Chief Medical Officer Directorate

E: CMO@gov.scot



3 February 2023

Dear Colleagues,

Thank you for your letter of 20 October 2022 regarding clinical provision of specialist gender identity healthcare within NHS Scotland to children and young people.

I apologise for the length of time it has taken to respond to you. Your letter raises a number of important points which I have sought to address below.

Current provision

Firstly, I fully recognise the sustained pressure the Sandyford Young Person's Gender Service continues to experience and the care NHS Greater Glasgow and Clyde (NHS GG&C) and NHS Lothian's paediatric endocrinology teams provide to the small number of young people referred to them from that service. I wish to express my thanks to all the clinicians who work in this complex and sensitive field. I know that all of the staff involved continue to endeavour to deliver the best care possible for these young people and their families.

I also understand that both NHS GG&C and NHS Lothian send both strategic and clinical members to the <u>National Gender Identity Healthcare Reference Group</u>. I would like to thank both Health Boards for this continued engagement, as well as their substantive input into the recent review and update of the national 2012 Gender Reassignment Protocol for Scotland led by NHS National Services Scotland, independently chaired by Dr Miles Mack.

Commissioning of a Young Person's Gender Service

I am reassured to note that NHS GG&C and NHS Lothian have continued to take steps to assure themselves of the current clinical pathway and governance arrangements in place for the provision of this specialist care.

I believe it may be helpful if I outline the position regarding work to commission a national Young Person's Gender Service, recognising the challenges and pressures Sandyford faces.

Commissioning context

St Andrew's House, Regent Road, Edinburgh EH1 3DG www.gov.scot







As you'll be aware in February 2020 the former Cabinet Secretary for Health and Sport, Jeanne Freeman MSP, met with a parent and child referred to Sandyford. This meeting also included clinical and strategic leads, including the then Director of Public Health from NHS GG&C. At that meeting NHS GG&C highlighted they were working towards the Young Person's Gender Service at Sandyford becoming a nationally commissioned service via NHS National Services Scotland (NSS) processes. This was an approach supported by the Health Board.

The Cabinet Secretary expressed her support for that approach which went on to be reflected in one of the commitments in the <u>NHS gender identity services: strategic action</u> framework 2022-2024 published December 2021. Scottish Government committed there to *'support the national commissioning of a young person's gender service'*, this commitment was agreed with NHS GG&C who were, at that time, leading that approach.

Following that February 2020 meeting the pandemic paused substantive progression of that agreed commissioning approach. I understand that a number of changes to senior clinical staff in the clinical service also contributed to a longer term pause.

I am aware that in summer 2022 NHS GG&C reassessed their position and formally advised Scottish Government it was no longer the Board's strategic intention to progress a commission for their clinical service.

Next steps

Since then I understand that Scottish Government officials, with support from Deputy Chief Medical Officer Nicola Steedman, have worked closely with NHS NSS, National Services Division (NSD) to identify alternate ways forward for a Young Person's Gender Service for Scotland. Substantive scoping of this commissioning work is still underway. However, given the total number of this patient cohort (including the numbers waiting) it is likely that rather than a single site national commissioning approach, it may involve progression via National Planning Board processes.

The work NHS GG&C is currently undertaking on full mapping of its pathways in the Sandyford Young Person's Service, and associated assurance, will be invaluable to inform this necessary process.

I would strongly encourage both your Boards to proactively share the results of that pathway work you are undertaking with NSD at the earliest available opportunity. I understand a meeting is in the process of being arranged.

Overall approach

The overall approach the Scottish Government is taking with work in this sensitive and complex field, was outlined by the Cabinet Secretary for Health and Social Care in a <u>recent letter to the Scottish Parliament's Equalities</u>, <u>Human Rights and Civil Justice</u> <u>Committee</u> on 21 November 2022. That letter set out the wider actions underway to improve access to, and delivery of, gender identity services and associated healthcare within NHS Scotland. I would like to encourage both your Boards to continue to engage substantively with ongoing implementation of that broader work programme.







Your requests

In your letter you set out three requests of me which I have sought to address below. You have linked several of these requests to work underway by the ongoing Cass Review. It may be helpful to give some background to Scottish Government's ongoing engagement with Dr Hilary Cass, her review team and our understanding of the current position.

Cass Review

As you will be aware, the independent review of gender identity services for children and young people chaired by Dr Hilary Cass ('the Cass Review') extends only to provision of current and future services as offered by NHS England for children and young people experiencing gender dysphoria or gender incongruence. It is not reviewing or considering clinical offering or pathways within NHS Scotland. Nevertheless, the Scottish Government has been consistently clear that it will fully consider the outcomes of the Cass Review, as they may relate to services delivered by NHS Scotland and its patients in a devolved context.

In March 2022 the Cass Review published its interim report which informed initial NHS England announcements in this space, in particular, a commitment made in July to substantively expand commissioned services offered by them.

The final report of that NHS England commissioned Review is not expected for some time, and further outputs – particularly concerning research results – may be even further in the future.

Engagement

Prior to your letter officials had already sought a meeting with Dr Cass and her review team. This was to better understand Review timescales, proposed research approaches and to explore opportunities, as appropriate, for shared learning.

As you will be aware officials from Scottish Government, Deputy Chief Medical Officer Nicola Steedman, Dr Ewan Bell, Associate Medical Director, NHS Dumfries and Galloway (as cochairs of the National Gender Identity Healthcare Reference Group) and representatives from NHS GG&C attended a meeting with Dr Hilary Cass and her team on 21 November 2022. A further meeting took place on 17 January.

On the basis of the recent meeting I understand that the National Institute for Health and Care Research research protocol research questions are not yet defined and there is considerable work to take place before they are.

We have specifically requested further details on timelines and outputs on this.

In this context, turning to your specific requests to:

- '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'







• 'That this includes 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'

NHS GG&C have previously confirmed to Scottish Government that the current service has effective links into local Children and Adolescent Mental Health Services (CAMHS). It is also my understanding that the majority of patients who seek access to, or will access, a specialist gender identity service for children and young people will not require any form of prescribed physical intervention. For example I believe that over the last eleven years – on average – there have been fewer than 10 young people a year referred for consideration for puberty blocking treatment in Scotland.

However, I am alert to the particular sensitivities which medical intervention in this space has generated both within some of the clinical community, as well as in society more broadly.

You will be aware that in January 2020 a Policy Working Group (PWG) was established by NHS England to undertake a review of the published evidence on the use of puberty blockers and feminising/masculinising hormones in children and young people with gender dysphoria to inform a policy position on their future use.

A NICE evidence review: *Gonadotrophin releasing hormone analogues for children and adolescents with gender dysphoria* was published in October 2020. The results of the studies that reported impact on the critical outcomes of gender dysphoria and mental health (depression, anger and anxiety), and the important outcomes of body image and psychosocial impact (global and psychosocial functioning), in children and adolescents with gender dysphoria are of very low certainty. Following your request, Scottish Government will 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. As part of that request HIS may also consider what other forms of evidence or intervention may be helpful in order to support clinicians in NHS Scotland making prescription decisions in this field

Given the small numbers involved, research into best practice in this area of care would ideally benefit from being linked to the largest suitable dataset. However as highlighted above it is my understanding that work in NIHR, with which the Cass Review is engaging, is in the early stages of definition.

The appropriateness of NHS Scotland involvement in research in this field will be dependent on further clarity on its parameters being made available, as part of ongoing discussions with colleagues in England with whom Scottish Government is proactively engaging.

Whilst I wholly agree with the need to fully engage with UK colleagues I require further information regarding the management, processes and extent of any research protocol before considering what, if any, NHS Scotland involvement would bring the best possible outcomes for patients accessing clinical pathways here. Scottish Government will continue to work very closely with NHS GG&C service managers and clinicians to engage with that process in a full and open manner.

Operational Concerns

Waiting times







As you know, I am alert to the severe pressures faced across the NHS at this time.

I share your deep concern regarding the length of waiting times to access the highly specialised clinical services supporting those with gender dysphoria or gender incongruence.

You will know that decisions on funding allocation rest with Scottish Ministers. I understand that both your Health Boards have now received allocation this financial year to support services.

I am encouraged to have been made aware of work NHS Lothian has carried out already to increase capacity via recruitment of additional nursing resource for their adult gender identity clinic. I understand management information from NHS Lothian indicates that it has now reduced its waiting list substantially. This is a trend I hope to continue to see. I would ask that NHS Lothian share its learning from that ongoing work, especially regarding recruitment and waiting list triage, with other Health Boards hosting gender identity clinics.

CAMHS engagement

Following your letter officials have spoken to NHS GG&C's Director of Public Health regarding what support Scottish Government could provide to facilitate cross-Board working. I am aware that there are ongoing concerns around the care of those waiting and, in particular, for the need to clarify the role of referring NHS Boards and their CAMHS, in assessing and managing any issues experienced by young people referred to Sandyford.

As you will be aware a meeting has now taken place and steps identified to progress improvements.

Staffing challenges and the need to progress service commissioning

As you will both also be aware, after being notified in late December of the forthcoming resignation of a clinical staff member at the young people's service and the further operational impact this will have on the Sandyford YP service, the Director of Population Health within Scottish Government has contacted NHS GG&C's Chief Executive for further discussion.

Conclusion

I recognise this is a lengthy letter. But I hope it demonstrates my understanding of the challenges, sensitivities, and also the opportunities for substantial improvement of clinical delivery in this small, specialist space.

I have copied this letter to Health Ministers and clinical colleagues who have an interest in ongoing improvement in this space.

Yours sincerely,

Professor Sir Gregor Smith









Chief Medical Officer for Scotland

Copied:

- Humza Yousaf MSP, Cabinet Secretary for Health and Social Care
- Maree Todd MSP, Minister for Public Health, Women's Health and Sport
- Kevin Stewart MSP, Minister for Mental Health and Social Care
- Caroline Lamb, Chief Executive, NHS Scotland
- Alison Strath, Chief Pharmaceutical Officer
- Nicola Steedman, Deputy Chief Medical Officer
- Susan Buchanan, Director of National Specialist Services & Screening Division
- Dr Emilia Crighton, Director of Public Health, NHS Greater Glasgow and Clyde





