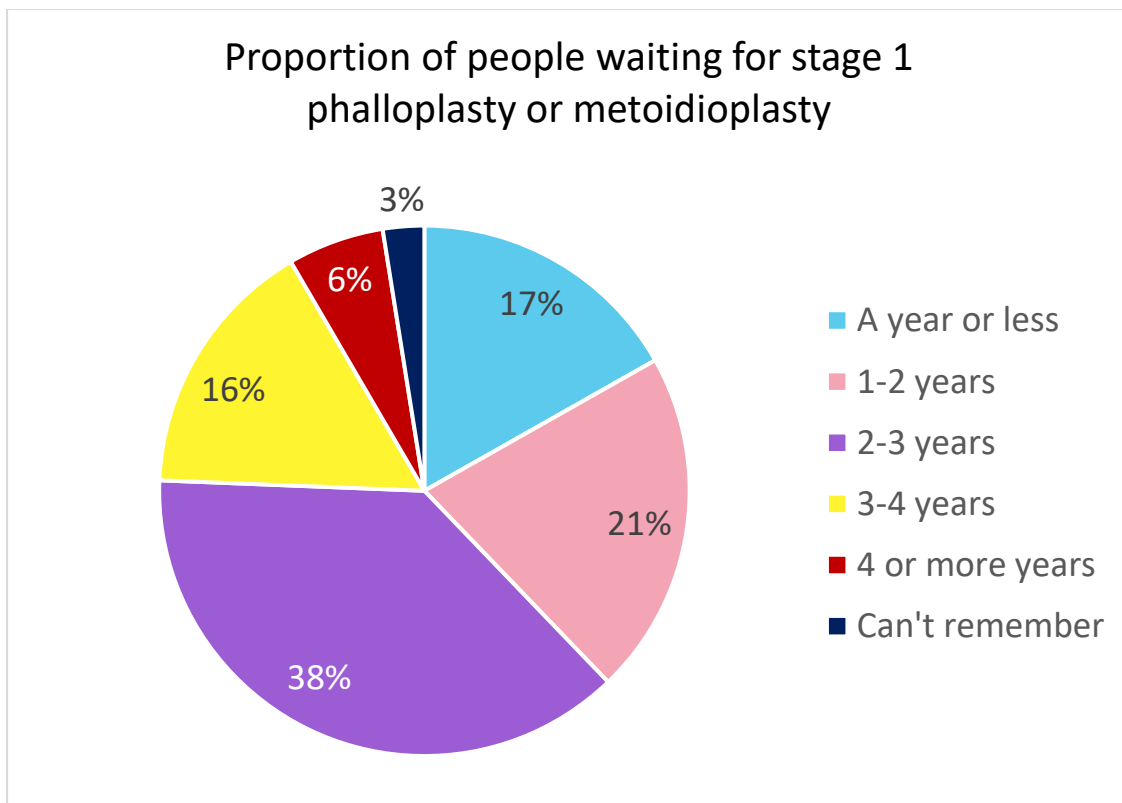
52% of survey respondents (100 people) are waiting for Stage 1 phalloplasty, and 10% (19 people) are waiting for Stage 1 metoidioplasty. Extrapolation from this data may indicate that 312 people are waiting for Stage 1 phalloplasty and 60 people are waiting for Stage 1 metoidioplasty.

### Waiting times

Most respondents have been waiting for Stage 1 phalloplasty or metoidioplasty since before the Covid-19 pandemic. 60% of our survey respondents were already on the waiting list in 2019.



Length of time	Proportion of people waiting for stage 1 phalloplasty or metoidioplasty
0-1 years	17%
1-2 years	21%
2-3 years	38%
3-4 years	16%
4+ years	6%
Can't remember	3%





## Status for stage 2 patients

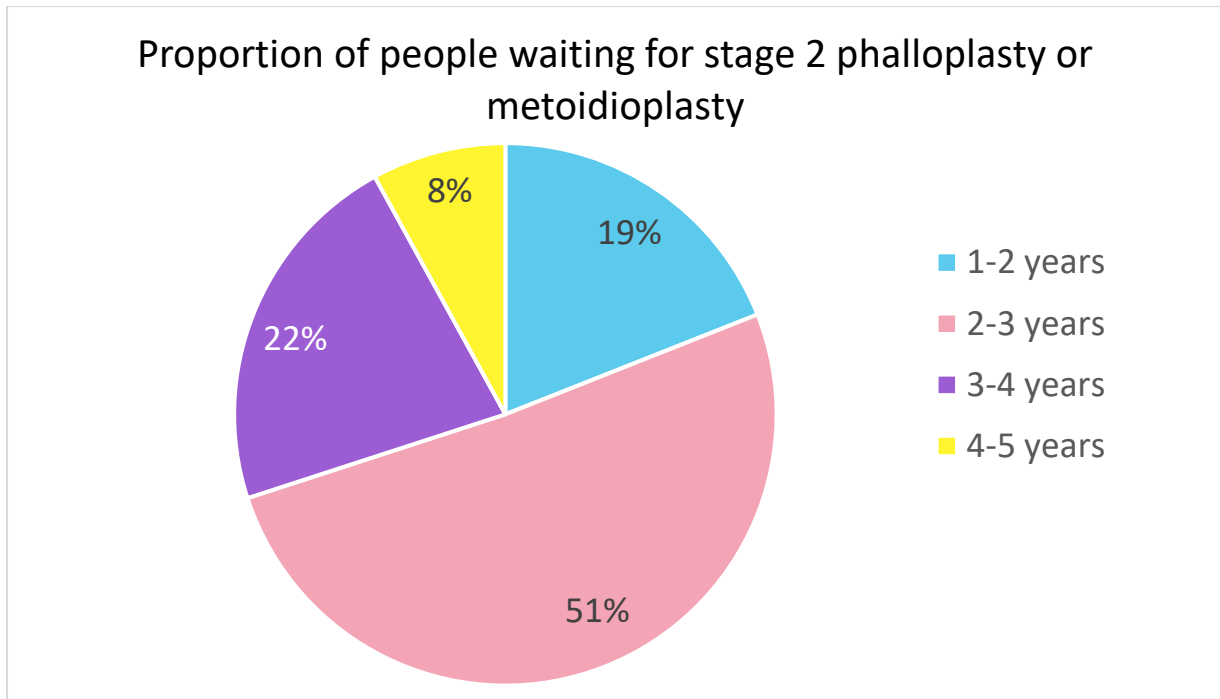
For both phalloplasty and metoidioplasty patients in the UK, stage 2 often consists of urethral hook-up (connecting the neo-urethra to the bladder via the natal urethra), vaginectomy, hysterectomy and scrotoplasty. For people undergoing phalloplasty, stage 2 surgery can also include glans sculpting and burying the clitoris inside the penis. The precise nature of stage 2 will vary from person to person, based on their preferences.

### Waiting list size

17% of survey respondents (32 people) are waiting for stage 2 phalloplasty, and 3% (5 people) are waiting for stage 2 metoidioplasty. Extrapolation from this data may indicate that 102 people are waiting for stage 2 phalloplasty and 18 people are waiting for stage 2 metoidioplasty.

### Waiting times

The majority of people waiting for stage 2 procedures have been waiting since before the Covid-19 pandemic. 81% of our survey respondents were already on the waiting list in 2019. This is no surprise, given that the contract for provision of the surgeries was removed in March 2020. We were surprised that some patients had undergone stage 2 surgeries after March 2020 – we discuss this later in the report.



Length of time	Proportion of people waiting for stage 2 phalloplasty or metoidioplasty
1-2 years	19%
2-3 years	51%
3-4 years	22%
4-5 years	8%

A man on the waiting list for stage 2 told us:

“I’m waiting for stage 2 phalloplasty. I knew that I would have to live like this for a little while – I was told it would be 3 to 6 months. It’s now been 2 years. I’m physically in a state of limbo due to having both a penis and vagina, but also my life is in limbo. I daren’t apply for a new job or progress my career because I can’t afford to go on a probationary contract where I might not get paid surgical leave. Dating is hard – it’s really difficult to explain my situation to potential partners. I didn’t consent to being in this in-between stage for this long.”



## Status for stage 3 patients

For UK based people undergoing phalloplasty, stage 3 is the point at which an erectile device is fitted inside the person's penis. This consists either of a malleable rod, or an inflatable prosthesis.

Stage 3 metoidioplasty typically includes mons resection to adjust the position of the person's penis. It may also include inserting testicular implants into the person's scrotum.

### Waiting list size

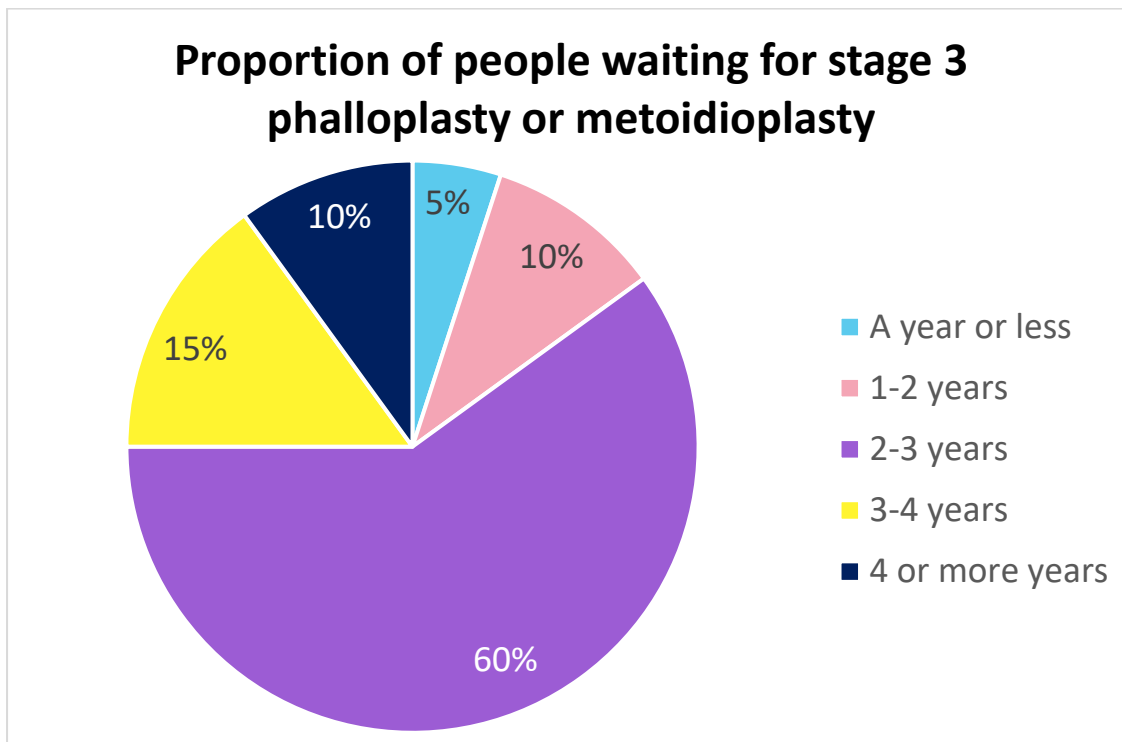
9% of survey respondents (18 people) are waiting for stage 3 phalloplasty, and 1% (2 people) are waiting for Stage 3 metoidioplasty. Extrapolation from this data may indicate that approximately 60 people are waiting for stage 3 phalloplasty and approximately 6 people are waiting for stage 3 metoidioplasty.

### Waiting times

Again, it is no surprise that most people (85%) waiting for stage 3 procedures have been waiting since before the Covid-19 pandemic. However, some people waiting for Stage 3 reported that their most recent phalloplasty or metoidioplasty surgeries took place after the contract for surgical provision had been removed from the surgical team – further discussion of this is included later in this report.



Length of time	Proportion of people waiting for stage 3 phalloplasty or metoidioplasty
0-1 years	5%
1-2 years	10%
2-3 years	60%
3-4 years	15%
4+ years	10%







## People awaiting surgical repairs

13% of survey respondents (26 people) told us that they're waiting for surgical repairs – either as part of a stage 2 or 3 procedure, or as a standalone operation. Extrapolation from this data may indicate that approximately 75 people are waiting for surgical repairs.

Of those awaiting surgical repairs, most reported that the issue arose pre-pandemic.

Type of issue	Proportion of people waiting for repair
Issue with erectile implant	27%
Issues relating to urethra	38%
Issues relating to scarring or poor healing	19%
Other	15%

One person awaiting repairs told us:

“I had my first surgery that went wrong, so I'm waiting for a repair. My repair is to reduce penis size and weight, as it's pulling on my genital area. It hurts. It's heavy, uncomfortable and sticks out. It was not at all what I was told or promised would happen. Its uncomfortable to sit down, or sleep. My mental health has been massively effected as I'm stuck, my life can't progress, I can't experience sex, I can't start a career out of fear of long term absence when I eventually get surgery,”



## Implications

To help us to get a better picture of waiting times now that the new contract has been awarded, it would be useful to know the following information:

- How many phalloplasty and metoidioplasty related surgeries will take place each week?
- How will surgery types and stages be prioritised and balanced?
- How will the waiting list be prioritised?

However, in lieu of that information, we have modelled a scenario based on the best information we have.

We have made the following assumptions:

- Operations begin on 1<sup>st</sup> November 2021
- The team works full time (225 working days a year)
- The team has the use of one operating theatre working at 100% utilization
- A current waiting list of 600 people, with 52% waiting for stage 1 phalloplasty, 10% waiting for stage 1 metoidioplasty, 17% waiting for stage 2 phalloplasty, 3% waiting for stage 2 metoidioplasty, 9% waiting for stage 3 phalloplasty, 1% waiting for stage 3 metoidioplasty and 5% waiting for repair surgery only.
- Patients waiting for stage 1 will access stages 2 and 3 and won't experience complications requiring either longer or additional surgeries.



Based on these assumptions, it will take until June 2025 (3 years 8 months) to complete all stages of surgery for those currently on the waiting list.

If priority were given to completing the surgeries of those waiting for stage 2, stage 3 or for repairs, it would take 8 months to work through the backlog. Almost everybody waiting for stage 2 or stage 3 has been waiting for more than a year at this point (100% and 95%). Even when given priority, many of these patients would have waited 20 months or more in physical limbo between stages. This is unacceptable.

Based on this prioritisation model, it would be June 2022 before any stage 1 patients were seen. 83% of patients have been waiting more than 1 year for stage 1 surgery. In a scenario where priority was given to people waiting for stage 2, stage 3 or for repairs, some stage 1 patients will have waited nearly 6 years for surgery. The majority will have waited for at least 20 months. Again, this is unacceptable.

This scenario would also mean that anybody added to the NHS waiting list now could expect to wait at least 3 years and 8 months from the point of referral before their first phalloplasty or metoidioplasty surgery. This means that someone referred to a Gender Dysphoria Clinic in 2017 might expect to access their first lower surgery operation in 2028, and take until 2030 to complete their medical transition. A 13 year wait to complete medical transition is absolutely unconscionable.



## Surgeries conducted after 31<sup>st</sup> March 2020

As we have alluded to, some patients reported receiving NHS phalloplasty or metoidioplasty related surgery after the contract had been removed from the surgical team. Of our survey respondents, 5 reported having surgery after 31<sup>st</sup> March 2020. Only 2 reported that the surgery had been to fix complications. The lack of clarity around this has led to confusion, increased anxiety, and a sense of isolation amongst those on the waiting list.

This information raises the following questions:

1. If NHS Specialist Commissioning were happy for the previous service to offer operations on those experiencing complications, why were no other patients awaiting repair surgeries offered them?
2. If NHS Specialist Commissioning were happy for the previous service to offer operations on patients not experiencing complications, why did the previous team not continue offering all procedures until the new contract was finalised?
3. Why has NHS Specialist Commissioning failed to communicate with patients about this issue?



## Discussion

NHS patients have the right to treatment within 18 weeks of referral. However, it is clear from our scenario modelling that most people on the phalloplasty and metoidioplasty waiting list will have waited well in excess of 18 months. It is important to reiterate that this is due to the issues with commissioning, rather than Covid-19.

Whilst we welcome the news that a contract has now been awarded for the provision of metoidioplasty and phalloplasty on the NHS, it's clear that the proposed provision is insufficient. Additional measures will be needed to reduce the pressure on the new service. We recommend that NHS Specialist Commissioning make funding available for patients on the phalloplasty and metoidioplasty waiting list to access surgery overseas and take urgent measures to increase the capacity of transition related care in the UK.

We also wish to highlight the impact that the combined uncertainty and long waiting times has had on the mental health of those waiting for phalloplasty and metoidioplasty. It is with this in mind that we recommend that NHS Specialist Commissioning ensure that all those on the waiting list can access timely and appropriate mental health support as a vital interim measure.