

Primary Care Output

5.2 Key recommendations

Deliverable

1. Recommendation and options for an improved formalised arrangement between local gender identity healthcare and gender specialists, including resourcing.

The Primary Care sub-group were asked to consider a range of deliverables as part of the review. Group membership included representatives from the British Medical Association (BMA), Royal College of General Practitioners (RCGP), Primary care and pharmacy staff, GIC colleagues and people with lived experience, and/or their representatives.

The group considered the current interface between Primary Care and Gender Identity Clinics (GIC). It was noted that for many TGD people, all care relating to gender transition is delivered by the Gender Identity Clinic (GIC), including monitoring and ongoing management of gender affirming hormonal therapies (GAHT). As the number of referrals to GIC services have increased, so too have the number of return appointments; this has resulted in significant service pressures. Consequently, individuals now experience long waiting times when accessing specialist GIC services.

In line with the National Clinical Strategy for Scotland that emphasises the importance of person centred care, it was recognised that some individuals wish to receive care closer to their home; this may facilitate access by reducing associated travel, time and financial costs. Additionally, following transition, some trans individuals no longer wish to attend the GIC for ongoing care due to this being perceived as stigmatising. The group were in agreement that this needs to be balanced against the need for specialist oversight or care, as not all this work can appropriately sit in general practice. However, the group recognised that the experience of care for people who are trans is highly variable. Differences exist throughout Scotland, particularly regarding the role and responsibilities of Primary Care and GIC services. Consequently, optimising the model of care between Primary Care and GIC services was noted to be a priority for the Primary Care subgroup.

The Sub-group were there in agreement with the following recommendations:

1. People who are trans that present to medical services with general health concerns and medical conditions should be reviewed and managed as per standard pathways in line with recommendations from the Royal College of General Practitioners (RCGP) and the General Medical Council (GMC).
2. There should be equitable access to GICs from Primary care across Scotland. Primary Care should refer individuals to local GICs. If the individual prefers,

Primary Care will signpost to any available self-referral pathway(s) into GIC services. Each NHS board should work with their local GP subcommittee to ensure:

- i. there is clear guidance on referral pathways to local GICs
 - ii. There is clear information for both professionals and service users regarding the assessment process and expectations from the GIC service (see additional documents for an example from NHS Greater Glasgow and Clyde GIC; although this is now out of date, the areas covered represent an appropriate level of information).
3. Information for individuals considering gender affirming hormone treatment (GAHT) and surgical interventions should be made available early in the referral process, prior to assessment. Any materials should include the risks and benefits of hormonal therapy. This should inform health improvement conversations around smoking, healthy weight and other health behaviours and modifiable factors early in the individual's journey, to optimise safety and outcomes of any later surgical or hormonal interventions.
4. The Primary Care subgroup endorse the Endocrine hormone monitoring protocol. This provides clear advice on the necessary monitoring and should be clearly signposted and easily available for those who need to access it.
5. Clear systems are required for the long term follow up of people who have accessed gender affirming treatments via GIC services. For most people, this is long term monitoring and management of GAHT. All NHS Boards should work with Primary Care, including GP subcommittees, and Endocrinology to agree clear processes for long term follow up; these may vary between NHS Board areas but should be based on the following principles:
 - i. Equal access to long term follow up across Scotland
 - ii. Care delivered close to home whenever possible
 - iii. Recognition that some individuals do not wish to attend the GIC for long term follow up; consideration of this should inform service models where possible.
 - iv. Processes should be equitable to other groups of patients who receive similar treatments for different indications, for example other groups prescribed testosterone and oestrogen.
 - v. Clear governance structures with pathways to access specialist advice when required
 - vi. Service models which reflect the Triple Aim, namely improving population health, providing high quality care and ensuring cost-effectiveness. Staff wellbeing in work should also be a key consideration to ensure sustainable services.
6. A range of specific options for delivering long term monitoring and management of GAHT were explored within the Primary Care subgroup. Whilst these are not exhaustive, the following options were recognised as possible service models and should be considered by all NHS Boards:

- i. **All phlebotomy and blood pressure measurements should be undertaken in the Community Treatment and Care Service (CTACS).** This should be resourced by the Gender Identity Service and will require new investment. This will provide care close to home in a standardised setting alongside other routine care. This should be facilitated through the HSCPs who both commission GICs and develop CTACS.

Options for the recall and review of results and individuals are either:

- ii. **In GP practices with an enhanced service.** This model would be beneficial in providing ongoing care, particularly in more remote areas. In order to be delivered, this will require funding for initial and ongoing training. Notably, some GP practices will have very few eligible patients and therefore there will be a requirement to maintain knowledge and skills for small numbers. Whilst this option has not undergone formal economic appraisal, it is anticipated to be costly overall. Furthermore, GPs can opt out of an enhanced service and therefore the NHS Board and GIC will require a mechanism to identify and provide a service for individuals affected by this. Opting out of this enhanced service may also worsen coverage and therefore exacerbate inequality of access.
- iii. **In a Gender Identity Service.** Provision of ongoing monitoring and management of GAHT is a service which the GIC is not currently resourced to provide. If resourced, this function could be integrated into the current GIC model or be provided through a wider Gender Identity Service or network. Within either model, reviews of individuals and results could be performed virtually; individuals with abnormal results or who are at high risk of complications would be proactively reviewed, virtually in the first instance. Individuals with results within agreed parameters would be eligible for Patient-Initiated Review; they would be advised to continue current medications and to contact the clinic if they have anything they wish to discuss.

This system is anticipated to be cheaper than an enhanced service; we estimate that one clinician would manage larger numbers of patients. Clinicians may be from medical, nursing, pharmacy or other professional disciplines. This would standardise follow up, with patients having access to an equitable level of expertise. Furthermore, many patients would not need to attend a GIC in person, which some find stigmatising or traumatic.

- iv. **The ongoing management of all complex and high risk patients** should be led by the Gender Identity Service, following discussion and agreement with primary care. CTACS should be used to obtain

convenient monitoring close to an individual's home. The number of these patients is expected to increase over time (see section 11).

Prescribing

- v. The GP/Primary Care team should prescribe as part of an enhanced service. Where a Gender Identity Service provides ongoing monitoring and management, the GP/Primary Care team should prescribe under a shared care agreement (SCA), with a letter being sent annually from the clinic to the patient, copied to the GP, following review. A draft SCA from NHS Lothian is available in Appendix 1a and b.



Masculinising
Treatment FINAL ADCTreatment FINAL ADC



Feminising
Treatment FINAL ADC

The exception to this is where individuals are deemed complex or high risk and are managed by the Gender Identity Service. In this circumstance, the Gender Identity Service should prescribe as it needs to carry the risk and not transfer this to the GP/Primary Care.

7. Where individuals are identified as having complex medical or psychiatric needs, partnership working between the GICs, Primary Care and other specialists is expected to ensure appropriate support is available.
8. Determining appropriate service models will require contractual agreement. Negotiations should be overseen by the Scottish Government to deliver a solution that addresses all stakeholder needs and can be agreed at local NHS Board level. Any service model should undergo economic and service user appraisal as part of service design.
9. GPs with Extended Roles, who work within GICs, may help to improve capacity, bridge between primary and secondary care and educate within General Practice. In a very small number of instances, these practitioners could be practice based. This would be guided by local population need but would risk a 'postcode lottery' effect. The development of GPs with Extended Roles may build capacity within the GIC service to support the development of future service models, including specialist locality clinics as part of a hub-and-spoke model of care.
10. A robust educational offering should be available to Primary Care to ensure adequate knowledge and skills within the team. NES should be commissioned to develop a transgender problem based small group learning (PBSGL) module specifically on shared care agreements, CHI change counselling, screening, hormone monitoring and ongoing care. In addition to producing educational materials, resourcing should be made available to facilitate time for CPD across the primary care team.

11. As the population of older TGD people increases, it is anticipated that the burden of comorbidities in this population will also increase. Future service planning should consider this and include training for professionals across the health service, specifically those within Primary Care, GICs, Endocrinology and Elderly Medicine. Clear referral routes for re-engagement with specialist care as an individual ages should be determined based on the risk of therapies. Services should be adequately resourced to meet any projected increase in demand.
12. All endocrine and shared care protocols should be reviewed regularly and in line with national guidance as the evidence base evolves to ensure optimal care for individuals. Scotland should contribute to this longitudinal evidence base by developing data systems co-designed with service users.

Deliverable

2. Recommendations for understanding the competence of gender specialists, including those not based in the NHS.

The group had extensive discussions in relation to NHS management of private healthcare referrals. It was noted that a significant number of individuals have sought private trans and gender affirming healthcare in response to long NHS GIC waiting times. Following assessment, private healthcare providers may directly prescribe GAHT. Alternatively they may direct recommendations for commencing GAHT to the individual's GP. The impact of this is that GPs may have to make decisions about prescribing and/or the ongoing monitoring of therapies, whilst remaining within the limits of their clinical expertise. The group acknowledge that whilst waiting lists for NHS services remain lengthy, this issue may increase over time. The associated patient safety concerns mean that this was identified as a priority area of the Primary Care subgroup. Consequently, the Primary Care subgroup recommended:

1. Individuals commenced on GAHT by an NHS GIC should continue to receive therapy and monitoring in line with local monitoring protocols if they move NHS area. They should be referred to the local GIC if there are any concerns.
2. Where individuals have sought private healthcare assessment and GAHT is recommended, the GP should refer the individual to the local GIC, including relevant correspondence from the private provider. The GIC should have a timely process to quality assure private assessments and provide any treatment recommendations based on this. Medications prescribed should align with standard NHS practice and utilise existing agreed NHS Board

Deliverable

3. Options for improved arrangements for TGD people who are or are considering self-sourcing hormone treatment until waiting times are normalised (this is a shared deliverable with the Endocrine and Fertility Preservation group).

mechanisms for ongoing prescribing and monitoring. GICs should be adequately resourced to undertake this assurance role, as should CTACS, Primary care and GICs for the ongoing prescribing and monitoring.

3. Healthcare Improvement Scotland (HIS) should support this by quality assuring private providers of gender identity assessments and prescribing through regulation and accreditation. This should be done at the level of the clinician and organisation. As part of this assurance, providers should have appropriate resilience and business continuity plans in place to ensure services are sustainable. HIS should liaise with the Care Commission to provide similar assurance for providers of these services within England and Wales. This will support GPs and GICs engagement with the private sector.

The group considered instances of self-sourcing of hormonal therapies that are prevalent in Scotland currently due to lengthy NHS GIC wait times. Self-sourcing of hormonal therapies is where hormonal therapies are purchased and used directly by an individual without any oversight from a health professional. It was recognised by the group that individuals often self-source hormonal therapies as an option of last resort. The literature estimates that between 0.5-25% of individuals on GIC waiting lists self-source. Self-sourcing is associated with a range of potential harms: the quality of the pharmaceutical product being sourced is often unknown and may come with risks, individuals may not have access to monitoring and administration of suprathreshold doses may occur. Therefore, the Primary Care subgroup recommends:

1. For individuals who are self-sourcing, a harm reduction approach should be taken. This should include signposting to the Injection Equipment Provider (IEP) scheme within Community Pharmacy where relevant.
2. The National Gender Identity Clinical Network for Scotland (NGICNS) should work with 3rd Sector organisations to develop information sources that detail the risks of self-sourcing hormonal therapies and increase awareness about the necessary monitoring for GAHT. These resources should also cover the risks associated with having gender affirming surgery performed outside of the UK.

3. Patients who report self-sourcing of hormonal therapy should have monitoring in line with recommendations for those prescribed GAHT in the NHS, utilising the agreed protocols and systems within the NHS Board.
4. The Primary Care subgroup endorse pilot projects which aim to reduce harm from self-sourcing. For example, the rapid GIC assessment of individuals who are self-sourcing hormonal therapy (Appendix 2: Lothian proposal). Unintended consequences of any pilots should be fully explored and mitigated against prior to implementation, including the risk of incentivising self-sourcing as a method of shortening waiting time for assessment. Consequently, self-sourcing should not be the sole entry criterion for obtaining a rapid assessment in the GIC.
5. Within each NHS Board, there should be clear agreed pathways that allow Primary Care to access timely advice from GICs regarding individuals who are self-sourcing, including when the pharmaceutical product in use may pose specific risks. This should facilitate risk assessment and substitution to a safer alternative where necessary, thereby reducing associated harms.

Deliverable

4. Consideration of the effectiveness of current screening arrangements and information provided.

The group considered current screening protocols, alongside changes to CHI. The group were in agreement that people who are trans need to be able to access the relevant national screening programmes, as well as any further targeted screening recommended by their care provider. It was noted that the evidence base for trans specific recommendations within national screening programmes is limited. Furthermore, the trans population is heterogeneous in terms of duration and level of hormone exposure. The call-recall system for several national screening programmes is reliant on a gender marker; in Scotland, this is currently the CHI number. The impact of an individual changing their CHI number as part of transition has been mitigated against through appropriate mechanisms. These largely ensure that ongoing invitation to relevant national screening programmes occurs. The NHS inform website provides detailed patient facing information using appropriate language, although the complexity for individuals navigating this is recognised by the Primary Care subgroup. The group recommends the following:

1. Information on NHS inform continues to be available as a useful, patient facing resource.
2. The existing mechanism when a CHI number is changed largely ensure that individuals continue to be invited to participate in the relevant national screening programmes.

3. The decision to change an individual's CHI number requires a clear and personalised discussion of the potential impacts on healthcare, including screening. This requires clinicians in both the GIC and Primary Care to have sufficient knowledge to discuss these issues and deliver personalised care. This should inform the PBSGL module recommended earlier in this document. This should include opting out of any screening programmes.
4. In addition to screening, the implications of a CHI number or gender marker change should also be discussed in relation to other elements of care, including laboratory test reference ranges. It was recognised that an individual's trans status may be relevant when determining appropriate care for non-trans specific healthcare, and this should be explained to individuals. This may be important for the individual to disclose in order to ensure patient safety and delivering high quality, person centred care.
5. Disclosure of an individual's trans status may occur inadvertently through details contained within the medical notes, such as repeat prescriptions, and individuals should be counselled regarding this.
6. NGICNS and the trans community should co-produce resources which detail the information in points 4 and 5, with this being available for both staff and patients. This information should also be supplied with the letter an individual receives from the NHS following the change of their CHI number.
7. Screening programmes should be alerted to potential inequity of access experienced by trans individuals and take active steps to address these.
8. Ongoing research into the appropriate screening for trans individuals should continue to be supported.
9. Screening teams should have ongoing training and support to ensure inclusive, accessible services. Appropriate advice should be available and should be person centred.
10. Individualised screening recommendations should be provided by Gender Identity Service Providers following any operative procedures. Any additional screening outside of the national screening programmes should be coordinated by the GIC.
11. A clear process for consenting and administratively changing CHI and Name changes should be made available. The current documentation should be reviewed by NGICNS to ensure this is accessible and available to the relevant clinicians.

Deliverable

5. Provision of a framework with examples for communication between the TGD person, their GP and their gender specialist.

The Group considered communication between GICs and Primary Care, and highlighted that this is fragmented in some areas. It was acknowledged that Primary Care providers may not have expertise in the delivery of trans specific healthcare issues and require specialist support. It was agreed that good communication links between Primary Care and GICs are necessary. Furthermore, strong communication is also required as part of patient centred care, ensuring that communication is transparent and clear for service users. The Primary Care subgroup therefore recommends:

1. Clear written communication templates should be used for correspondence from the GIC to Primary Care, clearly detailing any actions required (Appendix 3). Patients should also be copied into this correspondence where appropriate.
2. The use of patient facing apps and online platforms should be explored as part of the wider NHS digital strategy. Digital inclusion and the risk of inequality should be considered as part of this work.
3. A clear method of seeking urgent advice from the GIC should be available within each NHS Board and agreed by the GP subcommittee. This may be a dedicated email address or phone line depending on the preference of local services. This is particularly important to ensure that specialist advice is available if bridging prescriptions are being considered.
4. As previously stated, clear information materials should be made available for individuals referred to GICs at the point of referral.
5. A website should be developed which acts as a national information source for both clinicians and patients. This should be informed by the needs of stakeholders and should contain resources which could be printed to support those who are not digitally enabled. This could be achieved using the NGICNS website although alternative options should be explored.

Deliverable

6. Consideration of arrangements and strategy for long term monitoring of hormone treatment.

Narrative for this deliverable has been included within deliverable 1 of this section.

Deliverable

7. Summary describing the involvement of people with lived experience in the group's work and intersection with the principles of the Review.

Like the other sub-groups primary care had service user and third sector input alongside NHS staff. Each member was invited to participate in an initial evidence gathering exercise to assist in progression of the Sub-groups project deliverables. Actions were agreed in an open forum and assigned to smaller groups of volunteers to progress offline ahead of the next scheduled meeting. Key actions were then tabled at subsequent meetings with individuals, or their representative presenting associated papers to the wider group to stimulate discussion and further action.

All members were provided ongoing opportunities to track any suggestions for change on working draft documents for their Sub-group via their teams channel stream, GRP mailbox or online at meetings. Any changes were then reviewed in a wider group format for agreement. Individuals were regularly invited to suggest any ideas for group recommendations. These were discussed and agreed at Sub-group final meetings by all members.

Multiple public consultations took place throughout the project wider in order for each group to gain the views of a larger cohort. The initial feedback survey had 76 responses which were collated and key themes were reviewed at each groups first meeting. A further consultation followed once the group agreed their deliverables. There were 8 responses submitted during this period. Responses were then circulated to the group for consideration during group discussions at meetings.

Additional areas highlighted by Primary Care Sub-group

In addition to the agreed deliverables, other key areas were highlighted during this groups discussions. Consequently, the primary care group recommend:

1. The National Labs IT Programme should engage with the transgender community, GICs and Primary Care to ensure trans-specific issues are considered during the procurement of any new lab system. This should ensure that appropriate clinical information is made available to requestors and those who will interpret lab results. If clinically appropriate, laboratory reference ranges should be decoupled from gender markers and instead be relevant to the individual, with specific consideration of creatinine and troponin.
2. The governance around transgender surgeries should be strengthened to improve patient experience and safety and address unmet needs within this population.
 - a. Post-operative care should include appropriate community services, with practice nursing, CTACS and district nursing services appropriately trained and resourced.

- b. Educational materials for staff and post-operative care support should be available from nationally commissioned Gender Reassignment Surgical Services to ensure post-operative care is of appropriate standard. National service specifications for transgender surgeries should include an advice service, and should make provision for advice where these procedures are undertaken by alternate providers overseas.
 - c. The provision of a national advice line for post-operative care should be considered within Scotland, staffed by a specialist nursing team.
 - d. Within each NHS Board there should be an agreed local surgical service who will support aftercare of transgender related surgeries and act as a liaison between primary care and the tertiary services. These arrangements must be pre-agreed.
3. Systems within NHS Scotland need to allow for increasing gender identities for patients, specifically including non-binary identities. This should be done as part of a general move away from gendered healthcare.
4. As workload within and referral routes to GICs increase, there should be a robust mechanism for triage and prioritisation of patients. With the development of new care pathways, such as those for harm reduction or managing private referrals, consideration should be given to the risk of these incentivising certain behaviours and creating inequities. It should be the ambition that services are equitable for all individuals accessing them and this principle should guide service activity. Inequalities should be proactively monitored and action taken should these become evident.
5. There needs to be a consistent approach in NHS Scotland to the management of requests from private healthcare beyond transgender care.
6. Awareness and information for health professionals should be available around inadvertent disclosure of an individual's trans status and the legal consequences under the Gender Recognition Act

The group were in agreement that this work should be reviewed on a bi-annual basis.