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Paper Title: Non-surgical Gender Identity service review: Output of engagement report

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Background

As part of the review of non-surgical gender identity services for Transgender, non-binary and gender fluid (T+) adults in the South West (SW) NHS England and NHS Improvement (SW)'s Development team commissioned a regionwide LGBTQ+ support organisation, the Intercom Trust, to independently survey the views and experiences of gender non-conforming people over 16 living in the SW (n=645).

This provided rich information about the care, support, and treatment T+ adults have received in primary, community and secondary care settings; identified what interventions (if any) they aim to have or have had, including both NHS and non-NHS interventions; and any struggles and challenges they have faced in their gender transition. A summary of the findings was reported to DC SLT on 17 May and the Direct Commissioning Committee on 21 May 2021.

Although the target population for the GIC is Transgendered men and women, the Intercom Trust report revealed a significant number of non-binary and gender fluid individuals being referred to the service. Hence, the scope of this stage of the engagement programme was widened to explore what a more appropriate referral pathway may be for non-binary and gender fluid individuals.

The Intercom Trust findings, combined with insights provided by staff working at the current gender identity clinic (GIC) at the Laurels (Devon Partnership Trust - DPT) showed that the gap between demand and capacity caused by difficulties recruiting and retaining staff at the GIC and bottlenecks in other parts of the Gender Identity (GI) pathway has been exacerbating health inequalities, depression and anxiety among the T+ community as well as lowering the morale of staff at the GIC. This in turn has led to increases in staff turnover, which has further undermined the morale of staff and the experiences of T+ people who described the significant negative impact of having little continuity of care.

The SPRINT

A cross-sector, multidisciplinary SPRINT workshop was held on 30th June 2021 to develop solutions to the issues raised by local T+ people and staff at the Laurels, and thereby codesign a non-surgical GI pathway that makes the South West a better place for T+ people to live and a place where GI practitioners want to work.

Using an amalgam of the lived experiences that T+ people shared via the Intercom Trust survey, people at the SPRINT were asked to 'solve' four case studies that encapsulated the difficulties that the T+ community have been experiencing in relation to access, mental health and health inequalities. They were also asked to suggest ways to mitigate the challenges the current workforce face as they try to meet increasing demand. Please see Appendix A for the four case studies and the questions facilitators had available to keep discussions flowing and focused on the things that the T+ community said they would like commissioners to do:

Recommendations from the Intercom Trust Report

- Review the GIC waiting list to ensure only those that need it are on it.
- Agree criteria for prioritising those that are waiting.
- Improve communication and administration.
- Review training for GPs to better understand the needs of all gender non-conforming people.
- Consider what tasks/support could be carried out by VCSE (voluntary and community sector also known as the third sector) organisations and peer-supporters to release clinical capacity.
- Increase social prescribing to psychosocial and peer support.
- Work with the police and those who have experienced hate crime so that we provide appropriate support with the physical and mental health impacts.
- Understand the clinical implications of informed consent models of hormone prescribing.
- Review transition policies from GID to GIC so that young people who have already been waiting for several years do not start at the bottom of the waiting list for the adult service.
- Provide clarity over the referral and service delivery process and manage expectations.
- Consider the timing of appointments for people that have to travel long distances for care.

Attendance

Just under 60 people attended comprising members of the T+ community, GPs, national and regional NHS England and Improvement's (NHSEI) and CCG commissioners, health inequalities' leads, GIC managers and clinicians, community representatives from Healthwatch and Overview and Scrutiny committees and managers of voluntary and community sector (VCSE) LGBTQ+ support organisations.

After being welcomed by the SW Regional Director and the Director for Specialised Commissioning and Health and Justice, participants were given a summary of the Intercom Trust report by its author; a review of the four models of care pilot programmes that GIC staff had previously asked us to consider (Wales, London, Manchester and C Magic) from the GI programme manager; and an educational and motivational presentation from the European Ambassador for Trans Progression with the European LGBT Police Association, Bee Bailey regarding how to increase our own understanding of how Trans people would like to be treated.

Participants were then allocated to one of six breakout groups. All six breakout groups had at least one member of the T+ community, a scribe and a discussion facilitator present. All groups discussed all four of the case studies.

Output

22 pages of insights were collected during breakout discussions. This was collated together with further information people had added to each room's chat feed as well as additional ideas and offers of support that were sent from participants via email post-workshop.

Over 85 distinct and often interdependent themes for how the GI pathway could be improved were identified. These improvement ideas form the basis of an improved, more integrated model of care (in red) and have been paired with the current barriers to optimum care and other opportunities for improvement (in blue) that participants identified to make it easier to determine whether the new model leaves any opportunities for improvement unseized or any barriers still in the way of optimum care.

The following paraphrased quotes encapsulate the majority views in terms of the number of breakout groups that said similar things and the number of case studies people related them to.

Barriers to optimum GI services paired with suggested solutions

Unsurprisingly, participants highlighted many of the things that T+ people had said in the Intercom Trust report when they described the factors that stand in the way of practitioners being able to provide optimum care and support for T+ adults in the South West. However, SPRINT participants also focused on factors that underpin delivery that are of less concern to the people who access services such as contracting, commissioning, performance metrics, digital capabilities and regulations:

- Better communications between services and to patients
- Capacity (linked to increasing demand and ability to recruit and retain staff)
- Duplication and waste
- Rules and regulations

- Geographical variation in resource availability
- Knowledge/understanding among key professionals
- Integration (with local system initiatives and NHS and VSCE providers)
- Information governance and shared care
- Patient record demographic response options (we record sex, not gender identity – links to access to screening)
- Digital (incompatible systems, out of date records, information governance)
- Commissioning portfolios ((join-up between national/regional/ICS commissioning)
- Key Performance Indicators (incentivises quantity over quality)

Better communication between services and patients across the entire pathway were the most commonly discussed opportunity for improvement, both in terms of providing information to patients at the start and throughout their transition journey and in terms of communications between services.

> *'The lack of communications is an issue. We find out information through social forums. No one knows what's happening otherwise.'*
>
> *'No communication or information to people on the waiting list. No idea what the process is now is or what will happen next. Updates are required.'*
>
> *'Patients receive a letter saying that their referral has been received but hear nothing more for a very long time.'*
>
> *'Comms between GPs and the GIC needs to be improved before more GPs will feel confident about supporting people through their transition.'*
>
> *'Communication is key - keeping patients informed. Honesty is required around key issues such as waiting times for treatment instead of just leaving people wondering if they've been forgotten entirely.'*

What good communications look like

Key information should be clear, honest and transparent and avoid describing gender identity in terms of mental health.

> *'Ensure info about referrals is on routine local systems to reduce misinformation / misdirection.'*
>
> *'Provide people who come out with information packs, FAQs - where do we go from here, what will I be asked, waiting times, proof you have been out is not required etc., that kind of thing.'*

> *‘Knowing in advance what is required at each step in the process would have a hugely positive mental health impact.’*
>
> *‘We need comms to be very specific. We’re yet to overcome the stigma from years of the popular (incorrect) view that Trans is perceived as a mental health issue.’*
>
> *‘Communication is key - keeping Andrea informed. Honesty and transparency is required around key issues such as waiting times for treatment.’*

Regular updates are provided to, and services have regular contact (where possible) with, people who are waiting to progress to the next stage of their transition.

> *‘Ensure people are informed about waiting times and next steps throughout. Even just reassurance "don't worry, we haven't forgotten you, you are still in the system".’*

Information is accessible no matter where T+ people first come out or seek help, either to their GP or mental health worker or someone else. This information could also be online for people who self-refer.

> *‘Put the information and support where people will seek help - for under 18s this would be school. Not everyone goes to a GP.’*
>
> *‘Self-referral is now available (very recent), making it really vital to have an information pack readily available for people upon self-referral.’*
>
> *‘The GIC website should have links and resources for people to access – surgery, expectations, psychological services, fertility, mental health, parental information to support young people.’*

Information is provided in a range of formats and languages that reflects of the diversity within the T+ community in the South West.

> *‘Update and revamp the NHS web page with links and current information. Including information on how to change records, links to local peer support groups and charities who can provide a safe space. The current NHS webpage does not have information for non-binary people and it isn’t clear how people don’t have access to a computer or don’t read and write English can access the information.’*

Review all existing patient-facing information that is currently available before any new patient-facing information is developed as examples of existing sources were shared in the chat feed as a small sample of what is available.

> *‘This Patient leaflet is an amazing leaflet despite an unpromising title: https://www.optionsforsexualhealth.org/wp-content/uploads/2019/07/FQPN18-Manual-EN-BC-web.pdf - Could we adapt/adopt this?’*

> *'There is a CAMHS psychologist researching what things Trans and non-binary people living with autism have struggled with to look at how to weave this into the NHS guidelines. They have created a video including the results of the research and are now putting together an illustrated document for gender clinics to teach them how to offer support without sensory overload and know how appointments can be given.'*

Provide an up to date directory of community-based T+ support organisations that people could go to for psychosocial support and to reduce their sense of social isolation. Making this directory of services available to GPs and other potential points of referral would also support greater use of social prescribing and provide something more akin to the holistic joined up pathway that participants said was lacking in current provision.

However, it is recognised that developing any directory of VCSE services is likely to need regular reviews to ensure it remains current. Currently, typically, GPs across the region signpost people to where available to community link workers and community makers in PCNs who link them to what is available at community and neighbourhood level, matched to the needs of the specific individual.

> *'Social prescribing would be of huge benefit to many service users. Lots of support is available in the third sector. People just need to know what's available and how to refer people to it.'*

> *'GPs need to be aware of mental health support available in the third sector and be able to direct service users to it.'*

> *'Trained volunteers could help to support and advise at a community level. The Laurels already has them. There will be lots of others out there.'*

Training is needed to support and develop a cohort of gender-friendly GPs to make it easy for people to find the information and support they need. In doing so, we may increase the number of people who feel supported and reduce the number of people who report feeling isolated, discriminated against and go through multiple attempts to find a GP willing to support their transition.

> *'Identify a gender champion in each PCN. Ensure that person (a GP with a special interest) has a degree of accountability within that PCN (or whatever footprint) and they can support and train other GPs in the area, including in prescribing hormones.'*

> *'Because people haven't got time to wait for the training to roll out, in the meantime a list of fully trained GPs available in the South West could be made available to support people straight off.'*

> *'It comes down to word of mouth too often. An NHS register of those who have special interest in this area could be really useful.'*

Capacity across the entire pathway was also highlighted by every breakout group whereby limitations in access to services external to the GIC were said to be creating bottlenecks.

> *'Capacity is the obvious problem. The Laurels is great, but it's not enough for the whole of the South West.'*
>
> *'Only two GPs at the Laurels can give a 2nd opinion. That needs to be more to be able to meet demand, simple as that.'*
>
> *'Capacity to support the pathway is also needed. Good admin is the backbone for service delivery. If we had more admin the rest of us could spend less time doing paperwork and chasing things and more time with patients.'*
>
> *'Lack of medical and diagnostic capacity results in waiting lists not progressing.'*
>
> *'We need more providers to offer feminising surgery.'*
>
> *'More speech and language therapists are vital.'*
>
> *'Exits block GIC throughput. 50% patients want some sort of surgery but no national provider for phalloplasty (even though commissioned) – we are adding to a waiting list where it is not going to happen – why do we do this, it's cruel and unethical?'*
>
> *'GPs are at capacity, demands on them are already too high.'*
>
> *'Community mental health services have long waiting lists and are impossible to see. Only in absolutely crisis may you see someone.'*
>
> *'There is poor access to mental health services, especially crisis services, and not a warm welcome when accessing crisis service, just at the point when feeling very desperate because of the delays in the pathway.'*

Indeed, lack of access to other parts of the pathway such as mental health or surgical provision was the most common reason given for long waiting times for the GIC as the clinic continues to keep people on their caseload until their transition goal has been reached.

> *'The Laurels has about 300 patients listed for surgery. They all have to be seen every 6 months until all of their surgery is completed, which uses up appointments we could be spending with new referrals.'*
>
> *'When people are referred to the GIC now, if mental health concerns are identified by the triage team, they refer them back to generic local psychological / talking therapies services. However, there is another delay for*

> *people waiting for these and the perception is that these are not suitable and/or will not accept referrals for people wanting to explore and address these specific issues so they end up back with us.'*
>
> *'People are being turned away from MH (mental health) and autism services because they are already accessing Gender Services and similarly, being turned away from GIC services because of their mental health issues. There are also recurrent issues of GPs referring patients to mental health services in the first instance rather than GIC Services. All of this creates delays and additional anxieties for the people seeking our help.'*

Concerns about lack of access to mental health support and the delay this might impose on reaching people's transition goal was said to provide a further perverse incentive for members of the T+ community to avoid seeking help for any mental health concerns they may have.

> *'Do mental health issues stop the clock in terms of the gender journey? People are unsure, which in turn may mean individuals don't present with MH issues as they think it will delay process.'*
>
> *'Some people will identify as x to get treatments - they feel that their truth is less important than what they think the service needs to hear.'*

Delays between different steps and stages in the pathways, combined with prolonged difficulties recruiting and retaining staff, were creating a gap between demand and capacity that was not only creating long wait for ingress into the GIC, but was also having a detrimental effect on continuity of care for those who were waiting for surgery, and undermining staff morale.

> *'Existing services have high turnover and difficulties recruiting.'*
>
> *'Some people start working and then feel that the GIC isn't for them. I heard a statistic of 1:4 people move on. The biggest problem is turnover in medical staff.'*
>
> *'Lack of continuity of care is a problem. Maternity leave/rotation etc. How do we mitigate that?'*
>
> *'Once people reach services, they have continuity of care. However, given the timelines there will be natural turnover resulting in changes of staff between appointments.'*
>
> *'Multiple surgeries for Trans men magnifies the waits in between appointments. Each appointment feels like you're starting again, even if you're seeing the same person. If you last saw them 18months ago they don't remember you so you have to repeat everything.'*

> *‘High staff turnover at the Laurels and competing with the private sector is demoralising, made worse with waiting times all over media headlines.’*

Increase capacity

Develop a long-term workforce plan that includes a strategy for attracting and retaining staff. This should include ways to attract students studying relevant subjects to work in this field after they graduate.

> *‘Workforce planning is needed for specialist staff.’*
>
> *‘Is there an equivalent of a GIC teaching hospital, surely that would help replenish staff?’*
>
> *‘Provide training and an NHSE plan for next 5 years to reduce unpredictability, train staff, improve training, and keep staff.’*

Provide training for the range of professionals and VCSE organisations that T+ people already seek support from to increase the number of people who can triage and check up on people, as well as training for GIC staff to help them develop internal assessment processes that are more streamlined and efficient.

> *‘Volunteer section help at the Laurels – trained volunteers could help to support and advise at a community level.’*
>
> *‘More training within the GIC service to assess new people quickly and move people on quicker for referrals for services they require.’*
>
> *‘The NHS requires a lot of additional steps and check-ups whereas private practice is much more streamlined, so they get through a lot more people. What can we learn from them?’*
>
> *‘There have been some successes recently in GICs around expanding the diversity of the medical staffing – including GPs, gynaecologists and others beyond clinical psychologists.’*

Improve care navigation and reduce inappropriate referrals by working in partnership with existing community link workers/community makers in Integrated Care Systems/Partnerships (ICS/P), primary care networks (PCN) and local VCSE organisations.

> *‘The GIC could work in partnership with the voluntary sector to provide peer navigators, support groups and a support line, but we’d need extra funding.’*
>
> *‘Can services be provided elsewhere other than the GIC? Waiting list could be broken down into different service areas? Triage referrals to help reduce*

> *demand. Some people are very clear on specific service needs that don't require a complete surgical journey.'*
>
> *'Ensure GPs and referrers / first contacts understand the multiplicity of need and distinguish between the need for early - if necessary, non-specialist - intervention and specialist intervention which may not be available so soon. This requires a more person centred 'conversation' about 'why the world doesn't fit for me' because not everyone's situation requires GIC input. GPs aren't given time to have those kinds of conversations so there needs to be some kind of link worker attached to the practice who is trained to have those conversations.'*
>
> *'Training all GPs in South West is a huge undertaking. Alternatively, you could just recruit sign-posters who can support people to find the right intervention.'*
>
> *'Initial assessment is key. Not everyone wants surgery. Can't just be the Laurels or nothing. Needs to be much more. Need to be brave and creative. Look what's happening in Greater Manchester where they have care navigators. Client feedback has been fantastic. It could even be peer support with the right training.'*
>
> *'Initial support through care navigators could be online. That helps in terms of anonymity.'*
>
> *'The best pathway is where the initial contact is with a specialist GP within each PCN. People are then given a care navigator who then triages/discusses and signposts on to GIC or a different service, whatever is most appropriate. GIC then refers for surgery if necessary.'*

Validate the waiting list for the GIC clinic to identify and transfer people whose support needs could safely, and in some cases more appropriately, be met in primary care or the voluntary and community sector.

> *'Double check the waiting list, if people have died or changed their mind this will help reduce the waiting list and speed things up for the people who remain on it.'*
>
> *'Utilise the existing Central Waiting List Management System; have routine phone call/video appointments and a proactive named worker to contact people. Say we will contact you every X weeks for a 30 minute welfare check, and have a named point of contact. This could then also be potentially triaged/RAG rated to identify and prevent any potential mental health crisis, ensure only appropriate people are on the list and could inform things like prioritisation.'*

Expand the use of remote consultations to enable the GIC to see more people without time being taken up by covid-related standard operating procedures.

> *'Digital appointments can increase capacity.'*
>
> *'Greater use of digital appointments is popular with staff and many patients. However, there is a difference in preference from patients and for different purposes of appts. Offer choice to account for personal preference.'*
>
> *'More video consultations would be great. You only need face to face when you need to lay on hands.'*
>
> *'It's really positive that we now have video appointments - saves a lot of time in travel for patients and I hope means that the GIC can see more people. Since covid, the Laurels use 'attend anywhere' for all types of appointment - still some face to face work but having the option to meet people remotely definitely helps.'*
>
> *'The South West is a vast area, mobility issues exist. Video appointments is so much better and more efficient.'*

Duplication and waste

Participants also suggested capacity could be released by streamlining processes and grouping appointments where possible.

> *'Offer group check-ins as an option on top of one to one discussions. These types of workshops could save time further down the process, may reduce the number of one to one check ins we have to do, and prevent mental health problems from getting to the point that people then need to be referred for a mental health consultation.'*
>
> *'Daventry knew it was a 600-mile round trip for an appointment, so they moved appointments around. That way I only had to make one trip and had two appointments on the same day.'*
>
> *'Streamline the service. A lot of NHS appointments are completely pointless and repetitive. You should be able to have 2 assessments 3 months apart and receive a hormone/surgical referral on the same day.'*

Such steps would also improve the patient experience of people having to travel long distances from outside the region.

Rules and regulations

However, some opportunities for streamlining are a consequence of current rules and regulations that are nationally mandated. For example, the number of second opinions required by the current service specification and safety related standard operating procedures governing face to face interactions that came into effect at the start of the pandemic. This greatly restricts the ability of NHSEI (SW) or the GIC to relax or change them.

> *'At the moment there's a requirement to have 2 people sign off on proceeding We've been told that the new guidance coming will change this to one, but when?'*
>
> *'A second opinion is required by surgeons for lower surgery – this is double checking the professionals, not the patients, but the patients still have to be put through it.'*
>
> *'In the 2 years prior to Covid the GIC had halved its internal waiting time. This was scuppered by Covid because of lockdown regulations and enhanced safety procedures.'*

Geographical variation in resource availability

Reduce geographical variation in access by expanding provision where necessary to reduce current waiting times, increase activity, better meet predictable growths in demand, improve the resilience of the GIC against staff turnover and extended leaves of absence, and provide more out of hospital care closer to where people live.

> *'Increase surgical capacity. Patients are literally trapped with half completed procedures due to lack of ICU beds at St Peter's.'*
>
> *'The Laurels is not enough for the whole of the South West. Need to explore opportunities for more localities. The Laurels is also referred to from across the country, not just the South West.'*
>
> *'Alex could be supported by the intercom trust service which will assess and signpost. But that only covers Devon and Cornwall. Similar services are required elsewhere.'*
>
> *'If there were more localised GIC services then the referral would be sped up, including triage for bridging hormones. Then people wouldn't have to access private hormones and a prolonged wait could then be avoided. Then in the future, people can access more specialised services such as speech therapy though the local GIC.'*
>
> *'GICs that are based around the six counties to ensure accessibility.'*

‘Initial front door to be a sign-poster/care navigator (geographically spread) rather than a GP.’

‘A wider geographical footprint is needed with a regional ‘hub’ in the South and another in the North, with community based ‘spokes’ at ICS level in PCNs.’

Knowledge/understanding among key professionals

Some of the above suggestions could also help to reduce the number of inappropriate referrals made to the GIC and the level of reluctance to support people’s transition and prejudice that some T+ people had experienced.

‘Generic services don’t understand the complex needs of gender non-conforming people, so they refer to the GIC when they don’t actually want surgery. They just need psychosocial support.’

‘The GIC is getting referrals from mental health services just because someone has expressed gender dysphoria (or simply stated they were Trans).’

‘GPs are often unaware of the process, of how to refer, of what the wait is or isn't, that the distress isn't indicating a sub Mental Health referral necessarily.’

‘GPs need to be more aware of the needs of service users and the service they are referring in to. When I trained as a GP there was no trans changing. They need to know how to handle situations.’

‘It’s partially lack of knowledge/awareness, fear of doing/saying the wrong thing, and partially due to prejudice in some GPs/Practices.’

‘Some people experience hostility – GPs refusing to treat you – this is against guidance!’

‘GPs that don’t follow the recommendations of the GIC also needs to be addressed.’

‘There’s an over-reliance on the GP who doesn’t understand and doesn’t want to prescribe a bridging prescription. (CS)

‘Gender dysphoria was de-classified as a mental disorder by the World Health Organisation (WHO), but that was never reflected in the NHS. WHO declassified it as MH issue, but GPs still assume it is.’

‘So much is reliant on individual GP choice about taking up the training opportunities or agreeing to take Trans people on. I hear stories of young people being passed from GP to GP. With the waiting list so big they can’t afford time wasted being passed from GP to GP.’

> *‘We hear of many GPs refusing to take bloods as they are not prescribing the hormones, and they refuse to prescribe hormones so it’s a vicious circle - some GPs will, others won't. It’s as simple as that.’*
>
> *‘There are good GPs who are supportive and willing to provide bridging prescriptions, but a lot of them refuse because they have little knowledge of prescribing bridging hormones and are frightened of being sued / insurance going up.’*

This is important because difficulties in accessing Trans-friendly primary care and bridging hormones were directly linked to risky health decisions being taken by some members of the T+ community during most breakout group discussions.

> *‘Individual GPs may be very worried about being sued but their inaction may cause harm if it forces people into self-medication.’*
>
> *‘People are buying hormones online/going abroad for surgery because they’re so desperate and GP won’t give them. It’s really dangerous blood tests etc. are required to monitor hormone levels.’*

Increase understanding and capacity: Support for practitioners

Increase access to training and support for health professionals to increase confidence in prescribing hormones and raise awareness and understanding in other parts of the system.

> *GP’s need to help people with treatment immediately (prescribe hormones) – fear with YP (young people). GP training?’*
>
> *‘More training for mental health services staff is needed so they better understand the needs of non-binary people with autism.’*
>
> *‘Support groups exist. Training would be valuable to those groups.’*
>
> *‘Develop competencies for everyone: psychologists, experts by experience, local police force – public protection units, social workers, named professionals, liaison experts (E.g. Bristol hate crime service), pharmacists, GPs and legal advisors to combat discrimination.’*
>
> *‘More training with GP services including receptionists is required to increase understanding and awareness.’*
>
> *‘Provide information via mandatory training/GP awareness training. We all have to do mandatory equalities training so we know what laws we must respect etc., but they should include information about how best to do that too. For all NHS staff - Training packages – information on health inequalities,*

> *the diversity under the LGBTQIA+ umbrella. We have resources, but not in the right place at the right time.'*

Recognise excellence by encouraging practices to display when they have a gender champion or when a GP has undergone GI training. In taking this approach, health practitioners could provide a visible show of support for T+ people, helping challenge any stigma and prejudice and making neighbourhoods safer places to live.

Training should seek to widen understanding of the range of gender identities and how to avoid making people feel unheard and/or unseen.

> *'Could there be a star rating for a GP practice, for example a 5-star rating if all GPs in a practice are up to date on LGBT+ training? Could make use of the NHS staff training records.'*

> *'Patients don't feel heard and we need to work in ways that makes them feel heard.'.*

> *'12% GPs do not want to be involved. The others do, but a lot of them are unsure how. Find a way to get GPs who want to help by helping them understand this group of people and their varying needs and that's a good start.'*

As with previous discussions concerning communications and patient-facing information, participants shared a range of training that is already available.

> *'The Laurels have developed bespoke training for different organisations. Developing a role out for other services. Better informed = better support. Establish where needs are best placed.'*

> *'Royal college of GP's LGBT+ health hub - training is available there.'*

> *'My team and I have done a huge amount of work with NHS trusts, university medical schools and health-related charities. All of our trans trainers are trans people with a wealth of lived experience. Please see https://www.diversitytrust.org.uk/transgender-awareness-training and https://www.diversitytrust.org.uk/clients-partners ' (via email post SPRINT)*

Review all available training, who it is aimed at, and how to access it and work with relevant Deaneries, the T+ community and Health Education England (HEE) to codesign training packages to fill any gaps.

To encourage uptake, NHSEI (SW)'s Communication and Engagement networks could then promote this training via bulletins and newsletters for clinical and non-clinical partners.

Provide advice and guidance regarding legal risk to enhance the understanding of practitioners of the legal consequences of prescribing hormones to someone who later changes their mind, and the chances of someone doing so.

> *'There should be no issue of litigation for GP's in terms of referral. If private organisations like Gender GP and GenderCare are comfortable enough with the legal position and patient disclaimers, can we get our GPs to the same place where they don't see a disproportionate risk of litigation?'*

> *'Only one person at Laurels/intercom ever changed their mind post treatment so there is no need to be so concerned about people not being sure of what they want.'*

Provide access to expert clinical advice

> *'The model of care needs to include a need for a safeguarding lead - People educate themselves on bridging hormones but speak to GPs who currently lack the knowledge. And it needs a Clinical physiologist to talk to GPs, so people don't have to go back over old information wasting time and the GP feels confident about prescribing the hormones.'*

> *'The new model needs to provide easier access to bridging hormones under a harm reduction guise with the correct information. A simple informed consent model and endocrinology support for GPs is all you need.'*

Empower GPs to provide the things that don't require specialised GI training

> *'People could be triaged and access hormone treatment with the support of the GP practice, with the GP taking bloods and getting any training they need to be able to prescribe hormones etc in the period whilst people are on the GIC waiting list. It's also an opportunity to meet any other health needs including mental wellbeing.'*

> *'There are usually various issues, for example. depression, that GPs can manage even if they don't feel able to prescribe hormones.'*

Empower and enable T+ people to make decisions about their own care

> *'Can we do something about giving Trans people the right to make a medical decision once they have been informed of the risks? Akin to how people can discharge themselves from hospital early?'*

> *'We need a service user informed consent model. Service users can sign a waiver, so they go past GPs and straight to hormone replacement therapy. Model works elsewhere. Shouldn't take 5+ years to get someone approved for hormones.'*

> *‘GI clinics want all pre-existing health issues sorted before you are progressed. Treat the person’s needs first. Who decides what my priorities are? Does ‘No decision about me without me.’ not apply to Trans people?’*

Integration (with local system initiatives and NHS and VSCE providers)

Breakout discussions highlighted the need for better integration, communication and collaboration between those providing each part of someone’s care pathway. Indeed, all of the above suggestions would require oversight and coordination of all parts of the pathway at a primary, secondary and tertiary level, with the majority of someone’s support provided in local communities at a system level.

> *‘Some providers of fertility treatment are not approved, and integration with NHS services is therefore not possible. Assessments are required to keep it fair chronologically, but that does not mean you need a re-diagnosis.’*
>
> *‘There is a lack of support between GP and specialist services. There is a lack of information and the way information is passed on between different providers is inconsistent.’*
>
> *‘People need better access to a specialist holistic team that includes specialist and generalist support all working as one.’*

Indeed, people said the current paucity of joined up provision creates duplication that could potentially be avoided.

> *‘There needs to be a better integration between private treatment and NHS surgeries – is there a need for a new diagnosis after people that have been through private transition treatment?’*
>
> *‘Multiple appointments - are we wasting resources and not adding value with these?’*
>
> *‘Appointments don’t seem to have a purpose / value – appointments for appointments sake.’*

Providing a more integrated GI pathway

Integrating existing community services across the region with primary care and GIC provision would enable T+ people to have easier access to other health initiatives that aim to protect and improve the physical health of this community.

> *‘25% of homeless people are LGBTQ. Work through outreach services to be aware of what services are available and promote them.’*
>
> *‘We need to adopt a Community Care Hub model – safe, accessible space, 3rd sector organisations, network of skills and support, links to housing, police – community setting.’*
>
> *‘The community need more support groups, for example for trans people with autism. A model that shares care with social care charities is a good idea. Surely groups can be more than sitting around? How about a gym group (help physical care)? How about social groups? How about specific other links with other types of support like housing and addiction?’*

Some participants wanted services that are ringfenced for T+ people. However, community support groups already exist for lots of different health needs such as autism, diabetes, heart and stroke, respiratory and mental health etc. To avoid reinforcing the sense of isolation and discrimination that T+ people experience we need to encourage those existing groups to develop services that are inclusive and welcoming to everyone regardless of their gender identity within existing community care hubs.

Community care hubs are already being developed by PCNs at ICS level. NHSEI (SW)’s specialised and primary care commissioners can ensure T+ needs are met by these hubs by working in closer partnership with ICSs and PCNs.

Similarly, Community makers/link workers already operate at neighbourhood and community level to provide care navigation and support social prescribing. There is no reason why these practitioners cannot provide the same support to members of the T+ community as they do the rest of the population. Indeed, to do so, could further marginalise T+ people and separate them from the rest of society.

There is a growing body of evidence to show community maker/link worker model is already reducing frequency of calls to 999 and presentation to emergency departments (https://www.youtube.com/watch?app=desktop&v=MXtskdEtVRI).

> *‘The service spec needs to be able to describe an end to end pathway where the specialist gender services run alongside and join up with a wider offer that seeks to address an individual's health and social needs more holistically.’*
>
> *‘A joined-up process is required with ICS/Ps to provide all care required without people dropping off the gender pathway because there are no local GPs willing to prescribe hormones or no access to local mental health support etc.’*

Moreover, the turnover of community makers/link workers is considerably less than the 1:4 ratio cited by the GIC. Therefore, at least in the interim, (with sufficient training and support) the community maker/link worker model could also provide greater continuity of care. Hence, the GIC should be encouraged to become active members of each of the seven ICS provider collaboratives to forge links with existing community provision and to ensure local plans to reduce health inequalities explicitly include T+ members of the population in ways that recognise their diversity and does not just assume their needs are automatically the same as a lesbian, gay, bisexual or questioning person.

Information governance and shared care

Greater partnership working and integrated delivery can only work effectively if it is supported with information sharing agreements and universally accessible shared care records. However, incompatibilities between digital platforms combined with information governance (IG) regulations were said to be currently limiting the effectiveness and usefulness of remote consultations.

> *'IG rules give limited flex for auto transcribing from video conferenced appointments so we can share information between us and anyone else who needs to know about a patient.'*
>
> *'Establishing a shared care record between us and a GP practice and the private sector can be very tricky because we're all on different systems and we can run into IG issues.'*

The primary solution that most groups suggested to overcome this barrier was to *give patients ownership of their own records* and, with it, the ability to share them with any service they come into contact with.

> *'You can easily get around GDPR just by creating a digital app like the one we have for people now if they want to see their medical records, where the service user has all of their information in one place so that they can look at and take to all appointments – similar to the red pregnancy book.'*
>
> *'In an ideal world, remote appointments can be recorded which could help new staff members and their care team to ensure that they are not double working. Auto transcribing software could help keep an accurate account of the appointment to help any new people to the individual's case. If the record was printed and sent to the patient they could at least go armed with it at the next appointment wherever that may be so they can say they've had the conversation and don't need to keep repeating their situation to people.'*
>
> *'We need regional and national shared care protocols – define use of drug (including hormones) /class of drug/responsibilities of specialist/GP/patient and support for GPs if advice is needed. Support prescribing in primary care*

> *with information regarding safety for patients. Primary care Hubs – can they support prescribing? Could we get independent prescribers?'*

However, the current convention for recording demographic information needs to be reviewed before that happens.

Patient record demographic response options

Recording sex in terms male/female/unknown with no facility to record gender identity on current NHS record systems was said to create additional health inequalities and health risks for the T+ community.

> *'Online check-in services ask whether you are M/F and there are no other options. How can Trans people make the most of NHS services when systems are so off-putting?'*
>
> *'We can't be marked as 'non-binary' in the NHS record system and the summary care record doesn't change without recreating a different NHS number.'*
>
> *'People who manage to change their records to reflect their gender identity experience greater difficulties accessing screening and other support.'*
>
> *'GPs have said they won't change sex on someone's record as Trans people won't automatically receive invites for the services they need.'*
>
> *'I get invited to mother and baby classes but can't get the prostate exam I need.'*
>
> *'There are endocrine issues for people on the pathway and after. For example, Trans men with ovaries need support to manage the menopause, but that might not be obvious from just looking at their record if their sex has been changed.'*

Digital

Differences between digital patient record systems were also said to cause additional problems when individuals change address.

> *'There is a huge gap between care records on different systems. Current systems can't cope with modern society. May have updated records on one system but another still sends information to an old address with previous name.'*

However, given the vast range of organisations that would need to be able to access the shared care records of this diverse group and the differing digital platforms each currently uses, without a national mandate, the improvements below can only be implemented at a local level. Therefore, the following suggestion would need to be explored in partnership with ICS digital leads.

> ‘You need to have a distinct field in the record because 'sex' is different to 'identity' - just like we have a name and known-as field. At the moment 'Sex' cannot be updated until someone has transitioned fully - and they may have medical needs e.g. screening invitations that must be offered based on their anatomy irrespective of their identity.’
>
> ‘Instead of tick box stock letters for M / F have GPs select what services/check-ups an individual is eligible for (i.e. anyone with a prostate should be offered a prostate examination).’
>
> ‘The NHS needs gender fluid and non-binary categories, not just male and female.’

Commissioning portfolios

Integrated, joined up provision also requires joined-up commissioning. However, divisions in the current commissioning portfolios of the national and regional NHSEI commissioning teams and those of clinical commissioning groups at ICS level fosters a lack of alignment in priorities that has also created a postcode lottery.

> *‘Primary Care: what is their role and who commissions primary care pathways? Who will be the provider of less centralised support for these patients – PCNs (Primary Care Networks)? Localities? One Care? All of that needs to align and none of it currently seems to be very joined up at the moment.’*
>
> *‘Access to surgery is commissioned separately and additional to what the gender clinic can provide. This causes a separate wait and all those people waiting still need access to GIC support from the same team who are trying to triage new referrals.’*
>
> *‘There is wide variation in PCN priorities and capacity and the assets available at community level and all of those are commissioned by CCGs (clinical commissioning groups), so even if specialised commissioning reduce the waiting list for the GIC you still wouldn’t have equitable access.’*

Aligning commissioning policies and priorities with Integrated Care Partnerships and national commissioners is at the heart of the ambition in the government’s white paper for the NHS currently progressing through parliament. The model of care that has emerged from discussions with practitioners and people with lived experience suggests that strengthened partnership working between NHSEI (SW)'s commissioners and those of Integrated Care Partnerships (ICP) will help to further ensure regional and local priorities align and help to reduce postcode related variation in service offer and patient experience.

> *'National and local priorities need to join up.'*
>
> *'Commissioning whole pathway not bits of it in isolation. Primary and community care, GIC, mental health and surgery needs to be commissioned together. Pathway needs to consider gender identity as a whole not just transitioning.'*

A primary provider model of commissioning for all non-surgical aspects of the gender pathway may help to remove some of the barriers that are currently being reported due to a number of organisations responsible for commissioning different aspects of the GI pathway. This would reduce the need to have multiple contracts with all of the different LGBTQ+ organisations that provide much of the T+ community's care navigation and psychosocial support to ensure their continued sustainability and resilience.

Key Performance Indicators

Participants also suggested the metrics currently used to assess the effectiveness of GI provision needs to be reviewed as the way that it is currently contracted favours quantity (activity) over quality (patient experience), and only then if someone's transition goal is surgical.

> *'Block contracts cause problems: For example, the Charing Cross experience of squeezing what's on offer within the block funding.'*
>
> *'The current payment processes do not incentivise quality of service offer.'*
>
> *'Activity targets that focus on time to first surgery leave zero incentive for supporting someone's pathway if surgery is not someone's transition goal.'*

Therefore, any new contracted model of care needs to have key performance indicators that reflect quality of patient experience as well as clinical outcomes and measures of productivity.

> *'Outcomes focused targets that include feedback from patients are what you need.'*

Whilst the above model of care co-designed by a diverse cross-sector, multidisciplinary group of practitioners, commissioners and members of the T+ community addresses each of the things that the T+ community originally asked us to address, its success will depend on the sustainability and resilience of the services upon with the GIC is interdependent and the strength of partnership working, coordination and collaboration between different commissioning organisations and private, NHS and VCSE providers.

Not all of the things that participants suggested are within NHSEI (SW)'s control. Nevertheless, they are included here as a small step towards meeting our responsibilities as an anchor institution and so that, in circulating this document more widely, we may influence those who can help to improve the things we cannot.

> *'Support for T+ people within work environments is needed.'*
>
> *'International guidance sets requirements for one year on hormones and time spent living in role. Changes here would speed things up. Note: There is no national guidance for UK.'*
>
> *'There is a support gap post transition when people might need ongoing support with preserving family relationships, being the victim of hate crimes.'*

The development team and specialised commissioners would like to thank the 645 members of the T+ community who shared their experiences and insights with the Intercom Trust. This information has been invaluable in guiding the design of the engagement programme and the parameters of the recommended model. This report shows that those who provide GI services also want to be able to provide the same holistic, person-centred and responsive service that T+ people need. The team would like to thank all of the people who gave up their entire day to share the above ideas and concerns in order to help us codesign the recommended model of care.

Next steps

Further, targeted stakeholder engagement to develop ideas regarding training and curriculum development with HEE, relevant Deaneries, GPs, MH and VCSE organisations to decide what training is needed, by whom and how to maximise uptake would be advantageous.

The report will be shared with key stakeholders to include this as part of the wider integrated care discussions on these areas at sub-regional level as ICS' and PCNs engage with their populations to collaboratively develop ICP priorities and local community care hubs.

ENDS

APPENDIX A – Discussion Group Topic Guides

CASE STUDY 1 - ACCESS

Andrea, 24-year-old trans woman

I first built up the courage to speak to my GP about my gender identity around four years ago. The GP was obviously taken aback at the information and looked it up online while I was there. I was then (incorrectly) told that I could self-refer to the GIC at this time. It took me another year to build up the courage to go back and the GP subsequently made a referral and told me it should be about an 18 week wait. That was 40 months ago.

I received a letter of acknowledgement at the time but have heard nothing since then. I was hoping I might get some advice about what the pathway involves, what I can do in the meantime, and other avenues of support. I have heard of many people waiting for longer than I have been. I feel forgotten and hopeless about ever getting through the waiting list.

I have been living in my gender for three years now but have found that my body continues to become more “male”. Over time my mental health has worsened, and I have felt more isolated. I am now starting to experience a receding hairline and I’m terrified of losing my hair. I have become increasingly desperate for HRT. I have tried to move the process forward myself, but I cannot afford private care. I asked my GP for a prescription for bridging hormones but was told that they would not do this in case I regretted my choice later and started legal action. I have therefore started purchasing hormones on the internet which is costing me more than I can afford and means I can no longer join the social activities that used to keep me connected.

- **What support would Andrea need to protect her mental health and reduce the risk of her undermining her health by self-medicating?**
    - **Who could provide that support? (VCSE? GP? GIC?)**
- **What support could be given to Andrea to help her feel less isolated?**
- **How do you think Andrea’s GP feels?**
    - **What makes you say that?**
- **What could we do to support/empower Andrea’s GP? (Training; protocols; link worker)**
    - **Are there any precedents from secondary that could be usefully applied? (e.g. discharging oneself against medical advice?)**

CASE STUDY 2 – PATHWAY EFFICIENCY

Debbie, 58-year-old trans woman

I spent a long time coming to terms with my gender. I was first assessed by the GIC in 2017. I am now prescribed HRT and I have also had some laser hair removal on the NHS and some privately. I would like surgery to completely become myself before it's too late to live. From my perspective there is far too much repetition and red tape.

I also have mobility problems and had to travel a long distance for each appointment, taking a full day off work each time. I would much rather telephone or video contact. I have also struggled with staff changes as I have had three different Case Managers and I never know who to expect when I turn up. I believe this has contributed to feeling like every appointment is a 'first one' and that despite staff often being very nice and caring, no-one there really knows me.

I was recently told that I need another appointment before being referred for surgery, which will take 12 - 18 months. Although I understand the need for a second opinion prior to lower surgery, at each appointment it has felt like they give me a full and thorough assessment which I believe is unnecessary. I have now had several appointments like this. I don't like the thought that I am taking up appointment time that is so obviously needed for others. The wait time is intolerable – I don't know when my next appointment will be and can't even estimate how long the wait will now be for surgery.

- **What could we do to reduce waiting times?**
- **How could we increase capacity? How could we?**
    - **Recruit staff**
    - **Retain staff**
    - **Expand roles**
    - **New roles**
    - **Tasks given to partners (VCSE)**
- **What could we do to reduce the need for Debbie to travel?**
    - **Could any appts be completed digitally?**
    - **Could we group appts on a single day?**
    - **How could we reduce the number of people seeking treatment in the SW from out of areas?**
- **What could we do to make the wait more tolerable?**
    - **Explore role for VCSE partners; GPs; new roles such as community link workers**
- **What would need to change to speed transition between milestones?**
    - **Changes to rules/regulations/comms?**

CASE STUDY 3 – PSYCHOSOCIAL SUPPORT

Alex is a 30-year-old who identifies as non-binary

As a result of my gender identity, I have suffered abuse and estrangement from my family and been assaulted on the street.

I have struggled for many years with my mental health and rarely feel safe. I have a history of self-harm and am battling suicidal ideation on a regular basis. I have been prescribed medication for depression and anxiety but find engagement with GP and mental health teams difficult, at least in part due to regular misgendering. On my NHS records, I am female and the name recorded is the one I was given at birth. This contributes to me feeling distressed, but I have not found it easy to change my records.

I first spoke to a mental health professional about my gender 10 years ago but did not get any response and felt unheard. Around 7 years ago I asked for a referral to GIC but I was told I needed to go to counselling first. When I went to counselling, I was told I needed specialist counselling through the GIC. I was finally referred to the GIC by a GP 4 years ago. I am in and out of crisis and I feel helpless – I don't think I want surgery anymore but would mainly like therapeutic support and a safe place to explore my gender identity.

- **What happens now when people present as non-binary? What support are they offered?**
- **What would need to happen to ensure Alex has the support they need?**
    - **What support does Alex need? (break it down line by line)**
    - **How could we make it less difficult for Alex to engage with their GP and mental health team?**
- **How can we ensure people like Alex are seen in the right place first time?**
- **What support would we need to provide to ensure everyone responds appropriately to Alex's fluid and non-binary gender identity?**

CASE STUDY 4 – HEALTH INEQUALITIES

Sami is a 35-year-old trans man who has been transitioning for a decade, the last 8 of which have been with the support of the GIC. He has autism.

Sometimes I have struggled to participate properly at appointments due to environmental factors, short notice changes, and uncertainty over what to expect at each stage of the process. I know each appointment is precious and I want to make the most of them but my attempts to contact the administrative team to try to better understand ever-changing timescales or expectations have been met with stressed and unhelpful responses.

I have completed upper surgery and I am on testosterone but am currently stuck halfway through lower surgery (which takes several procedures). I waited patiently during Covid-19 for surgery to return only to find out on social media that the sole provider of this is no longer able to provide these procedures. I believe the waiting list I had been on no longer exists. I cannot afford private care and now have no hope for completing my lower surgery which is a source of immense dysphoria and self-consciousness for me.

- ***What could we do differently to avoid people like Sami from having similar experiences? (break it down line by line)***
- ***How can we ensure services are equally accessible to marginalised and vulnerable groups such as BaME, nomadic, homeless, living in some kind of statutory housing such as in a care home, prison or sheltered housing? (break it down by group)***
- ***How would we need to adapt services if Sami was non-binary?***