Waverley Gate 2-4 Waterloo Place Edinburgh EH1 3EG



Telephone: 0131 536 9000 www.nhslothian.scot.nhs.uk www.nhslothian.scot.nhs.uk

Date: 20/05/2024 Your Ref: Our Ref: 8704

Enquiries to : Richard Mutch Extension: 35687 Direct Line: 0131 465 5687 Ioth.freedomofinformation@nhs.scot richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – GENDER IDENTITY

I write in response to your request for information in relation to correspondence and gender identity.

Question:

 Please provide all emails between the health board and the Scottish Government between 11 March and 19 April 2024 that refer to the Cass Report, Sandyford gender identity service or puberty blockers.

Answer:

Enclosed are the only email trails/correspondence we are aware of from the Scottish Government with NHS Lothian. We do not have any further direct emails to the Scottish Government regarding this as we are waiting for the national meeting.

Please note that NHS Lothian has a policy of not releasing the names and details of staff below a senior level. This is considered exempt under Section 38(1)(b) of the Freedoms of Information (Scotland) Act 2002 – personal information.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.









Headquarters Waverley Gate 2-4 Waterloo Place Edinburgh EH1 3EG

Chair Professor John Connaghan CBE Chief Executive Calum Campbell Lothian NHS Board is the common name of Lothian Health Board FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <u>https://org.nhslothian.scot/FOI/Pages/default.aspx</u>

Yours sincerely

ALISON MACDONALD Executive Director, Nursing, Midwifery and AHPs Cc: Chief Executive



Professor Sir Gregor Smith Chief Medical Officer for Scotland Chief Medical Officer Directorate St Andrew's House, Regent Road, Edinburgh EH1 3DG JB Russell House Gartnavel Royal Hospital 1055 Great Western Road GLASGOW G12 0XH Tel. 0141-201-4444 Fax. 0141-201-4401 Textphone: 0141-201-4479 www.nhsggc.org.uk

Date: 27/03/2024

Our Ref: JA/TG/CMO Enquiries to: Jennifer Armstrong Direct Line: 0141-201-4611 E-mail:jennifer.armstrong2@ggc.scot.nhs.uk

Dear Professor Smith,

NHS England's Clinical Policy in relation to Puberty Suppressing Hormones (PSH) and implications for the Scottish Service

I refer to the previous correspondence of 20th October 2022 from Ms Tracey Gillies, Board Medical Director for NHS Lothian and myself, and your subsequent reply of 3rd February 2023, regarding gender services for children and young people.

In our letter, Ms Gillies and I requested that, in the light of the recommendation regarding PSH made by Dr Hilary Cass from her review of the Gender Identity Development Service (GIDS) for children and young people at the Tavistock and Portman NHS Foundation Trust (February 2022), it was important that NHS Scotland consider this recommendation. In particular we requested that the Scottish Government,

- Make arrangements for an independent review of the evidence base for puberty blocker/hormone therapy in the treatment of gender dysphoria in young people
- Consider doing this in collaboration with the NHS England review, and that
- this should include introduction of a long term follow up process for all young people who are and have received this treatment and this forms part of UK evaluation/ research process

In response to this, you advised that, whilst you fully supported engagement with UK colleagues, the parameters of any research proposal by the National Institute for Health and Care Research (NIHR) were in early stages. In the meantime, you advised that the Scottish Government would continue to engage with NHS England, and would work with Healthcare Improvement Scotland (HIS) to scope whether an updated rapid evidence review on outcomes surrounding puberty blocking intervention would add value to the available existing evidence base.

NHSGGC position on NHS England's Policy

As you will be aware, on 12th March 2024, NHS England announced that after a thorough review of evidence, there is insufficient evidence to support the safety or clinical effectiveness of PSH to make the treatment routinely available at this time.

The clinical significance of this has subsequently required NHSGGC and NHS Lothian to review their position. NHSGGC currently has national responsibility for the assessment of gender dysphoria in Young People, with subsequent referral for medication interventions to paediatric endocrinology services in NHSGGC and NHS Lothian.

Following consultation with senior medical staff and the clinical team responsible for the delivery of PSH our shared view is that Scottish practice should align with the position taken by NHS England, and to do otherwise would present significant risk. New referrals from the NHSGGC Young Persons Gender Service (based at Sandyford Services), to paediatric endocrinology services in NHSGGC and NHS Lothian, have been paused while we review the implications for our service. Aligning with NHS England, those patients who are currently on PSH treatment should continue on treatment with close monitoring and support, as they wish to and as guided by individual clinical assessments within each service.

As NHS England has taken the position that all access to PSH treatment will only be made available via a formal clinical research trial, we ask that any future PSH treatment is carried out in partnership with the NHS England research proposal and would see a Scottish centre within any research proposal.

Gender affirming hormone treatment for those not treated with PSH up to age 18

Currently in Scotland, Young People age 16-18 years who have not been treated with PSH may still access gender affirming hormone treatment (GAHT) via the NHSGGC YPGS and from aged 17 in NHS Lothian Adult Gender Service.

Clinical teams in NHSGGC and NHS Lothian recommend that this pathway is also reviewed in line with NHS England and that this intervention is only provided with multidisciplinary specialist Endocrinology input. We will also pause this service whilst this review is undertaken.

NHSGGC Young Persons Gender Service Model

It is important to recognise that the NHSGGC YPGS provides psychiatric and clinical psychology support, assessment and diagnosis of Gender Dysphoria and we propose no changes to this service at the present time. As you are aware, there are significant existing pressures on the service, and the proposals outlined above will not change this situation. Whilst the National Services Scotland Young Persons Gender Service Specification is awaited, alongside the specific actions outlined above, it is the strong clinical consensus that the YPGS model follows that set out by NHS England, <u>NHS England » Interim service specification for specialist gender incongruence services for children and young people (updated 12 March 2024).</u>

In summary, NHSGGC and NHS Lothian ask that you formally support the position set out above, namely:

- Pause to new referrals from the NHSGGC Young Persons Gender Service to Paediatric Endocrine services with immediate effect.
- Urgently explore the possibility that future PSH treatment can be carried out in partnership with the NHS England research proposal.
- Support a clinical review of the pathway for GAHT for those not treated with PSH up to age 18 to align with NHS England.
- Align the YPGS with NHS England model.

NHSGGC and NHS Lothian commit to individual communication with the young people and families who are impacted by these decisions to explain the change in treatment pathways. The distress these decisions may potentially cause is recognised and the service will ensure this is completed before a public position statement is issued.

There is therefore an urgent need for both a formal statement of support from your office and clarity on the Scottish Government's position on Young Persons' Gender Services in Scotland, in response to these developments.

We are of course happy to discuss any aspect of this in more depth if necessary.

Dr Jennifer L. Armstrong Board Medical Director Tracey Gillies Executive Medical Director, NHS Lothian **Chief Medical Officer Directorate**



E: CMO@gov.scot

By email:

Dr Jennifer Armstrona Board Medical Director, NHS Greater Glasgow & Clyde

Miss Tracev Gillies Executive Medical Director, NHS Lothian

9 April 2024

Dear Jennifer and Tracey,

NHS England's Clinical Policy in relation to Puberty Suppressing Hormones (PSH) and implications for the Scottish Service

1. Thank you for your letter dated 27 March, received by my office on 28 March, regarding NHS England's settled clinical policy in relation to puberty suppressing hormones (PSH) as a treatment option for gender dysphoria, announced on 12 March 2024 and corresponding implications for the Scottish Service as provided by NHS Greater Glasgow and Clyde (NHS GGC) via its Sandyford Sexual Health Service.

Response

- 2. Recognising you are awaiting my response to your letter before formally notifying patients potentially impacted by the new clinical position you are taking in this area; I have come back directly on your main points below. I am available to discuss broader points in your letter at a later date, if helpful.
 - Pause new referrals from the NHS GGC Young Persons Gender Service to Paediatric Endocrine services with immediate effect.
- 3. As Chief Medical Officer for Scotland I expect Health Boards to make decisions on the delivery of clinical care via agreed local governance processes, taking into account new and emerging evidence in a clinical field. This is no exception and I support your decision.
 - Urgently explore the possibility that future PSH treatment can be carried out in • partnership with the NHS England research proposal.
- 4. As you will be aware, following its announcement in summer 2022 the Scottish Government has proactively pursued links with NHS England commissioners on this matter, and is grateful for NHS GGC's subsequent involvement as this relationship has developed.
- 5. As part of this engagement, which now includes the Chief Scientist Office (Health), we have also facilitated involvement from representatives from the University of Glasgow in







discussions with NHS England and the National Institute for Health Research (NIHR), who are designing this study. This link, which NHS GGC is now building upon, should ensure an appropriately broad understanding of any implications in aligning an NHS Scotland provided service with a research protocol as currently being designed by the NIHR.

- 6. I would of course support NHS GGC, working with Chief Scientist Office as required, in making arrangements to join the NIHR study in this field and the associated alignment of a treatment pathway as a result.
 - Support a clinical review of the pathway for Gender Affirming Hormone Treatment for those not treated with PSH up to age 18 to align with NHS England.
- 7. As I have already stated, I support decisions taken by Health Boards via agreed local clinical governance processes to review and revise current care pathways, to consider new and emerging evidence in a clinical field. This is no exception.
 - Align the Young Person Gender Service, as offered by NHS GGC, with NHS England model.
- 8. As you are aware, the Scottish Government commissioned NHS National Services Scotland (National Services Division) in early 2022 to take forward a proposal for a young person gender service for NHS Scotland. This was to formally commission this offering via agreed national commissioning processes. I am grateful to NHS GGC for their engagement with this work.
- 9. I note your request on aligning the Young Person Gender Service as offered by NHS GGC with the clinical model as recently updated and published by NHS England. As referenced above, I am supportive of decisions taken by Health Boards via agreed local clinical governance processes to review and revise current care pathways, to consider new and emerging evidence in a clinical field. I know too that you will be aware of historical differences in clinical approaches in this field between comparable NHS Scotland and NHS England services, a reflection I understand was also commented on by the Cass Review during routine engagement by NHS Scotland with that Review.
- 10. I would however reflect that such a decision should be taken only after full consideration of its potential implications – which may require consideration of legislative and/or structural differences between NHS England and NHS Scotland – and how access to healthcare interventions previously offered may be impacted for NHS Scotland patients. I would also reflect that any decision to substantively amend a clinical offering for a service serving all NHS Scotland would likely benefit by following relevant NHS Scotland structures to reach collective agreement e.g. progression of a detailed proposal to Health Board Chief Executives.
- 11. Finally, with these points in mind, I would strongly encourage NHS GGC and NHS Lothian to substantively engage with the new clinical services established from 1 April 2024 by NHS England in this field, to better understand implementation of those new clinical pathways and their associated specification(s). I would note building robust





clinical links with other centres in UK nations will ultimately benefit NHS Scotland patient outcomes and service delivery in this sensitive field.

Conclusion

- 12.1 am encouraged to read that NHS GGC and NHS Lothian have a communication plan to sensitively handle this change in position for patients, as this can be expected to attract substantive public interest and has the potential to cause concern to those on the waiting list (and their families) if not communicated appropriately. In light of this I would ask both Health Boards to continue to maintain good links with relevant Scottish Government officials on this communication plan, to ensure a shared understanding of the position as it is implemented.
- 13. I remain grateful for the continued efforts of clinicians and staff working to care for children, young people and their families seeking their support. I know you agree we must collectively maintain our focus on delivering the best possible evidence-based care for NHS Scotland patients in what remains a highly sensitive, at times clinically complex, and highly polarised field of medicine.

Professor Sir Gregor Smith Chief Medical Officer for Scotland







FW: Parliamentary Question: Puberty Blockers - 11AM TUESDAY 26

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?									
То									
Mon 4/8/2024 14:31									
Dear									

Please see the NHS Lothian response below:

Sandyford Referrals to NHS Lothian Paediatric Endocrine Team											
	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024
Referrals to Lothian	0	<5	<5	6	12	10	7	<5	<5	<5	

Regards

Executive Assistant to the Chair & Chief Executive

NHS Lothian

Waverley Gate

2-4 Waterloo Place

Edinburgh EH1 3EG

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Some people who received this message don't often get email from genderidentityhealth@gov.scot. Learn why this is important

Hi again

and colleagues,

Thanks again for being so responsive with our request for numbers yesterday.

Similar to yesterday's request, would you also be able to provide the number of children under <u>16</u> referred to endocrinology for evaluation for puberty-suppressing hormones within NHS Lothian between in <u>2014</u> and <u>2015</u>, respectively?

We'd be extremely grateful if we could have these numbers this afternoon, if at all possible.

Many thanks,

(he/him)

Senior Policy Officer | Gender Identity and Healthcare Access

Population Health Strategy & Improvement Division | Population Health Directorate



 From:
 On Behalf

 Of genderidentityhealth@gov.scot
 Sent: 25 March 2024 15:21

 To: Endocrine, RHCYP <<u>RHCYP.Endocrine@nhs.scot</u>>; Media, Lothian <<u>Lothian.Media@nhs.scot</u>>;

 Mackay, Judith <<u>Judith.Mackay3@nhs.scot</u>>;

 Cc: Bath, Louise <<u>Louise.Bath@nhs.scot</u>>; Chetty, Tarini <<u>Tarini.Chetty@nhs.scot</u>>;

 Subject: FW: Parliamentary Question: Puberty Blockers - 11AM TUESDAY 26

 Some people who received this message don't often get email

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Also copying in RHCYP Endocrinology mailbox.

From: On Behalf Of Gender Identity and Healthcare Access Sent: Monday, March 25, 2024 3:18 PM To: Lothian.Media@nhslothian.scot.nhs.uk; Judith.Mackay@nhslothian.scot.nhs.uk;

Cc: louise.bath@nhslothian.scot.nhs.uk; tarini.chetty@nhslothian.scot.nhs.uk;

Subject: Parliamentary Question: Puberty Blockers - 11AM TUESDAY 26

Dear NHS Lothian colleagues,

In order to allow us to answer an urgent oral Parliamentary Question for the Cabinet Secretary for NHS Recovery, Health and Social Care, we would be grateful if you would provide the information below (or direct us to where it is published) by **11:00am tomorrow** (Tuesday 26 March). This question is due to be answered in Parliament this week.

• Can you provide us with the number of children under <u>16</u> referred to endocrinology for evaluation for puberty-suppressing hormones within NHS Lothian between <u>2016</u> to present (or latest available date)?

 We would expect these referrals to come from the Sandyford Clinic's Young People's Gender Service. (We already have figures for the number referred to NHS GGC endo services).

• It would be very helpful to us if you could provide a breakdown by year. Is this data published anywhere (e.g. an FOI)?

(Please note that we had asked NHS GGC to provide the figures above, but they have not been able to do so at short notice.)

With sincere apologies for the very tight turnaround, we have been asked by our Cabinet Secretary to answer this as soon as possible.

Best wishes,

Senior Policy Officer | Gender Identity and Healthcare Access

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Population Health Strategy & Improvement Division | Population Health Directorate



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RE: Today's National Gender Identity Healthcare Reference Group meeting- 17 April 2024

Wed 17/04/2024 11:04

Colleagues,

With sincere apologies for the short notice however the Co-Chairs have agreed to postpone today's National Reference Group meeting at 14:30-16:30, to be rearranged for 1 May. We believe moving this meeting by a fortnight would permit a much more effective use of your and the Group's time, in light of ongoing implications of the Cass Review's final report being published.

We will reissue a calendar update later this week to this effect (please do not dial into this afternoon's call).

Kind regards,

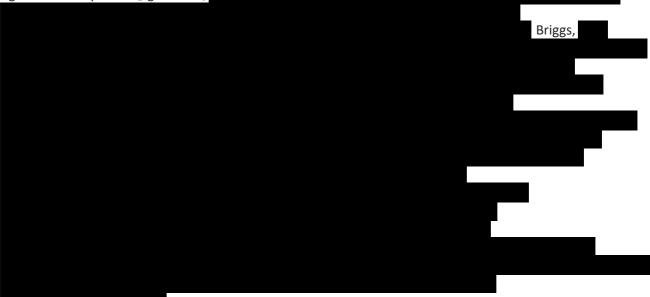
Gender Identity and Healthcare Access I Population Health Strategy & Improvement Division I Scottish Government I St Andrew's House I Regent Road I Edinburgh I EH1 3DG

From:

On Behalf Of Gender Identity and Healthcare Access

Sent: Tuesday, April 16, 2024 5:30 PM

To: Parent Group <transparentsees@gmail.com>; Gender Identity and Healthcare Access <genderidentityhealth@gov.scot>;



Subject: RE: Agenda and meeting papers - National Gender Identity Healthcare Reference Group - 17 April 2024

Hi everyone,

Looking forward to seeing many of you tomorrow at the reference group meeting. Can I remind members that we ask them to send any material they would like considered for circulation to the wider reference group membership, or for discussion at the group's meetings, to the secretariate at <u>genderidentityhealth@gov.scot</u> rather than mailing material or links directly.

With thanks and best wishes,

 Head of Gender Identity and Healthcare Access I Population Health

 Strategy and Improvement Division I Scottish Government I St Andrew's House I Regent Road I Edinburgh I

 EH1 3DG

From: Parent Group <<u>transparentsees@gmail.com</u>>
Sent: Tuesday, April 16, 2024 5:22 PM
To: Gender Identity and Healthcare Access <<u>genderidentityhealth@gov.scot</u>>



2024

papers - National Gender Identity Healthcare Reference Group - 17 April

Dear colleagues,

Some further reading before tomorrow. A summary of 10 potentially dangerous items in the Cass Review which were not in the 5 page summary

https://growinguptransgender.com/2024/04/16/ten-dangerous-cass-review-recommendations/? fbclid=IwAR3RLfkAoi9HX_VCrU9q_N7tyqxG04Qgaz1l4qpwSQhILDC2JfZVItofJEU

Best wishes

Transparentsees Parent and Carer Network

On Thu, 11 Apr 2024, 11:15 , <<u>genderidentityhealth@gov.scot</u>> wrote:

Dear colleagues,

Please see attached agenda and papers for our meeting next Wednesday, 17 April, 14:30 – 16:30. Please note Paper G will be sent out in the next few days.

Members will likely already be aware, the <u>Final Report</u> was published 10 April 2024, from the Cass Review, along with a number of systematic reviews <u>Gender Identity Service</u> <u>Series | Archives of Disease in Childhood (bmj.com)</u> that have informed the final report.

You may also be interested to note, a dedicated communication has been issued to Health Boards in April 2024, to confirm GIC clinical offering to be wrapped up into wider guidance implementation plans within Boards, you can view this letter here <u>NHS Waiting Times</u> <u>Guidance 2023 - application to Gender Identity Clinics</u>

If you have not had the opportunity already, please let us know if you are planning to attend by accepting or rejecting the meeting invitation in your calendar. If you are unable to attend please let us know if you are sending someone else in their place with their name and contact email address.

Please get in touch via <u>genderidentityhealth@gov.scot</u> if you wish to discuss anything in advance of the meeting.

Kind regards,

Policy Officer I Gender Identity and Healthcare Access I Population Health Strategy and Improvement Division I Scottish Government I St Andrew's House I Regent Road I Edinburgh I EH1 3DG

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