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2<sup>nd</sup> February 2024

[REDACTED]  
Dear Coroner,

**Re: Regulation 28 Report to Prevent Future Deaths – Alice Litman who died on 26 May 2022.**

Thank you for your Report to Prevent Future Deaths (hereafter “Report”) dated 5 December 2023 concerning the death of Alice Litman on 26 May 2022. In advance of responding to the specific concerns raised in your Report, I would like to express my deep condolences to Alice’s family and loved ones. NHS England are keen to assure the family and the coroner that the concerns raised about Alice’s care have been listened to and reflected upon.

Before addressing the concerns raised in your Report, may I respectfully remind HM Coroner that NHS England did not have a role in relation to Alice’s inquest. However, NHS England wishes to assure Alice’s family and HM Coroner that the concerns raised about Alice’s care have been listened to and reflected upon.

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, and the healthcare professionals directly involved in Alice’s care at Surrey and Borders NHS Partnership NHS Trust. We note that you have also addressed this Report to these NHS providers who no doubt will respond directly.

**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.

Unfortunately, NHSE 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, reflecting an international trend. 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. The knowledge and training for those in the mental health setting for managing and offering care to those in the transgender community**

Commissioning responsibility for local mental health services rests with Integrated Care Boards (ICB) 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. We anticipate the other recipients of your Report will address these concerns in more detail.

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-gihln> 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>

## **2. The delays in access to gender affirming healthcare**

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 of 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)

NHSE 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 of 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.

### **3. The lack of provision of mental health care for those waiting for gender affirming treatment**

Commissioning responsibility for local mental health services rests with 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. We anticipate the other recipients of your Report will address these concerns in more detail as they relate to the care provided to Alice.

From a policy perspective, the NHS England Long Term Plan 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 children and young people aged 0-25 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 CYP aged 0-18 accessed NHS support in the 12 months 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 NHS England Long Term Plan 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 – can access support within their communities. The NHS has committed to ensuring that by the end of 2023/24 370,000 people (including young adults) will have access support through these new models of care.

#### **4. The lack of clarity for clinicians who are in place to support young transgender individuals in Primary Care; and the lack of clarity for clinicians who are in place to support young transgender individuals in the Mental Health Setting**

We are responding to these two questions with a single response, and by reference to “young transgender individuals” we are focusing on individuals below the age of the 18<sup>th</sup> birthday, as the issues that relate to adults who are 18+ years have been covered in our response to the previous questions (above).

NHS England is currently leading a significant programme of work to reconfigure the provision of specialised services for children and young people with gender incongruence, in line with the interim recommendations of the independent [Cass Review](#). This involves the managed closure of the current CYP children’s gender service at the Tavistock and Portman NHS Foundation Trust on 28 March 2024, and the establishment of around seven new regional services by 2026, the first of which are planned to become operational in April 2024 through collaboratives hosted by Great Ormond Street Hospital for Children NHS Foundation Trust and Alder Hey Children’s NHS Foundation Trust.

As part of the transition to the new provider model the national waiting list for children and young people who are waiting for access to a specialist service is now held by NHS Arden & Gem Commissioning Support Unit on behalf of NHS England. As at November 2023 there were 5,662 patients on this waiting list. Following discussion with the new service providers and presidents of relevant Royal Colleges NHS England has drafted a service specification to change the referral pathway to move the CYP Gender service into tertiary access only with only two referral pathways via NHS general paediatric services and CYP mental health services. This will ensure that primary care and secondary care clinicians take a holistic view of each child or young person, to identify mental health needs including risk assessment for self-harm and suicide. NHS England is currently out to public consultation on the proposal and will make a final decision by the spring of 2024.

#### **Risk Mitigation**

In order to address the concern of unmitigated clinical risk of individuals on the waiting list NHS England has been supported by clinicians with expertise in younger people with gender incongruence at Nottinghamshire Healthcare NHS Foundation Trust working in collaboration with that provider’s CYP mental health clinicians. An MDT convened for this purpose has conducted a desk-top review of individual referrer forms held through the waiting list (which had been transferred from Tavistock and Portman NHS Foundation Trust), and this has identified risk of self-harm in around 40% of

cases reviewed, in response to which risk mitigation advice has been provided to the individual's GP.

However, in many cases the information on file was too limited to achieve an effective desk-top review, with many elements of the referrer form not completed by the referrer. As a result, a new approach has been implemented by NHS England - a process where the child and parents complete a 'Gender Experience Summary' (GES) which aims to provide more meaningful detail of the circumstances of the individual. All waiting list patients are now being asked to complete the GES form.

In order to strengthen further the approach to risk mitigation on the waiting list, NHS England is now in the process of implementing an enhanced risk assessment approach with local mental health services through an initiative that is being managed jointly by the NHS National Director for Mental Health and the NHS National Medical Director for Specialised Services. **It is planned that from April 2024 all local mental health services for children and young people across England will have arrangements in place to offer appointments to children and young people on the national waiting list for CYP Gender Services, and their families. Additional funding will be made available to local mental health teams by NHS England so that each mental health service can identify and deploy additional resource, thereby ensuring that local mental health service provision is not denuded and in order to secure timely access to the service.**

As an outcome of this initiative, the individual's local mental health team will initially screen for urgency based on the information from the GES, and a process of clinical triage will determine priority order, before providing an initial assessment of needs and risks including mental health needs and safeguarding. The outcome of the assessment might be for onward care within CYP mental health services or to remain under the care of their general practitioner for local support. All individuals will remain on the national waiting list for CYP Gender Service unless they ask to be removed. Additionally, with the support of NHS England's Medical Director for Primary care, a set of guidance will be distributed for general practitioners and other primary care professionals providing information on the CYP Gender Services, access to learning through the MindEd modules (see above) and signposting other resources while patients remain on the waiting list.

### **Other relevant matters that may assist HM Coroner: National Child Mortality Database**

It may assist the Coroner to know that as an outcome of recent discussions led by NHS England's National Clinical Director for Children and Young People's Mental Health and senior representatives of the National Child Mortality Database (NCMD):

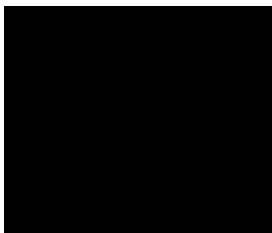
- A process has been agreed for Child Death Overview Panels (CDOPs) to alert NHS England following the death of every child or young person identified with gender distress.
- Improvements are being made to the NCMD alert system to NHS England when a child or young person with gender distress dies by probable suicide (whether or not they on the waiting list for CYP Gender Services).

- Changes have been made to the NCMD reporting form and supplementary suicide form to better identify children and young people with gender distress and those waiting/open to NHS/private provider for treatment.
- Agreement that in early 2024 NCMD will undertake an initial analysis of completed reporting forms for children and young people who have died between April 2019 to March 2023 with gender distress. This will help identify other factors and possible themes for learning that can be shared with local CYP mental health teams in advance of April 2024 as part of the mobilisation of the risk assessment service so that they are aware of increased risk and can consider enhanced suicide prevention strategies.

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,



[Redacted name]

National Medical Director