

Good Practice Guidelines for the Assessment and Treatment of Gender Dysphoria

Consultation Response by Christine Burns MBE

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Introduction

I would like to thank the Intercollegiate Committee on Standards of Care, chaired by Dr Kevan Wylie, for affording all stakeholders, including members of the trans community and their advocates (like myself), the opportunity to comment upon the draft guidelines they have put together.

Although I remain critical of the structure of the process by which these guidelines were produced, especially the lack of initial consultation upon the purpose and philosophy behind such a project, I am glad that the attempt has at least been made to produce a work such as this. Modern guidelines, tailored for the UK Healthcare landscape, and reflecting contemporary philosophy about medicine, are an essential foundation to underpin long-overdue reform in this field.

The Chair will know that I have adopted a supportive but constructively critical approach towards the entire project and that, although I am not a member of the drafting committee itself, I have made frequent recommendations throughout the process. Some of these recommendations have been taken on board by the committee. Unfortunately, some strong recommendations have also not been heeded. I have also strongly encouraged others to engage with this consultation process, whilst taking great care not to influence what they might say.

I approach this consultation from the perspective of being a leading commentator on the entire issue of health provision for trans people. The Committee will know that I have written extensively in this field and, because of that published work, I have also been in the position that trans people regularly advise me on their experiences of care as it is delivered in the UK today. It is the expert knowledge of those people's documented experiences, and the consequences of current practice, which inform the comments that I now make.

Comments About The Philosophy and Purpose

In this document I am not going to focus on minutiae. My concerns are about the broader picture and about fundamentals. It is in this sense that I feel most particularly disappointed by the committee's efforts.

Overall I think that an important opportunity has been missed. I forecast that this would be the case if the Committee did not consult upon the need for and purpose of guidelines to begin with. Unfortunately, my fears in this respect have been realised.

This exercise provided an opportunity to professionally re-evaluate the entire philosophy of care and support for people with gender issues within a social and legislative context that has changed out of all recognition in the last decade.

- ❖ There was an opportunity to review what role professionals should have, especially within the modern day vision of medicine's goals and the concept of client centred health delivery that has evolved in that period. That opportunity has been missed.
- ❖ There was an opportunity to recognise what a confident, well-educated and self-aware client community wanted from practitioners. That opportunity has been ignored too.

- ❖ There was an opportunity to provide important guidance for commissioners and primary care professionals, in order that they should understand and responsibly support the needs of service users rather than driving them away from care. That has not been realised.
- ❖ There was an opportunity for professionals to question their own habitual assumptions within the context of an increasing demand for evidence-based approaches. That opportunity has been brushed aside with a “we know best” attitude that only serves to emphasise the degree to which sacred tenets of practice have no evidence base at all.

The result is a document which, in spite of significant community input concerning the structure and topic headings, still manages to be no more than a collection of existing practices written down and labelled as “best”.

There is nothing about these guidelines, as drafted, that would oblige the clinical heads of existing Gender Identity Clinics to reappraise their existing practice in any way – at a time when many of those institutions are acknowledged to be unpopular and subject to criticism. This can only reinforce the conclusion that the drafting process has been dominated by people who do not accept the need for reform.

Practitioners invited to contribute to this committee had the opportunity to redeem their poor reputation among gender diverse people by doing so much more. This would have involved questioning what they are asked to provide, and even what the “goal” of treatment should be. Had they been prepared to do that then I believe that many of the more specific criticisms of their work would not have come about. Instead, in spite of the window dressing in the presentation, history will come to view these guidelines as an embarrassing reminder of how current practitioners in this field were afraid to really question what they were there for and to consider changing the way they work.

Specific Failings

This section deals with particular areas in which the guidelines fail to serve people who are going to look to them for guidance:

Do the Guidelines help GPs to understand trans patients’ treatment needs and options better?

Unfortunately not. There is no easy way in which a General Practitioner can read this large document and understand the philosophy and practice of modern care for people with gender issues. In part this is because the committee do not seem to have grasped this themselves. There is apparently no point in the process when the committee actually asked itself whether the care goal was to help the patient achieve well-being in terms that are right for them; it seems to have implicitly accepted the long-standing assumption that the goal is always associated with genital reassignment and getting there without risk for the professionals involved. Because of this lack of rigour, the care guidelines set out an approach to care which presumes all patients to have identical needs and objectives. This approach risks encouraging both service users and GPs to think that a care programme has nothing to offer them unless they want genital surgery at the end. If therapists genuinely wish to minimise the possibility of regrets then they ought to ensure that the guidelines communicate the need to be open minded about the options available to individuals.

This could be resolved by setting out a clearer philosophy to begin with and then also explaining that there is more than *one way that the care goal (and the patient’s) can be realised.*

Do the guidelines help to facilitate the design of better local commissioning policies?

Unfortunately not. The guidelines, through their eventual existence, ought to help commissioners to understand that gender treatment is not just about authorisation for genital surgery, and that the broader goal of facilitating well-being is an important necessity, fully in keeping with harm prevention and health promotion philosophy. The guidelines also ought to enable commissioners to engage their own local resources to achieve those therapeutic goals with local skills and resources as far as possible. In reality, however, the guidelines do little to answer the fundamental question of why care needs to be provided in the way it is described, and why the care is needed with any priority in the first place. The guidelines are instead likely to reinforce the view that treatment can only be provided as an expensive single tertiary referral to a remote clinic, with little benefit or value for money visibility.

This can be resolved by articulating a clearer vision of the philosophy of care in this field – especially the probable consequences of unreasonable delays and obstructions.

Do the guidelines reflect modern healthcare thinking and the need to encourage diverse approaches for diverse needs?

Unfortunately not. Although the committee has adopted a structure and headings reflecting concepts such as patient centred care, autonomy and informed decision making, the failure by individual specialist authors to embody those principles into their regurgitated current practice means that any care plan based on the guidelines is incapable of reflecting what patients and health service leaders now expect.

This could be resolved by the committee re-evaluating all statements which express what the patient must or must not do or achieve in order to progress towards their personal goals. It will also require careful rewriting of sections *which (wrongly) imply that care can only be provided through monolithic “Gender Identity Clinics”*. Instead, the language should express a philosophy of working with clients to help facilitate understanding of their own goals, and how to achieve those with the cooperative assistance of people who have the specialist skills required to get there.

Are the guidelines overly prescriptive? If so, is there a reliable evidence base for the policies advocated?

Unfortunately they are prescriptive without material justification. Indeed, this is the principal area in which it can be said that the committee has completely failed to establish a solid foundation for what should be “best practice”. The authors have simply repeated their own dogma on specific issues such as the ordering of therapies, the purpose of RLE, the minimum length for it, and the number of opinions needed for key steps, without showing any evidence that these specifics have been arrived at through robust comparative research. This is extremely dangerous, since the uncritical repetition of these “rules”, like tablets of stone, paradoxically serve to prevent responsible research to determine whether they are valid or not. The authors seem determined to cement their own practice for another generation in this manner, without adequately justifying why that should be the case.

This could be resolved by the committee demonstrating an ability to question its own dearly held beliefs in a normal scientific manner and changing wording of the relevant passages to employ a more advisory, less dogmatic tone.

Do the guidelines foster a climate within the UK's mixed health economy, where public and private healthcare can coexist for the patient's benefit?

Unfortunately not. Although language has evolved within the document to a degree, allowing that multidisciplinary teams need not all operate under one roof, the overall document still fails to reflect that patients have a right to find the best specialist for each step they need to take in transition and that, in many cases, that will involve private practice. The guidelines also fail to reflect the reality that many patients will have transitioned (and even obtained a number of treatments) prior to arriving within an NHS-organised care setting for further steps. The Department of Health has made it clear that it is not appropriate to penalise service users who do this, whether by refusal of care or an insistence on starting from an inappropriate step. These guidelines should similarly underline that instruction very clearly, and outlaw such inflexibility and exclusion.

This can be achieved by making it very clear that care paths need to be constructed around the needs of each individual patient and must be flexible enough to recognise that people enter care at different points, with different needs/goals and with legitimate preferences for who should be involved in their care. This is what differentiates "Guidelines" from "Standards".

Do the guidelines deal with the reality that people can and do manage their own treatment and that this will inevitably include non-prescription hormones and overseas surgeries if they are not being helped by the National Health Service?

Unfortunately not. Ironically the guidelines include a heading for "Harm Reduction", but the text under this is meaningless.

If the result of the application of current care practice is that people feel driven outside of the system, and if the committee fails to acknowledge that reality with adequate advice for mitigating that risk, then the guidelines will be manifestly failing in their aim. Far from preventing harm, it is self-evident that existing practice is actually fostering it. The committee's challenge is to help evolve care in the UK so that people with gender issues can work with responsible practitioners, rather than feeling driven away from them. In particular this requires a careful reappraisal of the concept of "gate keeping" – an old fashioned rod that psychiatrists have the power to remove from their own backs.

This can be resolved by providing clear guidance on steps which all health professionals can take to ensure that, even if patients self-medicate or go abroad for treatment, their health is properly monitored, and proper post-operative care is made available without prejudice.

Are the guidelines compatible with existing legislation?

Unfortunately not. The Mental Capacity Act sets out principles for how health and care practitioners should respond when citizens make far more serious decisions than whether to take sex hormones or undergo surgery on their primary / secondary sex characteristics. Above all, the purposive principles set out at the head of that legislation establish the right of people to take irrevocable steps regardless of whether those involved in their care think they are doing the right thing or not. Seen in this context the continued obsession with requiring patients to have permission to take steps in their gender therapy is wholly anachronistic.

This can be resolved by the committee establishing a client-centred statement of principles at the very head of the document, against which therapeutic recommendations should then be tested and revised.

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