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HM Assistant Coroner
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National Medical Director
NHS England
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24 May 2023

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Ms Sophie Gwen Williams who died on 20 May 2021

Thank you for your Report to Prevent Future Deaths (hereafter “Report”) dated 27 February 2023 concerning the death of Ms Sophie Williams on 20 May 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Sophie’s family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Sophie’s care have been listened to and reflected upon.

I am grateful for the further time granted to respond to your Report, and I apologise for any anguish this delay may have caused Sophie’s family or friends. I realise that responses to Coroner Reports can form part of the important process of family and friends coming to terms with what has happened to their loved ones and appreciate this will have been an incredibly difficult time for them.

The Trusts directly involved in Sophie’s care are better placed to answer many of the concerns raised in your Report, and NHS England have been sighted on the response from The Tavistock and Portman NHS Foundation Trust. NHS England are the commissioner for specialised gender dysphoria services, and we have therefore focused on the Matters of Concern relating to clinics providing gender identity treatment, where we are in a position to address the concerns raised.

Provision of support for patients from clinics providing gender-identity treatment

NHS England has directly supported NHS Gender Dysphoria Clinics in developing and establishing forms of support for patients while they remain on the waiting list. In a recent discretionary investment exercise, NHS England sought proposals from Gender Dysphoria Clinics that would either increase the number of clinical staff in their service or, in recognition of the workforce constraints, would improve the patient experience in other ways, such as support while on the waiting list. While not certain it would have changed the outcome in this case, there is clinical opinion that telephone

and online support are a useful service for patients on the waiting list. We have also commissioned support resources at Gender Dysphoria Clinics, to include:

- Screening at referral so that dedicated Named Professionals can work with patients and GPs to address complex needs, and for signposting to local services and local support groups in less complex cases.
- Gender Outreach Workers and Peer Support Workers who meet with patients in local community settings.
- Advice and support lines delivered by third-sector support organisations with NHS funding.
- Pre-Assessment workshops with people on a waiting list, providing them with information on assessment, intervention pathways and community-based support.

The Gender Outreach Worker role (referred to above) is directly commissioned by NHS England and is being formally evaluated by a host Gender Dysphoria Clinic so that learning can be shared across other NHS Gender Dysphoria Clinics (the evaluation will be delivered to NHS England in September 2023). The role has a number of potential positive benefits:

- Patients are signposted to local services for support in housing and employment, as well as mental and physical health needs – helping to ensure that such needs do not go un-met.
- Providing support at an earlier stage may mean reduced need for primary and secondary care services further along the pathway including A&E and crisis services.
- Patients are better informed and prepared for the process of assessment and diagnosis once they are seen by the Gender Dysphoria Clinic
- Demands upon administrative and clinical staff are reduced, including the need to manage distress, which frees up time for patients in the service.
- More tailored support can be offered to patients while on a waiting list, such as those who are particularly vulnerable or who may have particular needs (age; disability; ethnicity; health needs).

Additionally, NHS England has funded and established four new adult Gender Dysphoria Services in novel settings (primary care and sexual health clinics) as part of piloting activity since 2020, with the ambition of increasing clinical capacity through a newly trained clinical workforce (more detail is provided below). One of the pilot services (in Greater Manchester) is evaluating the role of Care Navigator, which is a non-clinical role that provides direct peer-support to patients from the point of referral including support in accessing local health services. Most of the pilot services are testing new delivery models that serve a defined local geography and population (Greater Manchester; East England; Cheshire and Merseyside) and this local model is proving to be helpful in establishing a community presence for these services, which facilitates the provision of integrated community support to patients on the local waiting list. The final evaluation of the Greater Manchester pilot, including the Care Navigator role, is expected in imminently.

By November 2023, NHS England will have disseminated amongst all NHS commissioned Gender Dysphoria Clinics a description of existing helplines used by Gender Dysphoria Services – and a description of other forms of support commissioned by NHS England - so that an assessment of ‘best practice’ may be made by Gender Dysphoria Clinics in forming their response to HM Coroner’s finding of concern about the lack of this support for the benefit of patients on their waiting lists.

Provision of mental health care for those patients on waiting lists

Commissioning responsibility for local mental health services rests with Integrated Care Boards (ICB), rather than NHS England. The make-up of local services will therefore differ according to each ICB’s commissioning strategy. Also, an individual’s GP plays an important role in supporting patients who have physical and mental health support needs, including referral to local NHS services (being mindful that evidence shows that transgender and non-binary people are more likely to experience poor mental health than the general population). The NHS Long Term Plan for Mental Health describes an expansion of local mental health care so that more people can access treatment by increasing funding at a faster rate than the overall NHS budget – and by at least £2.3bn a year by 2023/24. Since 2019/20 every local health system has received funding to deliver multi-agency suicide prevention services, and mental health crisis teams have been strengthened.

Descriptions of support and helplines being disseminated to NHS commissioned Gender Dysphoria Clinics will include mental health support. This will include direct wellbeing support from peer-support workers and Gender Outreach Workers.

The setting and implementation (where practicable) of criteria for deciding whether (and, if so, which) patients (other than those terminally ill) should be given priority for receiving gender-identity treatment.

Currently, based on expert clinical opinion, patients are seen based on the referral date to a Gender Dysphoria Clinic. This is considered an appropriate process in that if patients are triaged based on risk, this could negatively impact patients who do not exhibit significant risk and who have been waiting longest. In the absence of firm evidence, the solution is likely to be improving access to more timely healthcare for individuals with gender dysphoria.

The number of referrals into NHS gender dysphoria services has increased significantly, and it has not been possible to grow the specialist workforce at the required rate to keep pace with demand. In 2019, NHS England ran a national procurement exercise for both surgical and non-surgical services, in an effort to attract additional providers to start offering gender dysphoria services. Unfortunately, no new providers came forward, which reflects the difficulty in attracting, training, and retaining clinicians to work in this area of healthcare. For that reason, NHS England worked with

the Royal College of Physicians to design and fund the UK's first Gender Identity Healthcare Credential, which since 2020 has provided a route for clinicians to train in the specialty of gender dysphoria healthcare. In addition, NHS England has significantly increased financial investment in the Gender Dysphoria Clinics in recent years, to recruit additional clinicians where possible.

Additionally, the four new pilot services, referenced above, are testing how gender dysphoria healthcare delivered by Gender Dysphoria Clinics could be delivered in more local settings, and building a new clinical workforce rooted in primary care and sexual health clinics through appropriate professional training. These pilots work to a national service specification and are being independently evaluated. Positive evaluations of the pilots would present an opportunity to roll out the successful models of care more widely, thereby increasing assisting with reducing waiting times. The four pilots currently in operation are Trans Plus in London (Chelsea and Westminster Hospital NHS Foundation Trust), which opened in June 2020, Indigo Gender Service in Greater Manchester from December 2020 (managed by GTD Healthcare), CMAGIC in Cheshire and Merseyside from February 2021 (Mersey Care NHS Foundation Trust) and the East of England Gender Service from June 2021 (Nottinghamshire Healthcare NHS Foundation Trust, in partnership with Cambridgeshire and Peterborough NHS Foundation Trust). The fifth new service will become operational in 2023 at Sussex Partnership NHS Foundation Trust. All of the new services are prioritising patients who are on the waiting list of an NHS Gender Dysphoria Clinic. Most of the referrals into Trans Plus and the East of England service are taken from the waiting list of the Tavistock and Portman NHS Foundation Trust.

By December 2023, NHS England plans to have commissioned on a substantive basis the second new adult Gender Dysphoria Service in Greater Manchester, subject to a positive pilot evaluation and tender process.

Additional matters that may be helpful to HM Coroner

We note the following that is set out in the incident report prepared by the Tavistock and Portman NHS Foundation Trust, regarding Sophie's case:

"The patient had then contacted us with the hope that our GIC (Gender Identity Clinic) could honour the referral date of the Belfast clinic, thus not wait long for their first appointment at our clinic. They were informed that this wouldn't be possible, and that funding needed to be raised in order to be seen at our clinic".

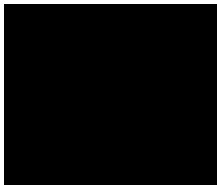
From the information available, it is unclear to NHS England as to why the Trust informed Sophie that funding would need to be identified in order to be seen at the Trust's Gender Dysphoria Clinic. The same incident report prepared by the Trust infers that by that time, Sophie had registered with a GP in London. If that is the case, then the Trust should have been aware that NHS England had become the 'Responsible Commissioner' for Sophie's referral to the Trust and that the referral was funded via the established contract in place between NHS England and the Trust (source: [NHS guidance on establishing the responsible commissioner](#); paras 19.5 and 19.6 that describe arrangements for patients who move across UK borders). While not certain

it would have changed the outcome in this case, NHS England will investigate the circumstances of this matter and ensure that the Trust is aware of, and is following, relevant guidance in this regard.

I would also like to provide further assurances on national NHSE work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors, and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around preventable deaths are shared across the NHS at both a national and regional level and helps us pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,



[Redacted name]

National Medical Director