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7th February 2024

Dear Coroner,

Re: Regulation 28 Report to Prevent Future Deaths – Amarnih Louis Lewis-Daniel who died on 17 March 2021.

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 11 December 2023 concerning the death of Amarnih Louis Lewis-Daniel on 17 March 2021. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Amarnih's family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Amarnih's care have been listened to and reflected upon.

I apologise for the delay to responding to your Report, and for any anguish this delay may have caused to Amarnih'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.

You will be aware that NHS England has previously provided a report on the commissioning of specialised gender dysphoria services to you, to assist with your investigation. For completeness, aspects of that report are repeated in the following response. Given that Amarnih was aged 24 at the time of her death, our response focuses on issues relating to the NHS pathway of care for adults with gender dysphoria, and to national policy on mental health services for young people up to 25 years of age.

In your Report you raised five matters of concern. Some of these matters of concern are better addressed by the Gender Dysphoria Clinic at the Tavistock and Portman NHS Foundation Trust, the healthcare professionals directly involved in Amarnih's care at North East London NHS Foundation Trust and the Care Quality Commission (CQC). We note that you have also addressed your Report to these organisations.

Background to NHS England's role as Commissioner

NHS England is the direct commissioner of specialised services for individuals with a diagnosis of gender dysphoria. Prior to 2019/20, seven specialist centres were commissioned in England, based in or near Newcastle, Leeds, Sheffield, Northampton, Nottingham, London and Exeter. Each of the Gender Dysphoria Clinics (GDCs) is operated by a Mental Health NHS Trust and is staffed by a multidisciplinary team to include the wide range of clinical professionals needed to deliver highly

individualised care and meet the presenting needs of the whole person (typically and variously: clinical psychologists; specialist physicians; consultant psychiatrists; consultant endocrinologists; clinical nurse specialists; voice and communication therapists; counselling therapists).

The consultant-led services provided by the GDCs when adult patients are referred to them are amongst those intended to commence within 18 weeks of referral. NHS England has been unable to commission sufficient capacity to meet that expectation because of the lack of specialist clinical staff (recruitment and retention) – against a backdrop of significant increasing demand. Unfortunately, waiting times for a first appointment at a GDC remain very high. Of patients who received their first appointment in November 2023 they had on average been referred 382 weeks previously.

You have raised the following matters of concern:

1. Very long waiting lists for Gender Dysphoria Clinics

NHS England has sought to address the serious imbalance between the demand for gender dysphoria services and the shortage in trained clinicians who are available to train and work in this field, which has led to long waiting times. In 2019/2020, NHS England re-procured the provision of gender dysphoria services for adults. The expectation was that that re-procurement would bring forward new entrants and enable NHS England to increase the number of GDCs, and funding was identified by NHS England for that purpose. That expectation was not met. In fact, no new providers came forward from either the NHS or independent sector. All of the seven existing GDCs submitted bids and award of renewal of contract was confirmed for all of them.

In the circumstances, NHS England sought to grow capacity in an alternative way. Five pilot services were developed. The proposal was to build a new clinical workforce using professionals who had tended not to specialise in gender identity healthcare previously, based in primary care and local sexual health services, which presented the opportunity to develop and expand clinical capacity to an extent not possible under the historical delivery model. There were various eligibility criteria for accessing the different pilot services (for example, being registered with a GP in the relevant geographical catchment area) but all the pilot services only took patients from the waiting lists of the established GDCs, in chronological order of waiting. Between April 2020 and August 2023 around 2,500 individuals were removed from a GDC waiting list to be seen by one of the pilot services. They were located as follows:

- a. The Trans Plus service, delivered in a sexual health setting at Chelsea and Westminster Hospital NHS Foundation Trust in London (from April 2020)
- b. The Indigo Service in Greater Manchester, based in primary care and delivered by GTD Healthcare (from December 2020)
- c. CMAGIC, a primary care service in Cheshire and Merseyside hosted by Mersey Care NHS Foundation Trust (from March 2021)
- d. The East of England Gender Service, managed by the Nottinghamshire Healthcare NHS Foundation Trust in partnership with Cambridgeshire and Peterborough NHS Foundation Trust (from June 2021)
- e. A primary care service in Sussex hosted by Sussex Partnership NHS Foundation Trust (from October 2023)

NHS England directly funded the pilot services on top of the funding provided to the seven established GDCs.

In 2023 the pilot services at Chelsea and Westminster Hospital NHS Foundation Trust (London) and GTD Healthcare (Greater Manchester) were moved to substantive seven-year contracts with NHS England following positive evaluations. The GTD service is now open to new referrals of patients who are registered with a GP in Greater Manchester, and the London service is now taking increased numbers of patients from the waiting list of its nearest GDC – the Tavistock and Portman NHS Foundation Trust. NHS England is currently out to tender to award a substantive contract for the service in Cheshire and Merseyside following positive evaluation of this service, and there is an expectation that a similar process will be followed for the other two pilots when their evaluations are complete in 2024 (East England) and 2026 (Sussex).

As mentioned above, to support the growth of clinical capacity NHS England also established and funded the UK's first accredited training programme in gender identity healthcare which was launched in 2020 and delivered through the Royal College of Physicians. The purpose of this investment is to encourage growth in the specialist clinical workforce available to contribute to the assessment and care of those presenting with gender incongruence and to treatment following a diagnosis of gender dysphoria.

NHS England also continues to support the expansion of services in the established GDCs where this is possible. In 2021/22 NHS England invited all seven GDCs to put forward a business case for funding for the expansion of clinical capacity or direct patient support as part of a discretionary investment process. An additional investment of £2.2m was set aside for this purpose. Although all this funding was deployed into the GDCs by NHS England, some of the funding was directed by the providers to non-clinical forms of support for patients on the waiting list due to the difficulties in attracting clinical staff to work in the service itself. 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.
- 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 being formally evaluated by a host Gender Dysphoria Clinic (Leeds and York Partnership NHS Foundation Trust) so that learning can be shared across other NHS Gender Dysphoria Clinics in 2024/25. 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).

NHS England's overall planned spend on all gender dysphoria services (adults and children) in 2023/24 is £78.17m – up from £33.4m in 2018/19, representing an overall increase in funding of 134% in five years. In 2024/25 NHS England will refresh the service specifications for adult gender dysphoria services, which will include consideration of how to identify and address inefficiencies that may reside in the way in which GDCs manage and deliver their services and which may contribute to long waiting times – and how to expand clinical capacity further taking the learning from the pilot services. It is too early in the current year to provide precise figures for the planned budget for gender dysphoria services in 2024/25 but the figure given represents recurrent funding commitments and so should be regarded as the opening baseline figure for planning assumptions.

2. Little local support for patients who are waiting for assessment at a GDC

Our response to concern number one above describes the support that GDCs may provide to individuals on the waiting list alongside support from local health systems.

Commissioning responsibility for local services rests with Integrated Care Boards (ICBs) rather than NHS England. The make-up of local services, and their approach to service delivery, training and education, can differ according to each ICB's commissioning strategy.

Generally, NHS England expects local mental health services to have the necessary skills, experience and competence to meet the needs of individuals who are on the waiting list for gender dysphoria services and who have co-existing mental health issues and / or personal, family or social complexities in their lives. Local services do not need to be expert in the diagnosis of, and response to, gender dysphoria to meet these needs, though the need to improve knowledge of the issues facing patients with gender dysphoria amongst healthcare professionals in all healthcare settings is recognised, and to that end there are various training and educational resources available to local services and health professionals including:

- Training materials and courses delivered by NHS organisations; see for example the courses available from the Nottingham Centre for Transgender Health (Nottinghamshire Healthcare NHS Foundation Trust) which include courses on “understanding trans youth” and “working with trans people at a time of crisis”: <https://ncth.nhs.uk/training>

- General Medical Council advice for medical professionals on “Trans Healthcare” including “the importance of providing good general medical services to transgender and gender diverse people including supporting their mental health”: <https://www.gmc-uk.org/professional-standards/ethical-hub/trans-healthcare>
- Professional guidelines such as the British Psychological Society’s guidelines for applied psychologists working with gender diverse individuals with mental distress, but which may also be applied by health professionals working in other disciplines including counselling, nursing, psychotherapy and social work: <https://explore.bps.org.uk/content/report-guideline/bpsrep.2019.rep129>
- Various online courses for GPs through the Royal College of General Practitioners including “Gender Variance” and “Mental Health and Suicide Prevention”
- More specific to pathways of care for gender dysphoria, NHS England commissioned the Royal College of Physicians to design and deliver the UK’s first accredited post-graduate training course in gender identity healthcare; the course began in 2020. Although aimed primarily at health professionals who wish to specialise in gender identity healthcare, individual modules are also suitable for other healthcare professionals who work in local settings and who wish to improve the experience of individuals with gender dysphoria in using generalist services intended for the whole population including mental health services or primary care services: <https://www.rcplondon.ac.uk/education-practice/courses/gender-identity-healthcare-credentials-qih>
- In September 2023 NHS England published online training materials for health and education professionals in how to support young people up to 18 years with gender distress: <https://www.minded.org.uk/catalogue/TileView>

Local Mental Health Provision

From a policy perspective, the [NHS Long Term Plan](#) (LTP) contains a number of commitments to expand access to community mental health support for those who require it. This includes commitments for 345,000 more young people up to 25 years to access to NHS funded support each year by 2023/24. This includes through brand new Mental Health Support Teams in schools and colleges. We have seen significant increases in the number of young people being supported. Over 732,000 children and young people aged up to 18 years accessed NHS support in the year to October 2023. This is an increase of 218,000 from the start of the LTP. However, the prevalence of mental health need has also increased in recent years, with 20.3% of 8 to 16-year-olds having a probable mental disorder in 2023, compared to 12.5% in 2017. Increasing access remains a challenge despite the increases in young people being supported.

The LTP also committed to delivering a comprehensive offer for 0 to 25 year olds that reaches across mental health services for children and young people as well as adult services. Integral to this is improving the care and support given to young adults aged 18-25, ending the use of rigid age-based thresholds which see young people automatically discharged from children and young people’s mental health services when they reach 18 years of age. Equally as important is improving the support given to young adults within adult mental health services and NHS England is investing an additional £1bn per year in transforming community mental health services so that

more people with severe mental health problems – including young adults – are able to access support within their communities. The NHS has committed to ensuring that by 2023/24 370,000 people (including young adults) will have access support through these new models of care.

3. Lack of clarity on who is responsible for the wellbeing of the patient during the waiting period

It is clear that no individual healthcare professional can be deemed to hold clinical responsibility for a patient that they have never seen for the purpose of a clinical consultation. Consequently, the individual healthcare professional that holds clinical responsibility for a patient while they remain on the waiting list for a GDC will be the patient's GP, if the patient presents to the GP, or other local healthcare professional who is involved in the provision of care to the individual. Our response above has described some of the various training and support materials that are available to the relevant health professionals.

We have also referenced the support that GDCs may provide to individuals on the waiting list alongside support from local health systems, and, the expected role of local services.

4. Local mental health services have very little specialist knowledge to support a person with gender dysphoria

Our response above describes that local mental health services should be expected to have the skills, experience and competence to meet the needs of individuals who are on the waiting list for gender dysphoria services and who have co-existing mental health issues and / or personal, family or social complexities in their lives. We have also detailed some of the various training and support materials that are available to local health professionals; and we have described the expansion of local mental health provision through the NHS LTP.

5. Guidance on bridging prescriptions

Your investigation found that Amarnih had sourced hormone medication from the internet. Although I understand distress may manifest as a response to the long waiting times for a GDC, and although I have no direct knowledge of the circumstances around Amarnih's own care, the NHS strongly discourages the sourcing of unregulated medications. The independent regulator of medical professionals in the United Kingdom, the General Medical Council (GMC) has provided guidance to GPs about patients who are awaiting to be seen by a GDC and who are self-medicating: <https://www.gmc-uk.org/professional-standards/ethical-hub/trans-healthcare#Prescribing>

In your accompanying letter to me you asked that I consider page 3 of the GMC guidance that deals with prescribing, monitoring and follow-up after gender reassignment treatment. This section of the guidance also provides advice to GPs (and to other relevant medical professionals such as consultant endocrinologists) on bridging prescriptions. The GMC explains that the information "*is aimed at reassuring doctors who wish to prescribe for their transgender and gender diverse patients that it*

wouldn't be against our guidance to do so, but it does not require doctors who do not feel that prescribing would be of overall benefit to a patient to go down a particular treatment route". It goes on to advise that doctors:

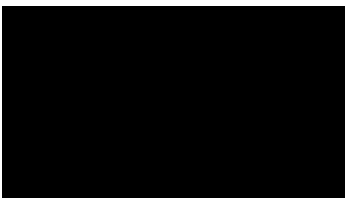
".. must work within their limits of their competence; should identify the likely cause of the patient's condition and which treatments are likely to meet their needs; should reach agreement with the patient on the proposed treatment, explaining the likely benefits, risks and impact, including serious and common side effects; what to do in the event of a side effect or recurrence of the condition; how and when to take the medicine and how to adjust the dose if necessary; how to use a medical device; the likely duration of treatment; and any relevant arrangements for monitoring, follow-up and review, including further consultation, blood tests or other investigations, processes for adjusting the type or dose of medicine, and for issuing repeat prescriptions".

Your investigation found that this guidance was not widely known. It may be helpful to know that it is referenced in various professional and regulatory guidelines, including the Royal College of General Practitioners' guidance on "[Transgender Care](#)" (2019) and also in the Care Quality Commission's guidance "[Adult Trans Care Pathway: what CQC Expects from GP Practices](#)" (2022). We note that you have copied your report to the CQC. GPs and other health professionals are also signposted to the GMC guidance through the various webpages hosted by the GDCs, such as that of the [Tavistock and Portman NHS Foundation Trust](#), which also offers GPs advice through a telephone "GP Hormone Advice Line".

I would also like to provide further assurances on national NHS England 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,



National Medical Director