

Information Re ‘Self Prescribing’: Leeds GIS

The aim of this document is to respond to queries around patients who are taking hormones from an unknown source.

GPs are faced with difficult clinical decisions, when trans people request prescription of hormone treatment, outside of NHS specialist pathways or while facing a long wait for assessment within an NHS specialist pathway. There are safety concerns regarding unregulated hormones and these patients may not have any documented specialist NHS assessment or gender dysphoria related diagnosis.

The General Medical Council’s Good medical practice guidance states that *“as a good doctor you will:*

- *make the care of your patient your first concern*
- *be competent and keep your professional knowledge and skills up to date”*

However, if a patient has been sourcing hormone treatment for gender dysphoria, without documented NHS assessment, there is a difficult balance between the *“care of your patient”* and being *“competent and keep professional knowledge and skills up to date”*. We aim to offer a framework to aid you in making decisions around these issues.

In these circumstances, Leeds GIS staff cannot tell a GP if their patient has gender dysphoria, as diagnosis requires a lengthy, comprehensive holistic assessment and no swift diagnostic test exists. Without a clear diagnosis, it is impossible to offer a clinical opinion regarding whether any proposed or unregulated sourced hormone treatment is needed. Leeds GIS staff cannot know if treatment would be likely to be beneficial or harmful. GPs must make an assessment themselves, before deciding on a management plan.

If a GP is considering prescribing in any of these circumstances the following factors are important, as they will be solely responsible for prescribing the treatment:

- Is the GP satisfied in their opinion as a non-specialist that the patient suffers from gender dysphoria?
- Is the GP satisfied that the prescription is needed, in the patient’s best interest and likely to be of benefit?
- Is the GP practicing within their competencies for the best interest of the patient?

Leeds GIS staff can only give general advice and guidance in these circumstances, which will not be specific to a particular patient or constitute a recommendation. Such advice and guidance might relate to factors to consider in assessment and potential strategies, but we cannot confirm a diagnosis, formulate a treatment plan for the patient or take any shared responsibility for interventions delivered in primary care in this way. These approaches lie outside specialist pathways and the treatment decisions lie entirely with the prescribing GP.

GPs may be asked to prescribe hormones when a patient reports taking hormone treatment bought online and requests the GP to prescribe treatment instead. GPs may feel pressured to intervene, especially in light of lengthy waits for NHS assessment.



Leeds GIS strongly advises against “self-medication” of this type. There is no guarantee that the products obtained are the medication stated or that the dose is accurate, as the substances are not necessarily from regulated pharmaceutical suppliers. However, we recognise that patients may choose to continue taking these substances and thereby expose themselves to risks related to the following:

- Exposure to harmful chemicals, because the “medication” is tainted, poor quality or a different chemical.
- Exposure to hormone preparations that are not recommended for treatment for trans people, such as the combined oral contraceptive pill or nandrolone.
- Unidentified adverse effects of “standard” hormone treatment.
- Excessive dosing with otherwise legitimate hormone preparations.
- Hypogonadism.
- Exacerbation of existing health conditions.
- Incurring unwanted effects of treatment, which they may not be aware of and may be irreversible, such as infertility.

In the first instance, we would recommend exploring the individual’s understanding of hormone treatment. Education regarding potential unwanted effects of legitimate hormone treatment and the risks of taking unregulated products may be helpful. The patient may not be aware of the risks, as the information available regarding hormone therapy for trans people is often inaccurate or of poor quality. We would advise you to use the information on our website and consent forms so the patient can be counselled regarding their use of hormones appropriately. These can be found here <https://www.leedsandYorkpft.nhs.uk/our-services/gender-identity-service/> under ‘consent forms’.

After discussion, some patients may agree to stop or reduce the dose or number of different agents.

If a patient is not willing to stop taking unregulated treatment entirely, the GP may wish to take harm minimisation approach. The options are:

- Harm minimisation, basic monitoring only.
- Harm minimisation, restricted prescribing and monitoring.

Leeds GIS can discuss these approaches and give limited advice and guidance, in general terms only. They cannot advise the GP of the likely presence of gender dysphoria, and benefits and risks of treatment to a particular patient. In these circumstances, the GP must provide care independently and monitor / prescribe in line with GMC guidance and without shared specialist responsibility.

Prescribers are advised to discuss their response to a request to prescribe from a patient with a colleague, at a practice team meeting or with pharmacy colleagues and to document the decision made, with reasons, clearly in the patient notes and communicate this to the patient.

Harm minimisation, monitoring only

Here, the GP does not provide a prescription for treatment but provides monitoring only, with the aim of supporting the patient to make an informed decision about continuing to source unregulated hormones. The GP can check the parameters outlined on our website, approximately 6 monthly, but may wish to avoid checking serum hormone levels. Thus, the GP and patient are able to identify some of the serious side effects or harm that can arise from treatment but, as serum levels are not checked, the GP cannot comment on dosing or make recommendations about sourcing other illicit products.

If the GP agrees to monitoring and checking hormone levels and these levels are high the GP will be able to express concern and communicate the risk to the patient and encourage them to reduce or cease the medication. GPs can be clear in their communication with the patient that they are not commenting on further dosing of hormones from an unknown source but potentially avoiding adverse effects from high dose regimens.

Harm minimisation, prescribing and monitoring

In this approach, the GP assesses for gender dysphoria and the need for hormone treatment and balances this against the risks of the patient continuing to take unregulated hormones. The assessment of gender dysphoria being made is not specialist, may be incorrect and could lead to harm secondary to prescribing hormone treatment but these challenges should be acknowledged by the GP and the patient. This approach can also be used for the GP to prescribe, if they feel the risks of the patient taking no treatment are intolerable and likely to cause greater harm than prescribing in the way outlined here.

The uncertainty inherent in this approach should be explained to the patient. They should be informed of the following:

- They will be prescribed a treatment, outside of recommended prescribing pathways.
- Treatment will be provided without a specialist assessment; there is a greater chance of such an assessment being incorrect.
- They may be unhappy with the effects of treatment in the future, which may be irreversible.
- Although the risks and burdens of treatment will be explored, including side effects, the GP is unlikely to be as familiar with the use of hormone for the indication and therefore the quality of the information the patient is basing their decision on may be of lesser quality.

In order to reduce the risk of inappropriate treatment, adverse effects and irreversible physical changes that may not be beneficial or desirable in the future, the GP may want to follow the guidelines on our website around 'bridging' prescriptions and starting hormones. They may wish to consider the following:

Before treatment

- Explain that this approach is dependent on the patient **not taking any unregulated hormone treatment** in addition to prescribed treatment.
- Explore the risks and benefits of treatment, as far as possible, using our **consent** forms.
- Discuss **fertility**, both the risk of infertility (which may be irreversible) and the importance of contraception due to potential teratogenicity.
- Consider referral to a fertility clinic.
- Consider any pre-existing conditions that may complicate treatment.
- Check baseline investigations.

Treatment considerations

- Use the agents with the least risk, in term of adverse effects.
- Prescribe a low, starting dose of a transdermal preparation of testosterone or estradiol. The GP may wish to provide limited or no dose titration upwards thereafter, which should be explained to the patient beforehand.
- 'Blockers': consider alternatives to GnRH analogues (e.g. Leuprorelin); without titration these are likely to cause unpleasant side effects but their effects may be priorities for the patient. Finasteride or Spironolactone may be used.
- Progesterone only contraception can be used for female birth assigned people, to achieve amenorrhoea and provide contraceptive protection.
- Check monitoring investigations, as outlined on our website.

None of these decisions are easy or without risk, and there can be difficulty in communicating this risk and uncertainty with an individual. We hope this can provide support for clinicians and patients when making these decisions together.

Other Support:

There is often distress associated with gender dysphoria which can be very difficult for your patient to manage. You can suggest that your patient contacts our **Gender Outreach Workers (GOWs)**. They offer advice and support to trans, non-binary and gender diverse people who are on the Leeds Gender Identity Service waiting list and care pathway. They can answer questions and provide support via their information and advice line, one on one sessions and peer support and social groups. It can help to talk to someone with lived experience. Further information regarding the GOWs can be found on our website: <https://www.leedsandYorkpft.nhs.uk/our-services/gender-identity-service/> under Gender Outreach Workers and other sources of help.

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