



Investigation report

Investigation report: Provision of care for children and young people when accessing specialist gender dysphoria services

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Access to care

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Considerations in light of coronavirus (COVID-19)

A number of national investigations were in progress when the COVID-19 pandemic significantly affected the UK in 2020. Much of the work associated with developing the investigation reports necessarily ceased as HSIB's response was redirected.

For this national report, while the learning described has not changed due to COVID-19, the processes HSIB used to engage with staff had to be adapted. This included fewer face-to-face interviews and interactions and an increased use of virtual interviewing. Owing to the nature of this investigation there was no need to visit clinical areas to observe work in practice.

About this report

This report is intended for healthcare organisations, policymakers and the public to help improve patient safety in relation to challenges that people may face in accessing gender dysphoria services. For readers less familiar with this area of healthcare, any specific medical or technical terms are explained in the body of the report.

Executive Summary

Background

This investigation explores the care of patients who present to child and adolescent mental health services (CAMHS) with questions about their gender identity and are referred to specialised gender dysphoria services. Gender dysphoria is a sense of unease, distress or discomfort that a person may have because of a mismatch between their biological sex and their gender identity. For example, a child who is registered as male at birth might feel or say

that they are a girl, or feel that neither 'boy' nor 'girl' are the right word to describe how they feel about themselves. Gender dysphoria is not identified as a mental illness by the NHS, but some people may develop mental health problems because of gender dysphoria.

As an example, which is referred to as 'the reference event', the investigation reviewed the care of a young person who was questioning their gender identity. This investigation's findings, safety recommendations and safety observations are aimed at helping to further direct ongoing national work to improve care across the NHS for children and young people who may be waiting to access gender dysphoria services.

The investigation of the reference event shows the complex range of local services that may provide support to patients waiting to access specialised gender dysphoria services. This may also be the case in other specialist areas of mental health such as learning disabilities or eating disorder services.

The reference event - December 2020

HSIB identified a patient safety incident involving an 18 year old transgender man. The Patient had been referred to CAMHS at 15 years old with concerns about his mental health and gender identity. At 16 years old, the Patient was referred to the Gender Identity Development Service (GIDS).

At 17 and a half years old, the Patient was advised by the GIDS that he would not be seen within GIDS before he turned 18 years old. His referral was then transferred to the waiting list of an adult gender dysphoria clinic (GDC), where his previous waiting time with the GIDS was accounted for. However, the Patient was told that this would still incur a further 22 month wait before he could access specialist gender dysphoria services.

The Patient continued to receive care from CAMHS beyond his 18th birthday while he waited to access the GDC, during which time expressed frustration at the waiting time to access specialist gender dysphoria services. The Patient sadly died by suspected suicide before his 19th birthday.

The national investigation

HSIB was notified of a patient safety incident relating to the waiting times and support available for patients accessing specialised gender dysphoria services. The notification was made by the Trust, which was concerned about its capacity and ability to care for patients waiting to access specialised services.

At the time of the investigation there was a 24-month wait to access the GIDS, and longer waits to access adult GDCs. The number of patients seen by the GIDS had increased year on year from 77 patients in 2009/10 to 2,383 patients in 2020/21.

The investigation gathered a range of evidence from the Patient's family, the Trust involved in the reference event, the Patient's GP, local voluntary and charitable sector (VCS) organisations, the GIDS, the GDC, and national stakeholders.

The investigation was carried out between June and September 2021 so that the initial findings could quickly be made available to inform rapidly progressing national work by:

- NHS England and NHS Improvement
- the independent review of gender identity services for children and young people (the Cass Review) which aims to improve gender dysphoria services for children and young people.

Findings

- There has been a significant increase in the number of patients wishing to access specialised children and young people's gender dysphoria services.
- There is significant national work underway to assist in improving care for children and young people waiting to access specialised gender dysphoria services.
- Child and adolescent mental health services, and other non-specialised services, have been required to provide care to patients and 'hold the risk' for patient care while patients wait to access specialised gender dysphoria services.
- There is a lack of capacity, capability, and specialist skills within non-specialised services to provide support to patients who have specific gender identity concerns. Gender dysphoria services are highly specialised and require specialist professional expertise.
- There is reliance on local voluntary and charitable sector organisations to supplement knowledge and expertise in caring for patients with gender identity concerns before they access specialised services.
- There are barriers to information sharing between networks of NHS and non-NHS organisations that may be involved in the care pathway for children and young people accessing and waiting to access specialised gender dysphoria services.
- There is a lack of capacity within the specialist workforce to support an increase in specialised gender dysphoria services to meet the reported increase in demand for these services.
- There is a lack of capacity and capability to ensure proactive risk assessment of the health of patients waiting on the GIDS waiting list.

- There is a lack of capacity and capability to ensure proactive risk assessment of the risk to individual patients who are transferring from the GIDS waiting list to a GDC waiting list.

HSIB makes the following safety recommendation

This safety recommendation is made to identify specific hazards to patient safety that may require further attention as part of ongoing national work in this area.

Safety recommendation R/2022/191:

HSIB recommends that NHS England and NHS Improvement incorporates the findings of this investigation into plans to further review and develop the service specifications for specialised gender dysphoria services. This should include further work with relevant stakeholders to:

A

- Identify the role of relevant voluntary and charitable sector organisations in supporting patients with gender identity concerns and facilitate information sharing between these organisations and regional professional support services.

B

- Identify work to improve the transfer of care, management, and proactive risk assessment of patients who are moving from the Gender Identity Development Service waiting list to a gender dysphoria clinic waiting list.

HSIB makes the following safety observations

These safety observations are made in support of ongoing national work exploring the care of children and young people with gender dysphoria

Safety observation O/2022/161:

It may be beneficial if professional bodies produced further advice and guidance to assist NHS staff who may need to provide care to patients with gender identity concerns while patients are waiting to access support from specialised gender dysphoria services.

Safety observation O/2022/162:

It may be beneficial if local healthcare commissioners had up-to-date and easily accessible resources to identify all relevant services within a locality that could provide support to patients with gender identity concerns.

Safety observation O/2022/163:

It may be beneficial if further work considered the ability to allow for shared record systems and ways to appropriately share information between NHS and non-NHS services involved in the care of patients with gender identity concerns.

Safety observation O/2022/164:

It may be beneficial if further work considered the availability and accessibility of specialist training to help in the care of children and young people who have gender identity concerns or gender dysphoria.

1 Background and context

1.1 Gender identity and gender dysphoria

1.1.1 Gender identity refers to how individuals perceive their own gender. A person's gender identity can be the same as or different from their biological sex, or gender assigned at birth.

1.1.2 Gender dysphoria is a diagnosis provided by a suitably qualified clinician. Gender dysphoria is a sense of unease, distress or discomfort that a person may have because of a mismatch between their biological sex, or the gender registered at birth, and their gender identity. People with gender dysphoria may wish to change their lives to express their gender identity. They may do this by changing the way they look and behave, including the option of medications or surgery (NHS, n.d.).

1.1.3 Gender dysphoria is not identified as a mental illness by the NHS, but some people may develop mental health problems because of gender dysphoria. A person's sense of unease or dissatisfaction with their gender may be so intense that it can lead to depression and anxiety and have a harmful impact on their daily life. People may also experience bullying or discrimination because of their gender identity.

1.1.4 A range of treatment options are available for children and young people who are diagnosed with gender dysphoria, with most focusing on psychological interventions (NHS England and NHS Improvement, n.d.). The investigation has not explored treatment options or legal issues surrounding the use of hormone therapy in children and young people.

1.1.5 In this report, the term 'gender dysphoria' is used to reflect the point of care at which such a diagnosis is made; for example, specialised services treat patients with gender dysphoria. The term 'gender identity concerns' is used to reflect the sense of unease or distress relating to gender identity for which a patient may seek help before they receive a diagnosis of gender dysphoria. For example, child and adolescent mental health services may see patients with gender identity concerns before they are referred to specialised services.

1.2 NHS commissioning

1.2.1 Commissioning is the process of assessing the need for healthcare services and planning, prioritising, purchasing and monitoring them to get the best health outcomes. NHS services may be commissioned either by clinical commissioning groups (CCGs) or by NHS England and NHS Improvement (NHSE/I).

1.2.2 CCGs are groups of general practices which come together in each area to commission services for the people in that area. CCGs commission a range of local services, such as planned hospital care, community care, and mental health care.

1.2.3 NHSE/I commissions primary care services (for example, GP services) and specialised services. Specialised services focus on rare or more complex conditions. They are not available in every region because they are delivered by specialist teams of doctors, nurses and other health professionals who have the necessary skills and experience.

1.3 NHS gender identity services

1.3.1 Specialised gender dysphoria services are commissioned to be provided by:

The Gender Identity Development Service

The Gender Identity Development Service (GIDS) is the national NHS service for children, young people, and their families who experience difficulties in the development of their gender identity. It is based in London and Leeds and accepts referrals from across England. It is commissioned by NHSE/I and managed by the Tavistock and Portman NHS Foundation Trust.

Gender dysphoria clinics

There are currently seven gender dysphoria clinics (GDCs) (previously known as gender identity clinics) in England. They treat patients aged 17 years and older. GDCs are commissioned by NHSE/I and provide formal diagnosis of gender dysphoria and access to other psychological and physical healthcare services, such as hormone medications and surgeries, for adults. NHS patients have the right to choose which of the clinics they are referred to, no matter where they live.

1.3.2 In 2018, NHSE/I carried out and published the results of a public consultation into specialised gender identity services for adults (NHS England and NHS Improvement, 2018). The consultation considered changes that could be made to the commissioning specifications for non-surgical and surgical gender dysphoria services (NHS England and NHS Improvement, 2019a; 2019b).

1.3.3 A key part of the new service specification for adult commissioned services was the development of 'trans health services'. This pilot scheme was intended to extend gender dysphoria care to multidisciplinary teams based in primary care that have received specialist training for that purpose.

1.4 Independent review into gender identity services for children and young people (the Cass Review)

1.4.1 In 2020, NHSE/I committed to support an initiative to review child and adolescent gender dysphoria services. It commissioned an independent review into gender identity services for children and young people (NHS England and NHS Improvement, 2020a). The review has become known as the Cass Review.

1.4.2 The aim of the Cass Review is to ensure that children and young people who are questioning their gender identity or experiencing gender dysphoria, and who need support from the NHS, receive a high standard of care that meets their needs and is safe, holistic and effective.

1.4.3 The Cass Review's terms of reference (NHS England and NHS Improvement, 2020b) outline a range of areas it has been asked to consider, including:

- pathways of care into local services
- pathways of care into specialised gender identity services
- clinical models and clinical management approaches at each point of the specialised pathway of care
- current and future workforce requirements
- exploration of the reasons for the increase in referrals to the GIDS
- any other relevant matters that arise during the course of the review.

1.4.4 The review is tasked with making recommendations to the NHS to improve how services and treatments should be delivered in order to provide the best support and care for children and young people.

1.5 The Care Quality Commission

1.5.1 The Care Quality Commission (CQC) is the independent regulator of all health and social care services in England. In January 2021, the CQC published an inspection report on the Tavistock and Portman NHS Trust. This included an inspection of the GIDS (Care Quality Commission, 2021).

1.5.2 The CQC inspection commented on a range of issues affecting the GIDS service, including:

- Challenges in patients accessing the GIDS. The CQC found that there were more than 4,600 young people on the GIDS waiting list and that some patients waited more than 2 years for their first appointment.
- Challenges in managing patient risk. The CQC found that many of the young people waiting for or receiving a service were vulnerable and at risk of self-harm. The size of the waiting list meant that staff were unable to proactively manage the risks to patients waiting for a first appointment.
- Staff did not always feel respected, supported and valued. The CQC found that some said they felt unable to raise concerns without fear of retribution.

2 The reference event

This investigation used the following patient safety incident, referred to as 'the reference event' to consider:

- issues surrounding access to specialised gender dysphoria services for children and young people
- the support available to children and young people with gender identity concerns from child and adolescent mental health service (CAMHS) when awaiting access to specialised services.

The reference event involved a complex period of care and the Patient had multiple contacts with CAMHS and other social, and voluntary and charitable sector (VCS) organisations.

The Parent then informed HSIB of specific concerns that, despite the anonymity provided in HSIB reports, specific aspects of the Patient's care which were described in Section 2 could identify the patient or Parent when the report was made publicly available. Due to this, HSIB has chosen to present only limited information in Section 2 from our publicly available report. This does not impact on the findings, recommendations and observations set out at Section 5.

2.1 HSIB identified a patient safety incident involving an 18 year old transgender man. The Patient had been referred to CAMHS at 15 years old with concerns about his mental health and gender identity. At 16 years old, the Patient was referred to the Gender Identity Development Service (GIDS).

2.2 At 17 and a half years old, the Patient was advised by the GIDS that he would not be seen within GIDS before he turned 18 years old. His referral was then transferred to the waiting list of an adult gender dysphoria clinic (GDC), where his previous waiting time with the GIDS was accounted for. However, the Patient was told that this would still incur a further 22 month wait before he could access specialist gender dysphoria services.

2.3 The Patient continued to receive care from CAMHS beyond his 18th birthday while he waited to access the GDC, during which time expressed frustration at the waiting time to access specialist gender dysphoria services. The Patient sadly died by suspected suicide before his 19th birthday.

3 Involvement of the Healthcare Safety Investigation Branch

This section outlines how HSIB was alerted to issues concerning children and young people accessing specialised gender dysphoria services and the support available to patients while waiting for specialist support. It also describes the criteria HSIB used to decide whether to go ahead with the investigation, and the methods and evidence used in the investigation process.

3.1 Notification of the reference event and decision to investigate

3.1.1 HSIB was notified of a patient safety incident relating to the waiting times and support available for patients accessing specialised gender dysphoria services. The notification was made by an NHS mental health trust that was concerned about the capacity and ability of its child and adolescent mental health service (CAMHS) to care for patients waiting to access specialised services.

3.1.2 HSIB has previously completed an investigation and made recommendations about the transfer of patient care between CAMHS and adult mental health services (**Healthcare Safety Investigation Branch, 2018**). It has not considered the transfer of patients from children and young people's to adult gender dysphoria services.

3.2 Decision to conduct a national investigation

3.2.1 HSIB conducted an initial scoping investigation which determined that the patient safety concern met the criteria for investigation (see below). HSIB's Chief Investigator authorised a national investigation.

Outcome impact – what was, or is, the impact of the safety issue on people and services across the healthcare system?

The Gender Identity Development Service (GIDS) has experienced a year-on-year increase in the number of referrals it has received. Within the last decade there has been an increase in referrals of more than 2,800% (see figure 1).

Figure 1 Number of referrals to the GIDS by year

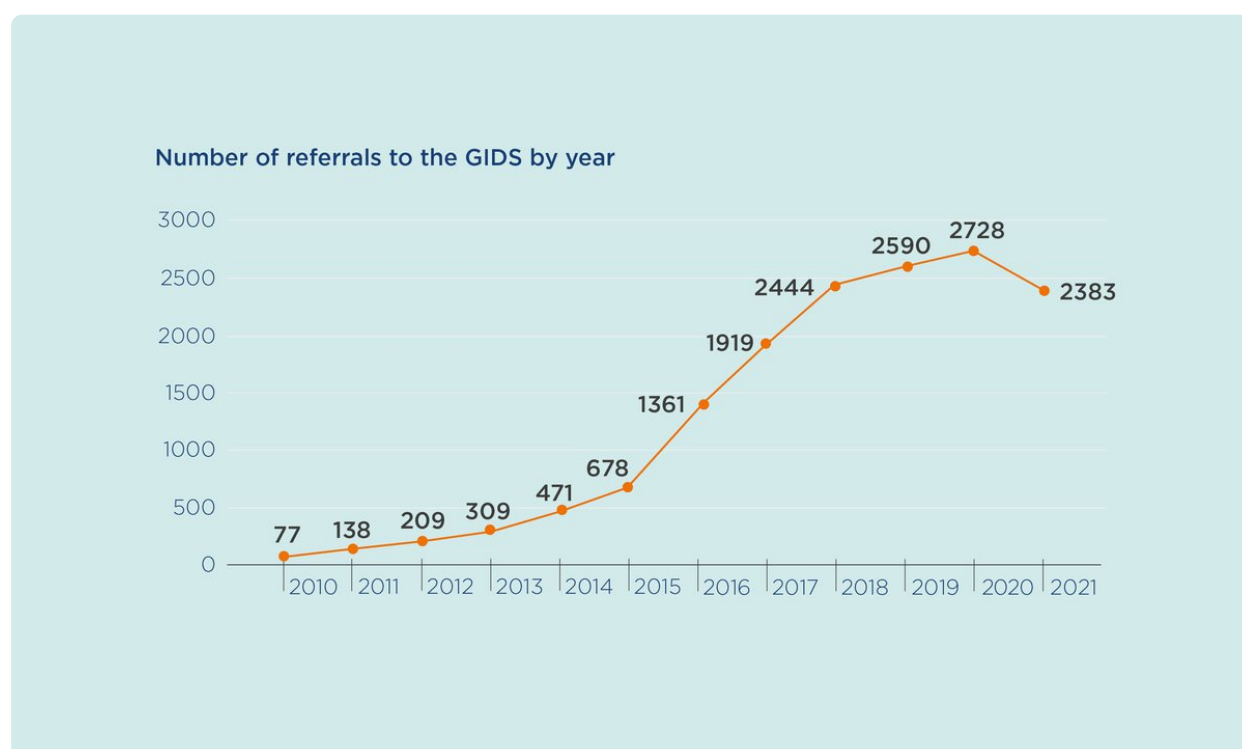


Figure 1 Number of referrals to the GIDS by year

Most NHS patients have the right to start non-urgent consultant-led treatment within maximum waiting times (NHS, 2019a). NHS England told the investigation that the GIDS is not 'consultant-led', and therefore not covered by these rules. However, NHS England has reflected the ambition of the 18-week standard (that is, a target waiting time of a maximum of 18 weeks) in its service specification for the GIDS.

At the time of writing, waiting times to access the GIDS were reported to be over 36 months from initial referral, with over 4,600 children and young people on the waiting list. In addition, waiting times to access adult gender dysphoria clinics were reported to be between 22 and 61 months from the point of referral into adult services at different gender dysphoria clinics.

In 2012, the Trans Mental Health Survey (McNeil et al, 2012) identified that more than half (55%) of transgender people had been diagnosed with depression. Patients with depression are at significantly higher risk of suicide (Bachmann, 2018).

The World Health Organization estimates that globally more than 700,000 people die by suicide every year (World Health Organisation, 2021). In the UK, the suicide rate in males aged 10 to 24 increased by 25% between 2017 and 2018, from 7.2 deaths per 100,000 (in 2017) to 9 deaths per 100,000 (in 2018) (Office for National Statistics, 2019).

The Trans Mental Health Study 2012 (McNeil et al, 2012) found that 48% of trans people in Britain have attempted suicide at least once and 84% had thought about it. An American study also found that, of 120,617 adolescents (aged 11 to 19 years) interviewed, those who identified as female to male transgender reported the highest rate of attempted suicide (50.8%), followed by adolescents who identified as not exclusively male or female (41.8%) (Toomey et al, 2018).

Systemic risk – how widespread and how common a safety issue is this across the healthcare system?

The NHS Strategic Executive Information System (a national database of serious patient safety incidents) was searched on 5 April 2021 for incidents reported as occurring on or after 1 April 2017 with the keywords 'waiting' 'gender' and 'identity'. The results identified 16 incidents between May 2017 and March 2021 involving death by suspected suicide where the person was either:

- receiving support from gender identity services
- on the waiting list to receive support
- had general concerns about their gender identity that were affecting their mental health.

Contributory factors cited in some of the incident reports included:

- the management of risk while patients were waiting for input from a gender identity service, and
- communication and collaboration between local mental health services and gender identity service providers.

Learning potential – what is the potential for an HSIB investigation to lead to positive changes and improvements to patient safety across the healthcare system?

Models for the provision of adult gender identity services are currently under review by NHS England and NHS Improvement and an independent review (the Cass Review) has been commissioned to consider outstanding issues relating to the GIDS. In addition, the provider of GIDS services was subject to a Care Quality Commission inspection in January 2020 which highlighted improvements that could be made to the service.

HSIB has explored the national issues arising from the reference event to consider whether current ongoing national work can address the safety risks identified and whether an HSIB investigation can further contribute to this work to improve patient safety.

3.3 Evidence gathering

3.3.1 The investigation was completed between June and October 2021. The condensed investigation timescale was designed to help provide additional evidence to influence rapidly progressing national work in this area.

3.3.2 A range of evidence was gathered and reviewed by the investigation from the Patient's family, the reference event Trust, the Patient's GP, local voluntary and charitable sector organisations, the GIDS, and the adult gender dysphoria clinic.

3.3.3 The investigation identified stakeholders across the healthcare system and sought their perspectives on the ongoing work surrounding gender dysphoria services. The investigation identified ongoing national work in this area and contacted a range of stakeholders. This included interviews and conversations with representatives from:

- NHS England and NHS Improvement
- Care Quality Commission
- the Cass Review
- Royal College of Physicians
- Royal College of General Practitioners.

3.3.4 The evidence gathering process adopted an iterative approach so that as further information was received, additional sources of evidence were identified.

3.3.5 The findings were shared with the stakeholders identified by the investigation. This enabled checking for factual accuracy and overall sense-checking. The stakeholders contributed to the development of the safety recommendations based on the evidence gathered.

3.4 Methods used to analyse the evidence

3.4.1 HSIB does not seek to apportion blame or liability in its investigations. It considers the healthcare system in its entirety to identify the factors that have contributed to a reference event.

3.4.2 A range of methods was used to collect and analyse evidence during the investigation.

3.4.3 An Actor-map (Rasmussen and Svedung, 2000) was used to identify relevant individuals and organisations within the local and national healthcare system that were involved within this area of care and would need to input into the investigation.

3.4.4 The Systems Engineering Initiative for Patient Safety (SEIPS) model (Carayon et al, 2006) was used as the primary framework for evidence collection. The SEIPS framework provides a way to understand the relationship between the structures, processes, and outcomes of healthcare systems.

4 Analysis and findings – the reference event

HSIB completed a full scoping investigation into the reference event to identify the systemic factors that may have impacted on the Patient's care. The Patient had several contacts with the health and social care system during his wait for treatment from specialised gender dysphoria services. The investigation noted that children and young people's mental health services (CAMHS), primary care, and local voluntary and charitable sector (VCS) organisations are not commissioned to provide specialist support for patients who come to them with gender identity concerns.

The complete draft report included a detailed summary of the Patient's care (Section 2) and detailed findings and analysis of the Patient's care (Section 4). The complete draft report was shared with the Parent, relevant stakeholders involved in the Patient's care, and stakeholders involved in delivering ongoing national work in the report's consultation period.

The Parent then informed HSIB of specific concerns that, despite the anonymity provided in HSIB reports, specific aspects of the Patient's care which were described in Section 4 could identify the Patient or Parent when the report was made publicly available. Due to this, HSIB has chosen to remove Section 4 from our publicly available report. This does not impact on the findings, recommendations and observations set out at Section 5.

5 Analysis and findings – the wider investigation

This section sets out the investigation's findings about key challenges in providing care to children and young people waiting to access specialised gender dysphoria services.

The reference event highlights the waiting times for patients seeking to access support from specialised gender dysphoria services in the context of the large increase in referrals to these services over the past decade. The reference event also highlights the lack of commissioned, specialist support within local services in this waiting period and the challenges that non-specialised services face when trying to provide support in this 'gap'.

The investigation has identified areas where ongoing national work is intended to address these concerns and where the investigation findings can be used to further improve care for patients.

5.1 National safety concerns identified via the investigation into the Patient's care

5.1.1 The HSIB investigation into the Patient's care (see section 4) identified specific themes concerning the provision of care to children and young people with gender dysphoria presenting via children and young people's mental health services (CAMHS).

5.1.2 The investigation of the reference event has highlighted that the current provision of gender dysphoria services to children and young people in England may result in hazards and associated risks that can potentially cause patient harm. A hazard is something that has the potential to cause harm or an undesirable patient outcome. A risk is the predicted likelihood of the hazard causing harm or an undesirable outcome.

5.1.3 The investigation has highlighted factors across the pathway of care for children and young people with gender dysphoria that create a hazard to these patients. The main hazard is the current waiting times for specialised gender dysphoria services. There is a 22-month wait to access the Gender Identity Development Service (GIDS) and potentially significantly longer waits once patients are referred to a gender dysphoria clinic.

5.1.4 In response to this, non-specialised services have been asked to 'hold' clinical risk for patients with gender identity concerns until they access specialised support. However, the investigation found significant hazards in this approach, including:

- the lack of commissioned specialist knowledge and support within CAMHS to support patients while they wait to access specialised gender dysphoria services

- the lack of commissioned specialist knowledge and support within primary care to support patients while they wait to access specialised gender dysphoria services
- the reliance on voluntary and charitable sector (VCS) organisations outside the NHS to help bridge the support and knowledge gap while patients wait to access specialised gender dysphoria services.

5.1.5 The investigation acknowledges that planned interventions from NHS England and NHS Improvement (NHSE/I) discussed later in this section are at an early stage and that it will take time to embed and evaluate them to gather evidence of their impact on gender dysphoria services. In addition, any work recommended by the Cass Review will also need support from the wider healthcare system and time to embed so that the impact on services can be evaluated.

5.1.6 Given this evolving landscape, it is challenging for the investigation to make targeted recommendations to improve specific elements of the patient care pathway. The provision of care to children and young people with gender identity concerns is facing significant changes because of the Cass Review, NHSE/I's work and work following the Care Quality Commission (CQC) inspection of the GIDS, and has moved on considerably since the Patient's initial referral to services.

5.1.7 The findings presented in this section provide additional evidence to support the prioritisation of work to ensure that the safety of children and young people waiting to access specialised gender dysphoria services can be improved. These findings should be used to help further develop and target strategies to improve the care of children and young people waiting to access specialised gender dysphoria services.

5.2 Progress in developing specialised gender dysphoria services

Waiting times to access specialised services

5.2.1 In January 2021, the CQC published an inspection report on the Tavistock and Portman NHS Trust, which manages the GIDS. The CQC inspection found concerns about the management of the GIDS waiting list.

5.2.2 At the time of the CQC inspection, the average waiting time for patients to access the GIDS was over 2 years from the point of their initial referral. The investigation contacted the GIDS to find out about the current waiting time for new patients referred to the service and was told that it was around 22 months.

5.2.3 The CQC inspection highlighted concerns about the GIDS's ability to assess and manage the risk to patients on its waiting list. The CQC found that many children and young people waiting to access the GIDS were vulnerable and that the GIDS was limited in its ability to

proactively manage the risks to patients waiting for a first appointment. The CQC advised that the GIDS must ensure it continued to work with commissioners to reduce waiting times for the 4,600 children and young people on the GIDS waiting list.

5.2.4 The investigation engaged with the CQC to understand what further work it may be undertaking to monitor the GIDS service and ensure the improvements it identified were taking effect. The CQC told the investigation that it had worked with the GIDS to develop a service action plan to address issues identified during the inspection. The action plan included work that focused on managing the GIDS waiting list. The GIDS told the investigation that new senior working groups had been established to help address these issues.

5.2.5 In addition, the CQC had hosted, and planned to host further, quality summits that brought together partners from across the healthcare system to help address the issues highlighted in its inspection report. This included representatives from the GIDS, CQC, NHSE/I and other agencies. This supported oversight of the challenges posed by the GIDS waiting list and helped to highlight the interacting factors that created pressure on the GIDS waiting list both within and outside of the GIDS service.

5.2.6 The Cass Review wrote to NHSE/I on 10 May 2021 (The Cass Review, 2021a). This letter highlighted that:

‘... the risk of having a national service as the first point of access is that assessment and treatment of children and young people who have the greatest need for specialist care is delayed because of the lack of differentiation of those on the waiting list.’

5.2.7 NHSE/I responded to the Cass Review on 12 July 2021 (NHS England and NHS Improvement, 2021a). It confirmed that it is carrying out work to develop a new national service for children and young people, which includes the provision of a new regional professional support service.

5.2.8 NHSE/I explained in its letter that this service will bring together specialists from a range of different clinical backgrounds to support the provision of ‘expert advice and support to referring healthcare professionals to help them to provide high quality information to the GIDS’. This will include a referral checking process to ensure referrals are appropriate and contain all the information that the GIDS requires.

5.2.9 The NHSE/I website gives further details of the planned service and how it will function (NHS England and NHS Improvement, 2021b). The new service will include early consultation between new regional professional support services and the healthcare professional making a referral. It will also be able to identify more complex cases that might need more urgent support, in consultation with the GIDS, including providing advice to referrers.

5.2.10 The ongoing work arising from the CQC inspection of the GIDS and NHSE/I's work to develop a national referral management service aims to help address hazards associated with inappropriate or incomplete referrals to the GIDS. The intention is that this will in turn have a positive impact on the waiting list by addressing issues with the referral information and reducing the burden on the GIDS to undertake further work to clarify referrals. In addition, the investigation was told that more work to reduce the current waiting time for the GIDS is planned.

5.2.11 Given the emerging nature of the national work, it will also be important that planned work to reduce the GIDS waiting list is evaluated to ensure it has been effective in meeting its aims and that these interventions can continue to be effective given the background of a consistent year-on-year rise in referrals to the GIDS.

5.2.12 The investigation acknowledges the challenges posed in taking proactive steps to assess and monitor the risk to individual patients given the current volume of patients waiting to access the GIDS. However, where possible, further proactive steps by the healthcare system to support the GIDS and local services to undertake dynamic risk assessments of patients on the GIDS waiting list would help to mitigate the risk to the most vulnerable patients. This may require more ability for services to share information with the GIDS after the point of referral to help identify patients whose risk factors may have increased following the point of referral to the GIDS.

Support and skills for non-specialist NHS staff providing support to patients with gender identity concerns

5.2.13 The Cass Review told the investigation that current evidence did point to concerns about the support available to children and young people on the GIDS waiting list. This included the support available from primary care, secondary care and other agencies.

5.2.14 The Cass Review wrote to NHSE/I on 10 May 2021 (The Cass Review, 2021a). One aim of the letter was to address the immediate situation facing children and young people waiting to access the GIDS and the support available to them from local, non-specialised gender dysphoria services.

5.2.15 The Cass Review highlighted that ‘having a single provider [the GIDS] may have been a logical position when the ... service was first set up, given that this is a highly specialised service that was seeing a relatively small number of cases each year’. However, the Cass Review reflected that ‘there has been an exponential increase in numbers of children with gender incongruence or dysphoria’ meaning that ‘concentration of expertise within a single service has become unsustainable’.

5.2.16 The Cass Review also highlighted further factors within non-specialised services that meant that:

‘... local services have not developed the skills and competencies to provide support for children on the waiting list and those with lesser degrees of gender incongruence who may not wish to pursue specialist medical intervention, and/or to provide help for children with additional complex needs.’

5.2.17 The Cass Review encouraged NHSE/I to consider a range of factors when developing an interim pathway of care for children and young people who needed to access specialised gender dysphoria services. One aspect highlighted by the Cass Review was that:

‘... all children and young people who are referred to specialist services should have a competent local multi-disciplinary assessment and should remain under active holistic local management until they are seen at a specialist centre.’

5.2.18 In addition, the Cass Review stated that it would test assumptions ‘with a range of clinical staff and ascertain whether there are other barriers that are preventing local engagement in this work’. The Cass Review told the investigation that intends to liaise with professional groups, service user groups and Health Education England as part of this programme of work with a view to identifying ‘an approach to training for professionals at local and regional level’ and ‘workforce recommendations’.

5.2.19 NHSE/I responded to the Cass Review letter (NHS England and NHS Improvement, 2021a), explaining that it was in the process of establishing an interim regional professional support service to address the recommendations made by the Cass Review. NHSE/I confirmed to the investigation that the new children and young people’s service ‘would operate across the country and provide care and support for patients’ with gender dysphoria while they remain on the waiting list for specialised services.

5.2.20 The NHSE/I website gives further details of the planned service and how it is expected to function (NHS England and NHS Improvement, 2021b). The intention is that the service will include liaison with and support for professionals in the health and care network while the patient remains on the waiting list for the GIDS (including GPs, children and young people's mental health services, paediatrics, education services and local authorities). The service will also co-ordinate any additional healthcare support services – including psychosocial and psychological support – according to patients' needs.

5.2.21 NHSE/I told the investigation that it was moving quickly to award contracts to specific NHS organisations for the new service and that the process of identifying organisations had begun. NHSE/I told the investigation it had an ambition for the new children and young people's service to be operational by November 2021.

5.2.22 In addition, the NHS Long Term Plan (NHS, 2019b) includes a plan to support new mental health support teams working in schools and colleges. These teams will receive information and training to help them support young people more likely to face mental health issues. LGBTQ+ children and young people are specifically named as groups that will be targeted for additional support for associated mental health concerns that may arise from their gender identity. However, this would not provide specific, specialist support to address gender identity concerns.

5.2.23 The investigation also engaged with the Royal College of General Practitioners (RCGP). The RCGP told the investigation that it had engaged with the Cass Review to further highlight the issues faced in primary care and by GPs in caring for patients with gender dysphoria. It had produced a position statement on caring for transgender patients in 2019 (Royal College of General Practitioners, 2019). This acknowledged that 'GPs are not experienced in treating and managing patients with gender dysphoria and trans health issues' and that core GP training did not address these issues.

5.2.24 In response to these concerns, the RCGP has developed its own online training package to provide some additional knowledge and support for GPs who are caring for patients with gender dysphoria. The training package includes content on caring for adults and caring for children and young people (Royal College of General Practitioners, 2020).

5.2.25 In a journal entry dated 27 July 2021, the Cass Review (2021b) confirmed that it had:

'... committed to prioritise work to explore how best to develop the workforce outside of the GIDS by working with a range of clinical professionals to understand what assessment tools

might be needed, what training is necessary, and what the implications are for the longer-term workforce plan.'

5.2.26 The Cass Review commented that, with regard to the organisation of local services to support gender identity concerns:

'... there will likely be a range of different models and options around the country, dependent on local resources, with some of the work being delivered through existing secondary service teams, and some being delivered at regional level.'

5.2.27 This reflects the complex local care landscape highlighted in the reference event. Within the landscape, this includes variation in available staff within CAMHS to provide any enhanced support for children and young people with gender identity concerns, local primary care services, and the local VCS landscape where additional services may be accessed.

5.2.28 Ongoing national work has identified a hazard associated with the centralisation of specialist knowledge about gender dysphoria and the lack of availability of additional support outside of the current specialist workforce. The commissioned service proposed by NHSE/I, and potential further recommendations and directions from the Cass Review, are intended to create an enhanced network of multidisciplinary professionals who can provide support to patients with gender identity concerns. This would grow capacity and capability to manage the complex needs of those with gender identity concerns and mitigate the risk to patients seeking support while they await care from specialised services.

5.2.29 This work could be supported by the adoption of enhanced professional guidance for the professional groups within the multidisciplinary teams to help provide further clarity and guidance on their role and remit in caring for patients with gender identity concerns.

HSIB makes the following safety observation

Safety observation O/2022/161:

It may be beneficial if professional bodies produced further advice and guidance to assist NHS staff who may need to provide care to patients with gender identity concerns while patients are waiting to access support from specialised gender dysphoria services.

5.2.30 The development of regional professional support services would be an opportunity to get a better understanding of the complexity of services operating within local regions. It would also help to ensure a consistent understanding of the multidisciplinary workforce available, both within the NHS and in other public and VCS organisations, that could support patients with gender identity concerns.

5.2.31 The findings of the investigation into the reference event show the significant role of local VCS services in the patient pathway. Without a clear understanding of the VCS and other support services available it can be difficult for clinicians to signpost patients with gender identity concerns to appropriate support.

HSIB makes the following safety recommendation

This safety recommendation is made to identify specific hazards to patient safety that may require further attention as part of ongoing national work in this area.

Safety recommendation R/2022/191:

HSIB recommends that NHS England and NHS Improvement incorporates the findings of this investigation into plans to further review and develop the service specifications for specialised gender dysphoria services. This should include further work with relevant stakeholders to:

A

- Identify the role of relevant voluntary and charitable sector organisations in supporting patients with gender identity concerns and facilitate information sharing between these organisations and regional professional support services.

HSIB makes the following safety observation

Safety observation O/2022/162:

It may be beneficial if local healthcare commissioners had up-to-date and easily accessible resources to identify all relevant services within a locality that could provide support to patients with gender identity concerns.

5.2.32 As well as identifying where additional support may be available, it may be important to ensure that these services are further integrated in order to provide patient-centred care across the gender identity care pathway. The investigation of the reference event highlighted challenges in sharing information across multiple providers.

5.2.33 Previous HSIB investigations have commented on the increasing importance of shared record systems across NHS care. In the case of support services for gender identity concerns, the need to share information spreads further across other public sector and VCS organisations that may form part of the care pathway for patients with gender identity concerns.

HSIB makes the following safety observation

Safety observation O/2022/163:

It may be beneficial if further work considered the ability to allow for shared record systems and ways to appropriately share information between NHS and non-NHS services involved in the care of patients with gender identity concerns.

The specialist gender dysphoria workforce

5.2.34 The investigation was told about challenges related to the availability of specialist staff to support gender dysphoria services. The RCGP position statement (Royal College of General Practitioners, 2019) stated that 'GPs face difficulties in accessing gender identity specialists in a timely way which often has severe implications for the mental and physical health of their patients' and highlighted the need for national workforce and training solutions to address these issues.

5.2.35 GIDS staff told the investigation that it had been difficult to recruit and retain specialist staff within the service in order to increase its capacity to deliver care. Reflecting the findings of the CQC inspection (Care Quality Commission, 2021), staff told the investigation that there was a sense of the team being "under siege" from external pressures. This included some staff being targeted on social media and being reluctant to advertise where they worked. Staff turnover within the GIDS was 24% in 2019/20 and staff thought this may be due to both internal and external pressures on the service.

5.2.36 NHSE/I told the investigation that it was aware of the need to build clinical capacity within the NHS by identifying and training a new, enhanced workforce with the specialist skills and knowledge to provide gender dysphoria services. The investigation was told by NHSE/I and the Cass Review that the Cass Review will involve Health Education England in its process for forming recommendations, and NHSE/I will consider how to support workforce development

and training when making any changes to care pathways or services that may arise from the Cass Review. Health Education England told the investigation it was engaging with NHSE/I about the possibility of developing a competence outline to support newly commissioned services.

5.2.37 In addition, NHSE/I highlighted ongoing work by the Royal College of Physicians (RCP) in this area to provide additional training and support. The investigation engaged with the RCP to understand more about existing training on gender dysphoria. The RCP told the investigation that it had become involved in providing training to clinicians about gender dysphoria in 2017 when, following a request from NHSE/I, it set up a working group to consider how it could respond to the challenge of providing care for adult patients with gender dysphoria.

5.2.38 The RCP told the investigation that it had decided that education around adult gender dysphoria would need to be separate from education around children and young people's gender dysphoria. A stakeholder group meeting identified that the clinical considerations for staff working with children and young people may be different to the clinical considerations for staff working with adults. The group also identified the complex ethical and legal landscape that exists around the care of children and young people with gender dysphoria.

5.2.39 The RCP subsequently partnered with a university to deliver a programme that provided pathways to education about adult gender dysphoria. The programme includes theoretical and practical courses resulting in a postgraduate certificate or diploma (Royal College of Physicians, n.d.). However, the RCP told the investigation that these courses are not yet routinely filled by participants and are therefore at risk of being suspended.

5.2.40 The investigation could not identify any similar formal postgraduate training courses to help in the development of a workforce to meet the needs of children and young people with gender dysphoria. Clinical staff working in the field of children and young people's gender dysphoria and wider stakeholders told the investigation that there was no formal, professional pathway into working within such services.

5.2.41 The GIDS does advertise a continuing professional development course on 'working effectively with gender diverse children, young people and their families'. This is designed to increase existing healthcare professionals' knowledge of gender dysphoria but does not lead to a formal qualification or specialty in this field. The GIDS told the investigation it would be delivering training to the regional professional support services being established by NHSE/I. The GIDS said that this would help to facilitate a better understanding of the issues surrounding caring for patients with gender dysphoria within these multidisciplinary teams.

5.2.42 Ongoing national work has identified a hazard associated with the fact that there are not enough specialist staff in the field of gender dysphoria when considered in light of the rise in referrals to specialised services. Planned work by the Cass Review to engage with Health

Education England may help form recommendations to develop a clearer educational and professional pathway for staff to enter gender dysphoria services. This may help develop longer-term workforce solutions and help mitigate the risk to patients by increasing the availability of specialist staff with professional qualifications, accreditation, competence and expertise.

5.2.43 Current formal education provided via the RCP has focused on care for adults and there is no formal qualification or professional pathway into children and young people's gender dysphoria services. The investigation found that this age group may have different concerns and considerations to adult patients that would require more targeted education. Further national work to consider the workforce and skills required to deliver gender dysphoria care to children and young people could seek to address this imbalance and to ensure equitable access to education across both adult services and children and young peoples' services.

5.2.44 However, it is important to note that existing educational programmes offered by the RCP and the GIDS have not been widely accessed, and in the case of the RCP, are at risk of being discontinued. The investigation heard from staff about the challenges they faced working within this speciality.

5.2.45 In addition to educational programmes, further national work may be able to identify and account for perceived challenges in recruiting and retaining staff in this area of care. If these challenges can be identified and addressed, this may improve uptake of educational courses and improve staff recruitment and retention in this field.

5.2.46 Consultation responses to the report raised questions about whether targeting HSIB recommendations at developing a specialist gender dysphoria workforce would be unhelpful. There are ongoing questions about whether a specialised workforce, or a broader workforce equipped with more specialist knowledge about gender dysphoria, would be most beneficial to improving care in this area. The investigation was told that the Cass Review was also considering workforce within its remit and it was anticipated that it may make recommendations in this area.

5.2.47 In whatever future service model may be developed there will still be a need to ensure that staff can access appropriate specialist training to help in the care of children and young people with gender identity concerns or gender dysphoria.

HSIB makes the following safety observation

Safety observation O/2022/164:

It may be beneficial if further work considered the availability and accessibility of specialist training to help in the care of children and young people who have gender identity concerns or gender dysphoria.

Transfer between the Gender Identity Development Service and gender dysphoria clinic

5.2.48 The reference event did not involve the transfer of a patient who had been seen and assessed by the GIDS to a gender dysphoria clinic (GDC). Instead, it demonstrated a situation in which patients are transferred from the GIDS waiting list to a GDC waiting list without having begun treatment with a specialised service. Typically, this scenario involves patients approaching the age of 18 who have yet to receive care from the GIDS.

5.2.49 The GIDS explained that it did make an offer of additional support to patients in this situation and gave patients the choice of staying in contact with the GIDS until their care was transferred to the GDC, or transferring to the GDC waiting list sooner.

5.2.50 The GIDS told the investigation that it had been piloting the use of transfer clinics with some GDCs to help address the issue of care for patients who are transferring from the GIDS to a GDC. The GIDS told the investigation that this involved a meeting between GIDS and GDC staff to discuss the care of patients moving between services. However, this was limited to patients who had received an assessment and care from the GIDS. It did not include a detailed handover of patients who had not already begun treatment and who were moving from one waiting list to another. The GIDS told the investigation that this was due to the resources available and volume of patients requiring transfer.

5.2.51 The GIDS also told the investigation that, in addition to a GDC co-located in the same organisation, it had to manage the relationships with six separate GDCs across England. The GIDS told the investigation that the “character” and processes of each GDC could be different and that it had no single point of access to manage its relationships with these providers. The GIDS told the investigation that the difference in service provision between GDCs meant it could be a challenge to provide guidance to patients on transferring between services.

5.2.52 The GDC also told the investigation that the service models at different GDCs were different. Some GDCs focused more on psychological therapies while others had a greater focus on other areas of care. In the Patient’s case, the GDC did not have the resource to provide psychological support during the time he was waiting to access treatment and therefore a suggestion would have been made to contact another GDC that may have had this capacity.

5.2.53 The NHSE/I website provides more details of the planned service changes and describes the intention to develop transfer services. It explains that there would be 'a coordinated transfer to appropriate adult services where young people are within six months of their 18th birthday' (NHS England and NHS Improvement, 2021b).

5.2.54 The importance of an effective process to transfer patients on the waiting list and provide appropriate support is highlighted by current waiting times to access the GIDS. At the time of writing, waiting times to access the GIDS were reported to be over 36 months from initial referral. In practice, based on current measures, this means that patients referred to the GIDS after the age of 14 may not have time to be seen within the GIDS before they have to transfer to a GDC. This in turn may mean that a significant proportion of patients transferred to a GDC would be moving from waiting list to waiting list.

5.2.55 Ongoing work via NHSE/I has identified the need to improve the transfer of care from the GIDS to a GDC when patients are approaching 18 years old. NHSE/I has told the GIDS that this is a priority work area and has asked the GIDS to produce a proposed transfer protocol between GIDS and adult GDCs for review and development by NHSE/I's Clinical Reference Group (CRG) for Gender Dysphoria. NHSE/I has also asked the CRG to provide NHSE/I with advice on the particular needs of young people aged 17 to 25 years who are on the gender dysphoria pathway. Further proactive methods to identify patient risk (see 5.2.12) may help to address some of these concerns.

5.2.56 Given the current waiting times for the GIDS, a significant number of young people may be transferred to a GDC without having accessed care from the GIDS. When this occurs, existing variations in the services and access requirements for GDCs may make it difficult to ensure a common approach across all providers, which in turn creates a risk that patients' needs will not be put first.

5.2.57 Challenges in transferring patients' care from children and young people's to adult services have been acknowledged in other areas of care. HSIB has previously investigated transfer arrangements in mental health services and made recommendations to help move from aged-based criteria for transfer towards more flexible criteria based on individuals' needs (**Healthcare Safety Investigation Branch, 2018**). The NHS Long Term Plan (NHS, 2019b) now includes an integrated approach for the delivery of care for people up to the age of 25 across health, social care, education and the voluntary sector.

5.2.58 There is an opportunity for a similar approach to be considered within gender dysphoria care, given the current crossover of waiting lists and proposed regionalised models of multidisciplinary support. This may help to address challenges associated with transferring patients between separate waiting lists and provide greater certainty about the services patients may expect to receive throughout their pathway of care, from young people to adults.

HSIB makes the following safety recommendation

This safety recommendation is made to identify specific hazards to patient safety that may require further attention as part of ongoing national work in this area.

Safety recommendation R/2022/191:

HSIB recommends that NHS England and NHS Improvement incorporates the findings of this investigation into plans to further review and develop the service specifications for specialised gender dysphoria services. This should include further work with relevant stakeholders to:

B

- Identify work to improve the transfer of care, management, and proactive risk assessment of patients who are moving from the Gender Identity Development Service waiting list to a gender dysphoria clinic waiting list.

6 Summary of findings, safety recommendation and safety observations

6.1 Findings

There has been a significant increase in the number of patients wishing to access specialised children and young people's gender dysphoria services.

- There is significant national work underway to assist in improving care for children and young people waiting to access specialised gender dysphoria services.
- Child and adolescent mental health services, and other non-specialised services, have been required to provide care to patients and 'hold the risk' for patient care while patients wait to access specialised gender dysphoria services.
- There is a lack of capacity, capability, and specialist skills within non-specialised services to provide support to patients who have specific gender identity concerns. Gender dysphoria services are highly specialised and require specialist professional expertise.
- There is reliance on local voluntary and charitable sector organisations to supplement knowledge and expertise in caring for patients with gender identity concerns before they access specialised services.

- There are barriers to information sharing between networks of NHS and non-NHS organisations that may be involved in the care pathway for children and young people accessing and waiting to access specialised gender dysphoria services.
- There is a lack of capacity within the specialist workforce to support an increase in specialised gender dysphoria services to meet the reported increase in demand for these services.
- There is a lack of capacity and capability to ensure proactive risk assessment of the health of patients waiting on the GIDS waiting list.
- There is a lack of capacity and capability to ensure proactive risk assessment of the risk to individual patients who are transferring from the GIDS waiting list to a GDC waiting list.

6.2 Safety recommendation and safety observations

HSIB makes the following safety recommendation

This safety recommendation is made to identify specific hazards to patient safety that may require further attention as part of ongoing national work in this area.

Safety recommendation R/2022/191:

HSIB recommends that NHS England and NHS Improvement incorporates the findings of this investigation into plans to further review and develop the service specifications for specialised gender dysphoria services. This should include further work with relevant stakeholders to:

A

- Identify the role of relevant voluntary and charitable sector organisations in supporting patients with gender identity concerns and facilitate information sharing between these organisations and regional professional support services.

B

- Identify work to improve the transfer of care, management, and proactive risk assessment of patients who are moving from the Gender Identity Development Service waiting list to a gender dysphoria clinic waiting list.

HSIB makes the following safety observations

These safety observations are made in support of ongoing national work exploring the care of children and young people with gender dysphoria

Safety observation O/2022/161:

It may be beneficial if professional bodies produced further advice and guidance to assist NHS staff who may need to provide care to patients with gender identity concerns while patients are waiting to access support from specialised gender dysphoria services.

Safety observation O/2022/162:

It may be beneficial if local healthcare commissioners had up-to-date and easily accessible resources to identify all relevant services within a locality that could provide support to patients with gender identity concerns.

Safety observation O/2022/163:

It may be beneficial if further work considered the ability to allow for shared record systems and ways to appropriately share information between NHS and non-NHS services involved in the care of patients with gender identity concerns.

Safety observation O/2022/164:

It may be beneficial if further work considered the availability and accessibility of specialist training to help in the care of children and young people who have gender identity concerns or gender dysphoria.

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