

Long-term health outcomes for patients of NHS gender identity services in Scotland.

[Redacted – s.38(1)(b)]

Foreword

This research was commissioned in November 2023. Since then three very significant developments have happened. The publication of the Cass Report and its aftermath, the extensive and unparalleled criticism of it by academics and the medical profession, and the suspension of healthcare for trans and non-binary people under 25 at Chalmers clinic. Consequently this research has needed to adapt to take account of the changed environment in the NHS in Scotland.

Summary

While to date, long-term health outcomes of trans and non-binary people in Scotland seem to have been very positive, which is a very strong endorsement of gender-affirmative healthcare, there are additional factors to consider that have come into play more recently including the political installation of anti-trans figures in management hierarchies all the way up to senior NHS level.

Trans people who have had gender reassignment surgery realise that this is produced by highlevel political transphobia in the UK, mostly – but not exclusively – from Westminster. As such the growing political interference does not merely seem to have made the system more inefficient but constitutes a growing attempt by the political establishment to undermine trans people’s human rights generally, which directly impacts on long-term outcomes in a number of ways.

1.0 Introduction/Background

It is impossible to make sense of the state of trans healthcare in the UK without talking about the Cass Review. The Cass Review is almost universally regarded by the trans communities as illegitimate pseudoscience. It excluded trans researchers from its analysis and oversight teams and included members of groups widely regarded as transphobic. It has been very widely discredited (for the long list of critiques see *[Redacted – s.38(1)(b)]*), indeed it is likely one of the most widely discredited pieces of ‘research’ in history. It has been discredited from the perspective of methodology, bias, lack of balance, omission of research,

exclusion of those with lived experience, process of appointment of lead researcher, and conclusions that are unsupported by evidence. Yet politicians, journalists, civil servants and others appear to have treated it with an almost religious reverence and a puberty blocker ban, unjustified by any evidence, has been imposed by politicians with no clinical or personal knowledge and without the consent of patients. In effect The Cass Review has given bigoted politicians and journalists permission to be transphobic.

This appears to have resulted in a significant loss of trust in NHS Scotland amongst trans people, and trust in politicians and others regulating the NHS in Scotland. It is hard to imagine any other patient group being excluded and treated with such disdain by politicians and the NHS. This initially made it very much harder for me to recruit participants for this research and I needed to reassure participants that I am a trusted interviewer in order to allay their fears about being misrepresented in the way the Cass Review did. To a significant extent my publication of a preprint “[Redacted – s.38(1)(b)]” which was widely circulated in trans communities, resulted in a sudden increase in the number of participants, as participants realised that I was trustworthy.

It did not end there however, once the unevidenced and clinically unjustified decision was taken by the management of Chalmers to stop providing healthcare to trans people under the age of 25 it once again appeared to become harder to recruit participants, although by this time I was reasonably confident that my data was close to empirical saturation, and that no new experiences were being reported.

[Redacted – s.38(1)(b)]

Suspicion now seems to be the most widely-reported commonality amongst participants, with many expressing considerable disquiet about the direction of travel by NHS Scotland and the way that these changes have been handled, in particular the absence of consultation with groups representing patients. This reflects one of the key problems with the Cass Review in particular and anti-trans politics in general, its exclusion of those with lived experience as trans or non-binary, something that cannot be justified in methodological or ethical terms has skewed the outcome badly. Treating one particular patient group in this way has resulted in a significant breakdown of confidence and trust in NHS Scotland.

There were a number of issues raised in data collection, some specific to different participants' circumstances, but some others that participants shared.

2.1 Participants

Initially one consideration that needed to be borne in mind is the possibility that those volunteering to participate may have been those with axes to grind, while those who were more satisfied would be less likely to participate. My fears over this do not seem to have been justified as most participants reported being broadly very happy with their long-term

outcomes. However there was one key factor that seemed to be the determinant of satisfaction in most of these cases; the date when they were treated by the NHS Scotland. Those expressing more positive outcomes and experiences tended to be those who had completed their surgery at the earliest dates. Patients seen before the late 2010s were happier with their outcomes and experiences, those transitioning more recently less so. There seems to be a relationship between level of long-term satisfaction and time since completion of gender confirmation surgery with more recent transitioners expressing lower levels of satisfaction. That said participants were generally very pleased with their medical outcomes. Gender confirmation surgery clearly greatly improves patient outcomes as very low detransition levels have demonstrated ([Redacted – s.38(1)(b)]), especially in comparison with all other forms of surgery, whereas denying healthcare has been shown to cause great harm ([Redacted – s.38(1)(b)]). In particular this makes the decision by Chalmers to pause gender healthcare for under 25s very concerning. It is very unlikely that this did not cause significant unnecessary harm to patients registered there, again this seems to have caused a breakdown in trust and suggests that management there are influenced by “gender-critical” rhetoric. Indeed it seems that trans healthcare in general is based on this, rather than science or feedback from patients and former users.

2.2 Findings

2.2.1 Personnel

One of the main factors that seems to have impacted the quality of care and outcomes seems to be the personnel at gender identity clinics. Most participants were very clear that staff who adopted a caring and pro-actively affirming stance made their transitions smoother and considerably less stressful. Gatekeepers seemed to differ greatly in this respect, while endocrinologists were almost universally regarded as much more helpful. This is of particular relevance given that the previous government made it clear during the election, that it had installed specifically anti-trans personnel in key positions in the NHS in order to facilitate transphobic policies, something [Redacted – s.38(1)(b)] characterised as ‘elite replacement’. This was one of the reasons why the quality of care seems to have declined over time; some former service users named the same personnel as each other, while more recent ones did not do this, indeed one participant, never saw the same person twice, despite having had a large number of appointments.

2.2.2 Situating prior experiences

In some instances gatekeepers seemed to regard a new patient as though they had made a very sudden decision to transition, something that my own research ([Redacted – s.38(1)(b)]), replicated by [Redacted – s.38(1)(b)] has demonstrated to be an assumption that should not, in most cases, be made.

[Redacted – s.38(1)(b)]

This demonstrates that staff may need improved training and need to be exposed to research conducted by trans academics in order to understand the likely range of histories of patients.

In most cases trans and non-binary people have known or had some idea that they were gender different from their gender assigned at birth for a very long time, in many instances since infancy. Assumptions about the history of any given individual's gender development often appear to be rooted in anti-trans rhetoric distributed by our hostile and almost hermetically trans-exclusionary mass media. Having to explain oneself to gatekeepers was something most patients felt to be problematic in that, in many instances, basic knowledge of the lives of trans people seemed to be lacking and this produced a lack of confidence and distrust in this part of the process. In particular participants felt that a desire, on the part of the GIC, to proceed with 'caution' was inappropriate in circumstances where they had waited a very long time (in some instances almost their entire lives) before seeking surgical/hormonal treatment because of barriers such as the social, cultural, emotional and epistemological.

2.2.3 Communication between NHS GICs

Communication between different NHS centres, when patients had moved either during the process or subsequently was also an issue that was common to all those who had moved geographically. This included patients moving between GICs within Scotland, from other constituent parts of the UK and from abroad. The initial suggestion when this happened, was, for some, that they should restart the entire process again, as though they were at initial consultation again. This was regarded as wasteful and unnecessary as communication between different clinics should not be particularly difficult, it also added a significant amount of stress. One of the common sources of stress was the feeling amongst patients that since they had waited such a long time, and now they had finally arrived at a situation in their lives to be able to transition, they were being forced to 'slow down', the media narrative that somehow people are being 'rushed' into transition seems to have taken hold despite a lack of any evidence to support it, and again the very low detransition figures indicate that the 'rushed-into-transition' myth is the opposite of reality.

2.2.4 Silencing by Pseudoscience

Trans people are already one of the most excluded and silenced groups in society. We are excluded from most mainstream media, we are excluded from most government bodies and, in particular, excluded from spaces where decisions are made about us. This included the Cass Review, where trans and non-binary people were excluded from the group producing its analysis as well as its oversight board. Since its publication it is evident, from data collected by some former patients, that Cass is being deployed by those in positions of power to further exclude trans people from decision-making about our healthcare – and indeed about

everything related to our human rights and access to resources. In effect it is now being deployed, at all levels from government on down, as a tool to silence trans people, in particular those who are concerned about these issues. It appears that it is being deployed to permit bodies to make decisions about trans healthcare in the absence of trans people, indeed with the deliberate exclusion of trans people. By invoking The Cass Report decision-makers can exclude trans people from the process of decision-making about trans people. This situation was noticeable prior to the publication of Cass, Cass seems to have made this process much more prevalent; “Following/implementing The Cass Review” is being deployed like a collective gag to exclude trans people from expressing concerns about policies being implemented at both government, overall NHS and local levels.

3.0 Analysis and recommendations

3.1 Analysis

This research’s findings represent analysis based on the most common themes apparent from the data.

The issues described in Sections 2.2.2 and 2.2.3 are clearly linked, and not exclusive to those who have moved geographically. The feeling that they are progressing too slowly through a system that seems designed to coercively slow them down is increasingly common for patients of all ages, especially those who have recently joined waiting lists.

[Redacted – s.38(1)(b)]

- *Tacit deferral* refers to the time prior to experiencing *epiphany* as a trans person when one does not have the language to describe oneself as trans or the realisation that the term ‘trans’ applies to oneself personally, this period can extend back to early childhood.
- *Epiphany* is the time when this changes, and the appropriate language is acquired or applied to oneself, this can happen either in an instant or over a period of years.
- *Discursive deferral* then describes the time, prior to coming out, when one participates in a community of similar people, usually online, to engage in selflearning and discovery, as well as to acquire knowledge and important information, for example about different medical healthcare available. In some instances individuals may have been subject to coercion to prevent them from coming out or taking steps to change their genders.

Understanding that the above schema applies to most trans people (and indeed this has been applied to cis LGBTQ people also), the only difference between individuals being the length of time each section takes is crucial for gatekeepers to understand.

[Redacted – s.38(1)(b)] also concluded that when young trans people come out it can often appear to others that identifying as trans or non-binary is a very sudden decision when in reality it has been weighing on them for a long time, in many cases years or even decades. It is also worth understanding that, during the *discursive deferral* period trans and non-binary people often acquire quite considerable knowledge about the medico-legal processes of transition. It would appear that the best gatekeepers had an element of understanding of deferral, the likely level of patient knowledge and the ability to empathise with patients during appointments.

3.2 Recommendations

3.2.1 Recommendation 1

The first recommendation is that gatekeeping, management and other staff understand that, in most (but not all) instances, when they present initially the patients are, and regard themselves as being, close to an end-point in a very long journey, and not at some initial starting-point as may be perceived. This is important because it means patients' needs can be better understood and catered for. The 'rushed-into-transition' myth is just that, a myth. Staff need to be fully aware of this if they are to fully understand their patients. It is recommended that this be part of induction training for all staff and administrators at all levels in the GICs as well as for those further up the NHS hierarchy administering them.

Furthermore it is recommended that all staff, in particular senior staff, at all levels throughout NHS Scotland, appointed since 2019 should be more to positions where they can no longer affect trans healthcare, and that Chalmers should end its ban on healthcare for adults under 25. There should be an inquiry into this decision and those responsible moved to different jobs in the NHS where they have no influence over trans healthcare. Those involved in trans healthcare should be believers in that healthcare and, if possible, advocates for it. Would abortion clinics employ anti-abortion campaigners?

3.2.2 Recommendation 2

That NHS Scotland adopts, as a matter of urgency, a policy of including those with lived experience as trans or non-binary people at all levels of decision-making in trans health and within the NHS hierarchy when any issues relating to trans-related healthcare are being discussed, and that those with lived experience are listened to and guide all decisions. Recent significant decisions, such as the puberty blocker ban should be revisited, and if necessary, reversed, on this basis. Excluding trans and non-binary people from decisions about their healthcare is ethically unacceptable and those involved in excluding us from spaces where those decisions are made should be redeployed to positions where they have no influence on

trans healthcare. All GICs should have a significant number of trans people on an oversight committee or governing body and they should be invited to all senior management team meetings.

3.2.3 Recommendation 3

That all patients should be treated as fast as possible unless there are very good reasons not to do so, and that any reasons for any kind of delay should be shared at all times with the patient. The nature of deferral means that most patients will experience significant stress if the pace of their treatment, or the length of time they spend on waiting lists, results in delays. This should include not automatically using neurodivergence as a pretext for slowing down progress through the system ([Redacted – s.38(1)(b)]).

3.2.4 Recommendation 4

That The Cass Review should not be deployed as a means of excluding trans people from decision-making about trans issues, in particular healthcare. As has been demonstrated ([Redacted – s.38(1)(b)]) the volume and quality of critiques of Cass is significant and so far I have seen no critiques of Cass that are not solidly based, most grounded as they are in solid evidence, methodological, ethical, medical and academic critique. A number have now been peerreviewed (E.g [Redacted – s.38(1)(b)]), unlike Cass, which gives them a higher scientific/academic status than Cass. NHS Scotland needs to acknowledge that the overwhelming majority of the trans communities reject most of Cass’s conclusions, as do medical/scientific communities around the world. It needs to acknowledge that Cass constitutes an outlier in relation to the totality of research about trans health, an outlier that has been firmly and actively rejected by the overwhelming majority of the global scientific community.

Failure to acknowledge this and act accordingly constitutes an act of silencing and exclusion that is extreme even in comparison with the levels of exclusion that preceded Cass. NHS Scotland needs to understand the significant faults of Cass and genuinely engage with trans people instead of using Cass as a pretext to exclude and ignore trans people. Cass has increasingly set Scotland and the rest of the UK apart from the rest of the world as well as excluding trans people from spaces where decisions are made about us, ending its misuse and acknowledging its faults and the depth and breadth of criticism of it needs to be a priority for the NHS in Scotland. The Scottish government needs to understand that Cass has been superseded and the critiques and alternatives are much more solidly-based

4.0 Conclusion

This is an overview of the research undertaken so far, in many respects it is turning out very differently from what I had expected when it was originally proposed in November 2023. This is because there have been a number of significant occurrences which have affected

trans people's lives both directly and indirectly. Given these circumstances it is to be expected that the data coming in from this study is considerably at variance from what was expected. In the UK at the moment trans people feel almost universally under attack and this affects all of us in every respect.

References

[Redacted – s.38(1)(b)]