# MDA No.: 1356

# Title: Health Committee – Improving Access to Healthcare for Trans and Gender Diverse Londoners

#### 1. Executive Summary

1.1 At the Health Committee meeting on 25 November 2021 the Committee discussed the topic of trans and gender diverse access to healthcare in London with invited guests and resolved that:

Authority be delegated to the Chair, in consultation with the party Group Lead Members, to agree any output arising from the discussion

1.2 Following consultation with party Group Lead Members, the Chair agreed the Committee's report on *Improving Access to Healthcare for Trans and Gender Diverse Londoners*, attached at **Appendix 1**.

#### 2. Decision

3.1 That the Chair, in consultation with party Group Lead Members, agrees the *Improving Access to Healthcare for Trans and Gender Diverse Londoners* report attached at Appendix 1.

#### Assembly Member

I confirm that I do not have any disclosable pecuniary interests in the proposed decision and take the decision in compliance with the Code of Conduct for elected Members of the Authority.

The above request has my approval.

Signature:

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Printed Name: Caroline Russell AM, Chair of the Health Committee

Date: 25 February 2022

## 3. Decision by an Assembly Member under Delegated Authority

#### Background and proposed next steps:

- 3.1 The scope and terms of reference for this investigation on trans access to healthcare in London was agreed by the Chair, in consultation with relevant party Lead Group Members, on 4 November 2021 under the standing authority granted to Chairs of Committees and Sub-Committees. Officers confirm that the letter and its recommendations fall within these terms of reference.
- 3.2 The exercise of delegated authority approving report will be formally submitted to the Health Committee's next appropriate meeting for noting.

#### Confirmation that appropriate delegated authority exists for this decision:

Signature (Committee Services): Diane Richard

Printed Name: Diane Richards, Committee Officer

Date: 23 February 2022

Telephone Number: 07925 353 478

#### Financial Implications: NOT REQUIRED

Note: Finance comments and signature are required only where there are financial implications arising or the potential for financial implications.

Signature (Finance): Not Required

Printed Name: Not Required Date: Not Required Telephone Number: Not Required

#### Legal Implications:

The Chair of the Health Committee has the power to make the decision set out in this report.

Signature (Legal):

Atran

Printed Emma Strain, Monitoring Officer Date: 23 February 2022 Telephone Number: 020 7983 4421

#### Supporting Detail / List of Consultees:

• Emma Best AM (Deputy Chairman of the Health Committee) and Onkar Sahota AM

## 4. Public Access to Information

- 4.1 Information in this form (Part 1) is subject to the FoIA, or the EIR and will be made available on the GLA Website, usually within one working day of approval.
- 4.2 If immediate publication risks compromising the implementation of the decision (for example, to complete a procurement process), it can be deferred until a specific date. Deferral periods should be kept to the shortest length strictly necessary.
- 4.3 **Note**: this form (Part 1) will either be published within one working day after it has been approved or on the defer date.

#### Part 1 - Deferral:

Is the publication of Part 1 of this approval to be deferred? NO

If yes, until what date:

#### Part 2 – Sensitive Information:

Only the facts or advice that would be exempt from disclosure under FoIA or EIR should be included in the separate Part 2 form, together with the legal rationale for non-publication.

Is there a part 2 form? NO

# Lead Officer / Author

Signature:

Jean Thead

Printed Name: Dan Tattersall

Job Title: Senior Policy Adviser

Date: 25 February 2022

Telephone Number: 07783 805825

#### **Countersigned by Executive Director:**

Signature:

Mue-

Printed Name: Helen Ewen

Date: 28 February 2022

Telephone Number: 07813 796 175



Trans health matters: improving access to healthcare for trans and genderdiverse Londoners







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# Health Committee



Caroline Russell AM (Chair) Greens



Emma Best AM (Deputy Chairman) Conservatives



Andrew Boff AM Conservatives



Dr Onkar Sahota AM Labour



Krupesh Hirani AM Labour

The Health Committee reviews health and wellbeing issues for Londoners, particularly public health issues. It also keeps a close eye on how well the Mayor's Health Inequalities Strategy is doing.

#### **Contact us**

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# Foreword



Caroline Russell AM Chair of the Health Committee

It may come as no surprise to many reading this report that trans and gender-diverse (TGD) people can experience health inequalities and discrimination when accessing healthcare in the UK. The barriers faced by TGD people in accessing timely and appropriate gender-affirmative healthcare has hit the headlines in recent years, with many TGD people waiting years for the treatment and support they so desperately need.

However, what is not as well-understood are the experiences of TGD people when accessing general NHS services to meet their non-gender related healthcare needs. This report seeks to shine a light on these often-overlooked elements of TGD people's NHS experiences and provide practical and achievable solutions to improve them.

Recent research shows that TGD people experience discrimination when accessing NHS services. Shockingly 70 per cent of trans people had experienced transphobia from their primary care provider, with 14 per cent refused GP care because they were trans. We heard that TGD people experience microaggressions, misgendering and the use of incorrect pronouns within the NHS and that this can have a huge impact on their health and wellbeing.

However, during our investigation we also heard that, in general, healthcare staff want to provide good quality care and support to TGD people, but they don't always know how best to achieve this.

Greater awareness and understanding of TGD people and their healthcare needs is required within the NHS to deliver good quality, personalised care and support. The absence of mandatory training for new and existing clinical and non-clinical NHS staff has hindered their ability to gain the confidence and skills needed to support TGD patients effectively. A fear of getting it wrong also makes it difficult to drive progress in this area.

In addition to the skills gap, there is an urgent need to address the absence of NHS data on TGD people, which has significant implications for TGD people individually and as a population. The inability of NHS IT systems to record trans status in a consistent and inclusive way affects not only the care an individual receives but also prevents the NHS from identifying problems and driving improvements. As Michelle Ross, one of our expert witnesses summed up so perfectly, "without data you are invisible".

During our investigation we heard that making NHS settings more inclusive would help TGD people feel comfortable, visible and heard. Our expert witnesses also highlighted that increasing awareness of the health inequalities faced by TGD people would help ensure they are included in wider health inequalities discussions.

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Underpinning all of the above, the Committee heard about the importance of ensuring solutions are made with, and led by, TGD people. Without this co-design and co-delivery it will be difficult to build trust and truly drive reductions in health inequalities for TGD people.

We hope this report and the recommendations it contains encourages discussion and increases awareness of the health inequalities that TGD people face, and acts as a catalyst to improve their access to healthcare.

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# **Executive Summary**

This report explores the health inequalities experienced by trans and gender-diverse (TGD) people when accessing the NHS. While much of the focus in relation to TGD people's healthcare has been on their experiences of gender-affirmative healthcare and the lengthy delays in accessing those services, this report focuses on the often-overlooked experiences TGD people have of the NHS more generally.

TGD people around the world are subjected to abuse, discrimination, stigma and violence. Evidence suggests that TGD people have a disproportionate burden of disease, with a greater risk of certain cancers and heart disease linked to hormone use, smoking and obesity.<sup>1</sup> They are also more likely to experience mental ill health because of their experiences of transphobia, discrimination and violence.<sup>2</sup>

A report by the House of Commons Women and Equalities Select Committee in 2016 concluded, "The NHS is failing to ensure zero tolerance of transphobic behaviour."<sup>3</sup> Indeed, research by TransActual found that 14 per cent of respondents reported being refused GP care because they were trans; and 70 per cent had experienced transphobia from their primary care provider. The worrying impact of this was that 57 per cent of transgender people had put off seeing, or chosen not to see, their GP if they were ill.<sup>4</sup> These findings were backed up by this investigation, which heard examples of microaggressions, misgendering and using incorrect pronouns within the NHS.

During its evidence session the Committee heard that lack of confidence and skills to support and treat TGD patients is a significant barrier to delivering good care. Dr Kamilla Kamaruddin (General Practitioner in Gender Healthcare, Gender Identity Clinic, Tavistock and Portman NHS Trust and East of England Gender Service) told the Committee: "In my knowledge and my experience, most GPs or the majority of GPs want to help trans people but sometimes they do not know how to help them." The absence of mandatory training for both clinical and nonclinical staff was seen as a major contributor to this skills gap, and can lead to a culture of fear amongst healthcare professionals.

This investigation also found that there is a dearth of NHS data on TGD people, and that this has significant impacts both individually and at a population level. Without this data, it is difficult for the NHS to provide patient-centred care and offer the most appropriate treatments to TGD patients – for example, cancer screening. It also limits understanding of the experiences, outcomes and needs of TGD people, making it harder to identify barriers and solutions to address these. While there are challenges in terms of ensuring TGD people feel comfortable disclosing their gender identify, and understand the benefits of do so, the main

<sup>&</sup>lt;sup>1</sup> Vanderbilt University Medical Center Program for LGBTQ Health, <u>Key Transgender Health Concerns</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>2</sup> World Health Organization, <u>WHO/Europe brief – transgender health in the context of ICD-11</u>, accessed 7 February 2022

<sup>&</sup>lt;sup>3</sup> The House of Commons, Women and Equalities Select Committee, <u>Transgender Equality</u>, 14 January 2016

<sup>&</sup>lt;sup>4</sup> TransActual, <u>Trans lives survey 2021</u>: <u>Enduring the UK's hostile environment</u>, accessed 20 October 2021

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barrier is that existing NHS IT systems do not enable TGD status to be recorded in a consistent and inclusive way.

The Committee also heard about the importance of making the healthcare environment inclusive for TGD people. Examples of how this could be progressed include making LGBTQ posters and leaflets visible in NHS settings; and promoting confidentiality policies that explain how TGD people are protected under the Gender Recognition Act.

During the investigation, the Committee was told about the urgent need to reduce health inequalities, with TGD people often forgotten in health inequalities discussions. Throughout the evidence session, the importance of involving TGD people in the development and delivery of solutions to tackle health inequalities was highlighted. Co-design and co-delivery with TGD people can foster trust and ensure that solutions truly meet the needs of the TGD population.

The principle of co-design and co-delivery therefore underpins each of the recommendations set out in this report.

<u>Key principle</u> – The overarching principle of this report is that solutions are led by the needs of, and co-designed and co-delivered with, TGD people. February 2022

# Recommendations

<u>Key principle</u> – The overarching principle of this report is that solutions are led by the needs of, and co-designed and co-delivered with, TGD people.

#### **Recommendation 1**

Using the principles of the Health Inequalities Strategy, the Mayor should convene a consultative group comprised of Londoners with lived experience and subject experts.

This group should consider the health inequalities implications of TGD people's healthcare, with this insight used to drive improvements in provision with partner organisations.

#### **Recommendation 2**

NHS Digital should improve NHS IT systems so that all healthcare providers are able to record trans status in a consistent and inclusive way.

#### **Recommendation 3**

In the interim, while system-wide NHS data collection improvements are made, the Mayor should urgently commission research in association with the NHS into the healthcare needs of TGD people in London. This insight should be used to identify areas of focus for the London Health Board and London healthcare providers.

#### **Recommendation 4**

The Committee endorses Stonewall's recommendation that training providers, medical and nursing schools, and royal colleges should review training and curricula to ensure that LGBT health inequalities, and the healthcare needs of all LGBT patients and service users, are included as part of compulsory and ongoing training.

#### **Recommendation 5**

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The London Health Board should work with the trans and gender-diverse consultative group to:

- a) assess how to commission trans-inclusive training programmes for primary care services, such as Pride in Practice, across all London boroughs
- b) work with NHS Trusts to encourage and support non-clinical staff to provide a trans and gender-diverse inclusive environment
- c) encourage GP practices to:
  - i) review existing policies to ensure they are trans and gender-diverse friendly. These revised policies should be available on practice websites.

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- ii) review their surgeries to ensure they are trans friendly, including by displaying LGBT+ posters and leaflets.
- d) work with NHS partners to consider how to monitor and map healthcare services that have undergone and maintained training, so that trans and gender diverse Londoners can identify and locate inclusive services.

Once the above recommendations have been embedded across the NHS so that trans status can be recorded in a consistent and inclusive way and healthcare staff have the skills to support transgender people effectively:

#### **Recommendation 6**

The Office for Health Improvement and Disparities should fund an awareness campaign to explain how to disclose trans and gender-diverse status to healthcare providers and the benefits of doing so.

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# Introduction

TGD people<sup>5</sup> around the world are subjected to abuse, discrimination, stigma, and violence. The Office of the High Commissioner for Human Rights at the United Nations states:

"At the root of the acts of violence and discrimination lies the intent to punish based on preconceived notions of what the victim's gender identity should be, with a binary understanding of what constitutes a male and a female, or the masculine and the feminine."

While TGD people are a diverse and heterogenous population, it is evident that they are at increased risk of experiencing a range of intersecting challenges. These may include:<sup>6</sup>

- Exclusion and marginalisation, which may take the form of being bullied at school, rejected by their family, pushed out onto the streets or denied access to employment.
- When they are people of colour; belong to ethnic minorities or are migrants; live with HIV; or are sex workers, they are particularly at risk of violence, including murder, serious assault, rape, and other forms of abuse and maltreatment.
- Human rights violations when their name and sex details in official documents do not match their gender identity ("a person's innate sense of their own gender … which may or may not correspond to the sex assigned at birth"<sup>7</sup>) or expression (how a person chooses to outwardly express their gender, within the context of societal expectations of gender).<sup>8</sup>

Evidence also suggests TGD people are more likely to experience unemployment. The National LGBT Survey 2018 found that while the overall UK employment rate during the time of the survey was 75 per cent, only 63 per cent of respondents identifying as trans and non-binary ("people whose gender identity doesn't sit comfortably with 'man' or 'woman'"<sup>9</sup>) had a job during that period.<sup>10</sup>

This investigation explored the inequalities experienced by TGD people in accessing nongender-related NHS healthcare. By focusing on TGD people's experiences of the NHS more generally, the Committee hopes to shine a light on the often hidden aspects of discrimination

<sup>&</sup>lt;sup>5</sup> The United Nations Office of the High Commissioner defines the term "gender-diverse" as referring to persons whose gender identity, including their gender expression, is at odds with what is perceived as being the gender norm in a particular context at a particular point in time, including those who do not place themselves in the male/female binary. The more specific term "trans" is used to describe persons who identify with a different sex than the one assigned to them at birth.

<sup>&</sup>lt;sup>6</sup> Office of the High Commissioner for UN Human Rights, <u>The struggle of trans and gender-diverse persons</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>7</sup> Stonewall, <u>List of LGBTQ+ terms</u>, accessed 15 February 2022

<sup>&</sup>lt;sup>8</sup> Office of the High Commissioner for UN Human Rights, <u>The struggle of trans and gender-diverse persons</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>9</sup> Stonewall, List of LGBTQ+ terms, accessed 15 February 2022

<sup>&</sup>lt;sup>10</sup> Government Equalities Office, <u>National LGBT Survey</u>, July 2018

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and inequality experienced by TGD people when accessing healthcare and the role that the NHS, the government and the Mayor can play in addressing these.

TGD people experience a disproportionately high burden of disease.<sup>11,12</sup> TGD adults are at a greater risk of certain cancers and heart disease linked to hormone use, smoking and obesity.<sup>13</sup> They are also at greater risk of experiencing mental ill health because of their experiences of transphobia, discrimination and violence.<sup>14</sup> A survey from Stonewall reported almost half (48 per cent) of TGD people in Britain have attempted suicide at least once; 84 per cent have thought about it and more than half (55 per cent) have been diagnosed with depression at some point.<sup>15</sup> There is also evidence that TGD people experience poorer health outcomes than cisgender people<sup>16</sup> ("someone whose gender identity is the same as the sex they were assigned at birth"<sup>17</sup>).

While there is no robust data on the size of the UK trans population,<sup>18</sup> the charity Stonewall estimates that around 1 per cent of the population might identify as trans, including people who identify as non-binary, which is equivalent to about 600,000 people.<sup>19</sup> There are no statistics available on the number of TGD Londoners; however, given the size of the estimated UK population, it is reasonable to assume that there are significant numbers of TGD people living in London and accessing NHS services.

#### Gender-affirmative healthcare

While this investigation didn't focus on gender-affirmative healthcare, during its evidence session the Committee heard that there are significant delays for many TGD people awaiting treatment for gender-affirmative healthcare to tackle gender dysphoria ("when a person experiences discomfort or distress because there is a mismatch between their sex assigned at birth and their gender identity"<sup>20</sup>).

<sup>&</sup>lt;sup>11</sup> World Health Organization, <u>WHO/Europe brief – transgender health in the context of ICD-11</u>, accessed 7 February 2022

<sup>&</sup>lt;sup>12</sup> Much of the research cited in this report uses the term "transgender". It is not always clear what definition of this term has been used by the researchers, and whether gender diverse people are included in the research. For the sake of consistency, we have used the term "trans and gender diverse" (TGD) throughout this report when referencing research, but note that there may be variations in the definitions used by different pieces of research.

<sup>&</sup>lt;sup>13</sup> Vanderbilt University Medical Center Program for LGBTQ Health, <u>Key Transgender Health Concerns</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>14</sup> World Health Organization, <u>WHO/Europe brief – transgender health in the context of ICD-11</u>, accessed 7 February 2022

<sup>&</sup>lt;sup>15</sup> Stonewall, <u>Trans Key Stats</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>16</sup> Winter, S. et al, *The Lancet*, <u>Transgender people: health at the margins of society</u>, 16 June 2016

<sup>&</sup>lt;sup>17</sup> Stonewall, List of LGBTQ+ terms, accessed 15 February 2022

<sup>&</sup>lt;sup>18</sup> Government Equalities Office, <u>Trans People in the UK</u>, 2018

<sup>&</sup>lt;sup>19</sup> Stonewall, <u>The Truth about Trans</u>, accessed 20 October 2021

<sup>&</sup>lt;sup>20</sup> Stonewall, List of LGBTQ+ terms, accessed 15 February 2022

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There were already long waits for gender dysphoria clinics before the COVID-19 pandemic, with average waiting times in 2019 of 76 weeks.<sup>21</sup> However, the Committee heard that the pandemic has made the situation worse, with some TGD people waiting five years for their initial consultation. It is clear that this is causing acute distress for many TGD people, and fails to meet the NHS Constitution commitment that patients start their consultant-led treatment within a maximum of 18 weeks from referral for non-urgent conditions.<sup>22</sup> Rico Jacob Chase (Director, TransActual UK) explained the impact of the wait to the Committee:

"We are 100 per cent in survival mode. You are asking someone to live in survival mode for five years for the first appointment. There is no other service that could put you on a five-year waiting list where that would be seen as appropriate, but for some reason it seems sufficient to offer that to trans and nonbinary people."

The Committee heard that sustainable investment in gender-affirmative healthcare is needed to ensure there is sufficient workforce and capacity to meet current and future demand. In the meantime, GPs must be supported through specialist training and easy access to consultants so that they can undertake prescribing of drugs (including bridging prescriptions) within their competences and the GMCs Guidelines<sup>23</sup>. This will greatly assist TGD patients waiting for gender dysphoria clinic appointments, and assist the GPs to signpost them to further support.

The Committee also heard that there is a need to provide mental health support to TGD people providing TGD services, to help them cope with the impact of having to hear the distressing stories of others on a regular basis.

There is evidence that TGD people face discrimination when accessing healthcare. A report by the House of Commons Women and Equalities Select Committee found that trans people encounter problems when using the NHS owing to the negative attitudes and lack of knowledge or understanding from some healthcare professionals. The report stated:

"Trans people encounter significant problems in using general NHS services, due to the attitude of some clinicians and other staff who lack knowledge and understanding — and in some cases are prejudiced. The NHS is failing to ensure zero tolerance of transphobic behaviour."<sup>23</sup>

One challenge faced by trans people is a phenomenon known as "trans broken arm syndrome". This is "when healthcare providers assume that all medical issues are a result of a person being

<sup>&</sup>lt;sup>21</sup> Parliament, <u>Gender Recognition: Clinics: Written question – 259018</u>, 3 June 2019

<sup>&</sup>lt;sup>22</sup> Department for Health and Social Care and Public Health England, <u>NHS Constitution Handbook</u>, accessed 8 February 2022

<sup>&</sup>lt;sup>23</sup> The House of Commons, Women and Equalities Select Committee, <u>Transgender Equality</u>, 14 January 2016

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trans,"<sup>24</sup> which can detract from the actual health problem that the person is presenting with. This can make some people reluctant to disclose their trans status.

For some types of procedure, Dr Alison May Berner (Specialist Registrar in Gender Identity, Gender Identity Clinic, Tavistock and Portman NHS Foundation Trust) explained to the Committee that many trans men and non-binary people would prefer to use a trans-specific service: "From a piece of research that we did of trans men and non-binary people that we surveyed, 64 per cent felt that they would still prefer their cervical screening test to be in a trans-specific service."

The Committee heard strongly about the importance of involving TGD in the design and delivery of health services. Dr Alison May Berner explained this to the Committee: "Co-delivered and trans-led work that involves the community is a way to build trust in healthcare." Michelle Ross (Founder, CliniQ) told the Committee about the work of CliniQ, which was "the first sexual health and holistic wellbeing clinic by trans people, for trans people."

The principle of co-design and co-delivery with TGD people therefore underpins every recommendation within this report.

## CliniQ

CliniQ is a trans-led community interest company offering a holistic sexual health, mental health and wellbeing service for all trans people, and their partners and friends. Its multidisciplinary team of professional support workers includes greeters, psychotherapists, counsellors, caseworkers, nurses and advisers. It offers a safe, confidential space for those who may not feel comfortable accessing mainstream services. The team provides a range of services including counselling, mentoring, cervical smears, hormone injections and hormone blood tests.

CliniQ was established in 2012 and works in partnership with King's College Hospital as well as trans-inclusive third-sector organisations.

<sup>&</sup>lt;sup>24</sup> PinkNews, <u>The dangers of trans broken arm syndrome</u>, 9 July 2015

# Ensuring transgender and gender-diverse people's health needs are considered by policymakers and healthcare providers

#### **Recommendation 1**

Using the principles of the Health Inequalities Strategy, the Mayor should convene a consultative group comprised of Londoners with lived experience and subject experts.

This group should consider the health inequalities implications of TGD people's healthcare, with this insight used to drive improvements in provision with partner organisations.

There is evidence that TGD people experience discrimination when accessing healthcare. Research by TransActual, an organisation that shares information about trans people's experience and trans rights, found that 14 per cent of respondents reported being refused GP care because they were trans, and 70 per cent had experienced transphobia from their primary care provider. The problem was worse for trans people of colour and trans people with disabilities. The impact of these experiences was that 57 per cent of transgender people said they put off or chose not to see their GP if they were ill.<sup>25</sup>

70 per cent of trans people have experienced transphobia from their primary care provider.

This reluctance of some TGD people to visit their GP when ill is particularly concerning given they may have a disproportionately high burden of disease.

Dr Kamilla Kamaruddin spoke of the importance of addressing health inequalities for TGD people and the barriers they face in accessing inclusive NHS healthcare:

"There is an urgent need to address the barriers that trans people face and to improve the health inequalities."

The Committee also heard that intersectional characteristics, for example, disability, poverty and ethnicity – can further increase the health inequalities TGD people may face. Dr Alison May Berner highlighted to the Committee how education or socio-economic status can affect a person's ability to access healthcare, as those with higher incomes or education levels may be better able to access private healthcare to meet their needs. Rico Jacob Chase explained to the

<sup>&</sup>lt;sup>25</sup> TransActual, <u>Trans lives survey 2021: Enduring the UK's hostile environment</u>, accessed 20 October 2021

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The importance of including TGD health in wider discussions on health inequalities came across clearly during the investigation. Dr Kamilla Kamaruddin flagged concerns that transgender people are often forgotten in health inequalities discussions:

"It is crucial that trans people are included in health inequalities. We [the NHS] are supposed to provide access to healthcare to anybody, irrespective of their race, gender, sexuality, colour or religion. Somehow the equalities of trans people have often been neglected."

There is no reference to TGD people and the health inequalities they experience in the Mayor's Health Inequalities Strategy.<sup>26</sup> However, the Mayor's 2021-24 Health Inequalities Strategy Implementation Plan does pledge to work with LGBTQ+ community groups to address structural inequalities.<sup>27</sup>

<sup>&</sup>lt;sup>26</sup> Mayor of London, <u>The London Health Inequalities Strategy</u>, September 2018

<sup>&</sup>lt;sup>27</sup> Mayor of London, <u>Health Inequalities Strategy Implementation Plan 2021-24</u>, 9 December 2021

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## Data

#### **Recommendation 2**

NHS Digital should improve NHS IT systems so that all healthcare providers are able to record trans status in a consistent and inclusive way.

#### **Recommendation 3**

In the interim, while system-wide NHS data collection improvements are made, the Mayor should urgently commission research in association with the NHS into the healthcare needs of TGD people in London. This insight should be used to identify areas of focus for the London Health Board and London healthcare providers.

"Without data you are invisible." Michelle Ross, Founder, CliniQ

The importance of good-quality data in understanding patient care, treatment and outcomes is well recognised. Data is used "to improve understanding of health problems, support world-class medical research, and make the NHS better"<sup>28</sup> and is "vital for your individual care, and to improve health, care and services across the NHS."<sup>29</sup>

One significant challenge for improving TGD people's experiences of healthcare and reducing health inequalities is the lack of NHS data on TGD people. During its evidence session, the Committee heard that there is a dearth of data within the NHS on TGD people; and that this can have significant impacts for TGD people at both individual and population levels.

"It is very difficult for a GP to provide person-centred care for the patient. If a patient rings up, we have no knowledge of whether the patient is trans or not."

Dr Kamilla Kamaruddin, General Practitioner in Gender Healthcare, Gender Identity Clinic, Tavistock and Portman NHS Trust and East of England Gender Service

<sup>&</sup>lt;sup>28</sup> NHS Digital, <u>Data</u>, accessed 7 February 2022

<sup>&</sup>lt;sup>29</sup> Understanding Patient Data, <u>Why is it important to use patient data?</u>, accessed 7 February 2022

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The difficulty healthcare professionals face in identifying TGD patients can have significant and detrimental impacts on the experience of care TGD people receive and the treatment they are offered.

When a healthcare professional is unaware of a patient's gender identity, they might not use the patient's preferred gender pronouns. This is "mispronouning".<sup>30</sup> The impact of using incorrect pronouns is that patients can be left "feeling misunderstood, invalidated and unaccepted."<sup>31</sup>

Michelle Ross illustrated the impact that misgendering and using incorrect pronouns had on a TGD person she knew when they were admitted to hospital:

"On the day they entered the hospital, they were mispronouned and misgendered. Not only were they recovering from quite a bad accident for a couple of weeks in hospital, but they were also suffering from mental health issues because of how they were being treated. I am not saying they were not cared for, but they [the staff] just kept mispronouning. They kept misgendering. They kept using the wrong terms completely throughout their whole stay. When they came out, they were physically a lot better, but their mental health had deteriorated."

While there are challenges in terms of TGD people being comfortable to disclose their gender identity and understanding the benefits this could bring, the Committee heard that existing NHS IT systems do not enable TGD status to be recorded in a consistent and inclusive way. Michelle Ross explained the current situation to the Committee:

"There is no real recording of data on non-binary, trans, trans masculine or trans feminine at all throughout the NHS except in something called the HIV and acquired immunodeficiency syndrome (AIDS) reporting system. That is the only service that actually records trans people's identity."

The availability of appropriate read codes (clinical terms providing standard vocabulary for clinicians to record patient findings and procedures, in health and social care IT systems<sup>32</sup>) or SNOMED CT codes (structured clinical vocabulary for use in an electronic health record<sup>33</sup>) in primary care was highlighted as a particular challenge. Dr Kamilla Kamaruddin explained to the Committee:

<sup>&</sup>lt;sup>30</sup> WordSense dictionary, <u>Mispronoun</u>, accessed 7 February 2022

<sup>&</sup>lt;sup>31</sup> NHS Confederation, <u>Why pronouns matter</u>, 20 October 2021

<sup>&</sup>lt;sup>32</sup> NHS Digital, <u>Read codes</u>, accessed 14 February 2022

<sup>&</sup>lt;sup>33</sup> NHS Digital, <u>SNOMED CT</u>, accessed 14 February 2022

"The lack of data identification in general practice is one of the main barriers. I have tried very hard to introduce transgender monitoring in general practice, but it is the system that is failing us. How we work in general practice is that we use read codes to identify certain things. We use read codes to identify patients who are diabetic, for example, and so we use 'diabetes mellitus' as a proper title so that we can identify the people who have diabetes. For trans people there is no read code. There are old read codes like 'transsexual'. We do not use those anymore. There are no read codes to say that you are a trans man, trans woman, trans feminine or trans masculine. It is very difficult for a GP to provide personcentred care for the patient. If a patient rings up, we have no knowledge of whether the patient is trans or not."

The way gender is recorded in GP records determines who is automatically invited for screening programmes such as breast and cervical screening. Screening invitations are sent out to people based on the gender they are registered as at their GP practice; these invitations don't take account of patients' individual circumstances and whether they are a person with a trans history. This means that TGD patients may not be invited to the screening appointments most relevant to them. In the case of breast screening, when registered as male with their GP, trans men and trans women who have received female hormone therapy do not receive invitations but are still eligible for screening if they have any breast tissue. It is the responsibility of GPs to contact their local breast screening programme to ensure their TGD patients are correctly invited for screening.<sup>34</sup> This relies on GPs knowing who those patients are and then acting accordingly.

Dr Alison May Berner explained how the current cervical screening system doesn't work well for TGD people:

"Large numbers of trans men are choosing to not have a hysterectomy, and nonbinary people even more so, because they are choosing to think about whether they want to become pregnant in the future and do not necessarily want to have that surgery."

This means that "there will be a large proportion of trans and non-binary people with a cervix'. Problems arise because of "a lack of automatic calling if you are registered as male with your GP".

The challenges the NHS faces in consistently recording TGD status in patient records has broader implications for the TGD population. The Committee heard from Dr Alison May Berner about the impact it has for understanding population risk and outcomes for cancer:

<sup>&</sup>lt;sup>34</sup> Public Health England, <u>NHS screening programmes: information for GPs and practice staff</u>, 23 October 2018

"We do not have good quality incidence data. We do not collect trans status in the cancer registries. While we make inferences about this risk from other populations, we do not have the proof that those incidence rates are higher or lower in this country."

Dr Berner explained the impact of this: "We are unable to pinpoint those exact health inequalities and what is causing them. Cancer is just an example of that."

Michelle Ross demonstrated to the Committee the benefit that CliniQ had found from recording trans status in patient records:

"With the HIV and AIDS reporting system, it is not just that we collect numbers of people living with HIV, we are able to compare the issues of living with HIV for trans and nonbinary people with cis people living with HIV. We have really clear similarities and inequalities from that. It is really important that we have that as an example of really collecting inclusive data that not only looks at the rates of HIV but looks at the other issues as well: the social issues, the health issues, the adherence to HIV medications, the many, many issues involved."

In addition, without accurate data on the TGD population, it can be difficult to make the case for more research funding or specialist services for TGD people. Dr Alison May Berner told the Committee:

"Time and time again I come up with a great idea and then am told, 'No one is ever going to fund it, because you do not have any pilot data, nobody knows what your denominator number is and you do not know where people are.'... We are trying to bring a business case to NHS England for a specialist service, but I cannot tell them what the demand for that service would be because I cannot put a number on it because it is not monitored."

As Michelle Ross summed up for the Committee: "Without data you are invisible."

The Committee heard that a simple way to increase understanding in this area would be to improve GP systems to enable trans status to be recorded in a more consistent and inclusive way. Making these changes would enable healthcare professionals and researchers alike to analyse existing data through a TGD lens and identify opportunities for improvement. Dr Kamilla Kamaruddin explained this to the Committee:

"The data is out there. The data is in general practice. All of us are registered with GPs. If you have cancer it is documented in your medical notes in your GP practice. The problem is that there is no trans-status monitoring."

Improving IT systems would help enable GP practices to provide a better level of care to their TGD patients, and avoid the need for time-consuming and imperfect workarounds. For example, the Committee heard from Ryan Smith (Pride in Practice Manager for London and the South East, LGBT Foundation) of a GP practice that had resorted to the inappropriate workaround of flashing a pop-up warning on GPs' screens to let them know when their next patient was transgender. As Ryan Smith said, "That is not ideal... Things need to change."

# Education and training for clinical staff

#### **Recommendation 4**

The Committee endorses Stonewall's recommendation that training providers, medical and nursing schools, and royal colleges should review training and curricula to ensure that LGBT health inequalities, and the healthcare needs of all LGBT patients and service users, are included as part of compulsory and ongoing training.

During its evidence session the Committee heard that lack of confidence and skills to support and care for TGD patients is a significant barrier to delivering good care. Dr Kamilla Kamaruddin told the Committee: "In my knowledge and my experience, most GPs or the majority of GPs want to help trans people but sometimes they do not know how to help them. That is the main barrier."

As highlighted earlier, cancer screening can present unique challenges for TGD people. The Committee heard that there is a lack of awareness amongst healthcare professionals about these challenges. Ryan Smith explained how this issue has come up in the Pride in Practice training:

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"In a lot of practices, when I bring up trans men or people with cervixes being missed off screening, it is often met with, 'Oh'. I ask for feedback after the training and a lot of the feedback I get is, 'That was really insightful about the screening because I did not know that.' When we are being told by GP practices, 'I did not know that,' that is a worry."

Dr Alison May Berner highlighted a lack of confidence amongst oncologists:

"Michelle [Ross] mentioned cervical screening for trans and nonbinary people. That is an area I am particularly interested in. That is a specific healthcare need where there might be particular barriers for trans people, and not all medical professionals are aware of those areas of particular need. We did a survey of oncologists and this was in a broader category. This was just saying, 'How confident are you in the specific needs of LGBTQ patients with cancer?' Only 8 per cent said that they felt confident. There is no other group where it would feel appropriate that 8 per cent of your clinicians felt confident in managing a healthcare issue, or even knowing what that healthcare issue was."

The Committee heard that there is an element of fear of litigation amongst some GPs, which discourages them from providing support to transgender patients. Dr Alison May Berner told the Committee:

"They [GPs] are not made to feel safe in the decisions they make around trans healthcare in the same way they are for other things because trans healthcare has become so politicised. When I do training, I can sense that fear of getting it wrong, 'I would just rather not be involved because, if I get this wrong, I am going to lose my licence.'"

Ryan Smith reiterated this point:

"I would say one of the biggest things is fear, fear of getting it wrong, fear of offending, fear of not doing the right thing."

The Committee was told that the mandatory diversity and inclusion training that health professionals must do when joining a new trust does not adequately inform staff about transgender health. Dr Alison May Berner explained this to the Committee:

"The equality and diversity 'click a button and get a certificate' training you do every time you join a new NHS trust does not even factor in here. It is basic knowledge. It does not delve into these issues. It does not cover this in anywhere near the depth needed ... As a health professional, every time as we join a new NHS trust organisation of any kind we have to click through a variety of training modules. Often you are not remunerated for the time you do them. You do them very quickly. You do the same one every year or every six months. They are tickbox exercises. They do not delve into any of these issues."

The Committee also heard that unconscious bias training for GPs doesn't adequately cover LGBTQ issues, as Dr Kamilla Kamaruddin explained: "I have been to some unconscious bias training in general practice, but none of them touched on LGBTQ issues and none of them touched on trans issues, not even a single mention."

There are some voluntary learning resources to upskill healthcare professionals in TGD health. The Royal College of General Practitioners provides an optional e-learning course, with guidance on care for adult and adolescent transgender patients.<sup>35</sup> The LGBT Foundation's Pride in Practice programme empowers primary care providers to support their transgender patients.<sup>36</sup>

In London to date, Pride in Practice training has taken place in Lambeth, Lewisham and Wandsworth, and in the NHS in north-west London.

However, at present, there is no mandatory training on TGD issues for existing NHS professionals. The Committee heard that TGD health advocates are resorting to delivering training themselves to plug the gaps but that this is unsustainable. Dr Kamilla Kamaruddin explained the work she has been doing:

"What I have done is concentrate on the GP vocational training scheme for the young future GPs. They have an afternoon when they have training. I wrote to the programme directors in London, and every GP vocational training scheme is interested in inviting me to do teaching. I have done four or five. I only started about a month ago. I have another one this afternoon. It is very well received. A lot of the young GPs are very enthusiastic and very engaged. They were telling me, 'This is what we really want. We have not been taught this in any medical curriculum.' I taught them about hormone treatment for trans people and bridging prescriptions; we also talked a little bit about doing exercises about humanities and about unconscious bias and talked about barriers to healthcare for trans people. It is very successful, but the only caveat is, that I am doing it in my free time and no one is funding me."

<sup>&</sup>lt;sup>35</sup> Royal College of General Practitioners, <u>Gender variance course</u>, November 2020

<sup>&</sup>lt;sup>36</sup> LGBT Foundation, <u>Pride in Practice</u>, accessed 14 February 2022

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Ensuring the new and existing health workforce is trained in transgender health needs is a challenge in a system where healthcare professionals find it difficult to fit in training within their busy schedules. Without training being compulsory, this is even more challenging. Ryan Smith told the Committee:

Sometimes I feel the attitude is that it is a separate issue, it is a bit of an extracurricular thing and it is a choice. 'We might do a bit of LGBTQ training.' I want a waiting list. I want practices to be knocking at my door saying, 'Please, we need this.'

In addition to the absence of mandatory training for existing NHS professionals, there is also no requirement for it to be included in medical schools' curricula. This means there is no guarantee that the future healthcare workforce will be trained in this area. Dr Alison May Berner explained why this is significant:

"The trans population of the UK ... is as many people as the population with Addison's disease – that is the number we commonly quote. None of us would dream about not being taught about that in medical school. It is a recognition of importance and not letting any of these organisations, be it the NHS, the Medical Schools Council, individual medical schools, say that this is not a high priority."

Dr Alison May Berner told the Committee that TGD health needs to be considered throughout the curriculum rather than in isolation: "What we need is vertical threading through the curriculum that covers screening and discusses all the issues related to trans and non-binary people and screening. It needs to be more like that."

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#### Pride in Practice programme

The LGBT Foundation's Pride in Practice programme works with GP practices, dental surgeries, pharmacies and optometrists to ensure that all lesbian, gay, bisexual and trans (LGBT) people have access to inclusive healthcare that understands and meets the needs of their communities.

This voluntary programme provides quality assurance and social prescribing to strengthen and develop primary care services' relationships with their LGBT patients.

Pride in Practice is nationally endorsed by the Royal College of General Practitioners and the Royal Pharmaceutical Society.

# Making the healthcare environment more inclusive for TGD people

#### **Recommendation 5**

The London Health Board should work with the trans and gender-diverse consultative group to:

- (a) assess how to commission trans-inclusive training programmes for primary care services, such as Pride in Practice, across all London boroughs
- (b) work with NHS Trusts to encourage and support non-clinical staff to provide a trans and gender-diverse inclusive environment
- (c) encourage GP practices to:
  - i. review existing policies to ensure they are trans and gender-diverse friendly. These revised policies should be available on practice websites.
  - ii. review their surgeries to ensure they are trans friendly, including by displaying LGBT+ posters and leaflets.
- (d) work with NHS partners to consider how to monitor and map healthcare services that have undergone and maintained training, so that trans and gender diverse Londoners can identify and locate inclusive services.

"I was training a GP practice the other day, and they had an incident when they called up a patient who had a seemingly female name and is female on their records, but the person who called recognised a male voice and therefore would not speak to the patient. They thought they were lying about who they were and refused to speak to them. This patient wanted to talk about their healthcare and therefore could not. That was just yesterday in a training session, and that sort of thing comes up all the time."

## Ryan Smith, Pride in Practice Manager for London and the South East, LGBT Foundation

In addition to increasing the confidence and skills of healthcare professionals, the Committee also heard about the need to upskill the non-clinical workforce, for example administration staff, receptionists and hospital porters. This is particularly important for staff working at GP practices, as it is there that many patients have their first interactions with the NHS and get referred to secondary care. While TGD people's interactions with the GPs themselves are important, the way that other GP practice staff interact with TGD people is vital too.

"As a GP myself, I would like to think that discrimination is not very common in general practice, but probably what is more common are microaggressions, everyday slights against trans people that come across as equally devastating for a trans person. If you ask for some specific examples, it is like the receptionist who tells someone else, 'God, she is trans and so just be careful what you say.' This in itself is really not very nice for trans people to hear."

#### Dr Kamilla Kamaruddin, General Practitioner in Gender Healthcare, Gender Identity Clinic, Tavistock and Portman NHS Trust and East of England Gender Service

Ryan Smith explained this to the Committee:

"Your first point of call is not the GP, is it? It is often that phone call. I mentioned earlier that phone call by the patient where the receptionist did not believe they were them because of the tone of their voice. Straight away, that patient's first experience of calling up the GP practice is one of feeling they are not being listened to, not being heard, not being seen, and facing discrimination, essentially, because they made an assumption. Assumptions are bad."

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The Pride in Practice programme works with GP practices, dental surgeries, pharmacies and optometrists to ensure that all lesbian, gay, bisexual and trans people have access to inclusive healthcare that understands and meets the needs of their communities.<sup>37</sup>

When GP practices undertake Pride in Practice training, it is important that a broad range of staff attend the training. Ryan Smith explained this to the Committee:

"Sometimes when we deliver Pride in Practice training they say, 'We can give you the doctors at this time or it is just these staff,' and we do insist we will only deliver training if there is a selection of staff. We make sure we are delivering training to receptionists, to support staff, to administration staff, to the GPs, so we have that wide selection at that level. It is important for everyone at every level, because any interaction could be a negative one that stops someone accessing that service. Healthcare is all about people feeling confident to access that service and that is why it is so important for every member of staff to have that awareness and training."

Along with staff training, it is important that healthcare settings are visibly trans-friendly. One way this can be achieved is by making the waiting room environment inclusive for TGD people, as Ryan Smith explained:

"We have spoken about GPs a lot but, like we have said, it is reception staff, nurses, the waiting room environment, having a poster on the wall ... Just having an LGBTQ poster on the wall could essentially save someone's life because someone sitting there who is scared to talk about who they are or their health concerns will see that a practice has a poster on the wall or a leaflet. 'That means I am seen. I am visible. I am heard. Therefore, I might be able to speak about my issue.'"

The LGBT Foundation Pride in Practice Patient Survey 2018 found that where services displayed LGBT posters, trans patients were 21 per cent more likely to share their trans status.<sup>38</sup>

GP practices can also demonstrate their inclusivity through their confidentiality policies. Ryan Smith explained how Pride in Practice helps practices to do this:

<sup>&</sup>lt;sup>37</sup> LGBT Foundation, <u>Pride in Practice</u>, accessed 14 February 2022

<sup>&</sup>lt;sup>38</sup> LGBT Foundation, <u>If We're Not Counted, We Don't Count: Good practice guide to monitoring sexual orientation</u> <u>and trans status 2021</u>, July 2021

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"When we work with a practice, we encourage them to put their confidentiality policy on their website that explicitly mentions that trans patients are protected, the Gender Recognition Act, their zero-tolerance policy specifically mentioning those things and LGBTQ mentioned on their website."

There is evidence that improving a practice's trans-inclusivity makes a difference and is viewed positively by the TGD community. Ryan Smith explained this to the Committee:

"When a practice gets a good reputation for dealing with trans people, they will talk to each other... then we see certain practices that do have a higher population of trans patients because that word of mouth has happened. Visibility and reputation are very important."

The Committee heard there are several challenges in getting the Pride in Practice programme rolled out more widely. In his evidence to the Committee, Ryan Smith highlighted lack of awareness that there is a problem and that it is a priority; lack of time to undertake training; and lack of funding for Pride in Practice training as some key challenges. On the latter, he highlighted that Pride in Practice is funded in Lambeth and Lewisham only until March 2022. "Essentially, after March there could be no Pride in Practice in London."

# Raising awareness in the TGD community

Once the above recommendations have been embedded across the NHS so that trans status can be recorded in a consistent and inclusive way and healthcare staff have the skills to support transgender people effectively:

#### **Recommendation 6**

The Office for Health Improvement and Disparities should fund an awareness campaign to explain how to disclose trans and gender-diverse status to healthcare providers and the benefits of doing so.

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As highlighted above, the Committee heard that there are benefits to TGD people individually, and the TGD population more widely, if healthcare providers know who their TGD patients are; and can record this data sensitively and confidentially. Providing this information can improve the care that patients receive by ensuring it is relevant to them; and can also help policymakers and researchers develop a better picture of the current health landscape for TGD people to enable improvement and research opportunities to be identified. Ryan Smith explained how sharing trans status can break down barriers:

"From a survey we did, 62 per cent of trans people were more likely to feel their GP met their health needs when they shared their trans status with their GP practice. That initial sharing of your status, having it on a form and being monitored can already break down lots of barriers."

However, the Committee also heard that it can be challenging for TGD people to disclose their gender identity to their healthcare providers, especially for older people. Dr Alison May Berner explained this to the Committee:

"We are still treating patients who lived through it being illegal to be gay, and we are still treating patients who grew up in a time when they would not even dream of mentioning their gender identity. Those are the patients who come to see me with cancer now. For them to disclose is such a massive thing."

#### Michelle Ross agreed:

"I know a lot of older trans people who live in stealth, who are not out about being trans and who do not want to be, and who have never accessed health services in all that time. There is an embodied fear and an embodied stigma that they walk with every day of being known as trans and accessing health services that are going to discriminate against them. There are a lot of issues."

Once data systems have been revised and the health workforce has been upskilled to provide inclusive, compassionate and supportive care to TGD people, it will therefore be important to communicate this progress and encourage TGD people to disclose their gender identity to healthcare providers. Indeed, an LGBT Foundation patient survey found that, of those trans people who would not disclose their LGBT identity, 65 per cent said they would be encouraged to do so if they saw monitoring being used to improve services.<sup>39</sup>

<sup>&</sup>lt;sup>39</sup> LGBT Foundation, Primary Care Survey 2017, accessed 8 February 2022

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The Committee heard that awareness campaigns could help the TGD population understand the importance of disclosing their status and the benefits this can bring both individually and to the wider trans community. As Dr Alison May Berner explained to the Committee:

"Healthcare campaigns that are embedded within the community... that allows them to understand why disclosing is important, what the relevance of their healthcare might be, so that they can understand why that information is important directly to them and why having the registry information is important for the community as a whole. That would be hugely important."

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# About the investigation

The Health Committee held an evidence gathering session with expert guests on 25 November 2021. We would like to extend our thanks to all those who took part:

**Dr Alison May Berner**, Specialist Registrar in Gender Identity, Gender Identity Clinic, Tavistock and Portman NHS Foundation Trust

Rico Jacob Chase, Director, TransActual UK

**Dr Kamilla Kamaruddin**, General Practitioner in Gender Healthcare, Gender Identity Clinic, Tavistock and Portman NHS Trust and East of England Gender Service

Michelle Ross, Founder, CliniQ

Ryan Smith, Pride in Practice Manager for London and the South East, LGBT Foundation

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# Other formats and languages

If you, or someone you know needs this report in large print or braille, or a copy of the summary and main findings in another language, then please call us on: 020 7983 4100 or email <u>assembly.translations@london.gov.uk</u>

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Εάν επιθυμείτε περίληψη αυτού του κειμένου στην γλώσσα σας, παρακαλώ καλέστε τον αριθμό ή επικοινωνήστε μαζί μας στην ανωτέρω ταχυδρομική ή την ηλεκτρονική διεύθυνση.

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