Improving the integration of care for trans adults: ICTA a mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Scientific summary

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Scientific summary

Background

Throughout this report we use the term trans to refer to the diverse people whose gender identities do not correspond to how they were assigned at birth or in early life. The term includes non-binary people.

This research concerns improving the range of NHS health services that trans adults need. These include services intended to support people in making a medical transition, and many other services relevant to wider aspects of physical and mental health and well-being. Not all trans people need to make a medical transition, and transition can take many different paths, including hormone therapy, various types of surgery and other procedures such as hair removal.

At the time of writing, trans people over 17 years of age who need to make a medical transition can seek care at one of the UK's 10 specialist NHS Gender Identity Clinics (GICs), sometimes also known as Gender Identity Services (GIS). In recent years, people encounter very long waiting times before they are seen. Further, issues of co-ordination arise between different aspects of transition-related care and also between transition-related care and general health care.

Because of the barriers to accessing NHS care they need within an acceptable timescale, many trans people in the UK, who can afford to, turn to private providers of hormone therapy and gender-related surgery, both within the UK and abroad. Many also access private provision of procedures that are important to their transition which are not offered by the NHS, such as facial feminisation surgery.

This research has sought to build on initiatives to improve care and its integration, including those involving third-sector lesbian, gay, bisexual, transgender, queer and intersex, plus (LGBTQI+) organisations working in partnership with primary care organisations or with GICs. It has also explored how lessons about the effective integration of trans health care can best be implemented in the context of an NHS that is still coping with the impact and consequences of the coronavirus disease discovered in 2019 (COVID-19) pandemic.

Research questions

The research addresses the following questions:

RQ1. What is the range of models recently used in the UK for providing integrated care for meeting the specific health and well-being needs of trans people?
RQ2. Which factors make services more or less accessible and acceptable to the variety of trans adults who need them?
RQ3. In the different integrated service models, how effective are the different aspects of services and their interaction in meeting the needs of people at different stages of their gender transition and at different ages?
RQ4. What lessons emerge as to how models for providing integrated care can be successfully implemented and further improved in meeting the needs of trans people, within limited resources and continuing constraints resulting from the COVID-19 pandemic?

Research design and methods

The overall research design is a multicomponent and mixed-methods study of current realities and initiatives to improve health care for trans people, leading to the identification of areas for improvement and the production of educational materials. The research took place over a period of 2.5 years, from March 2019 to September 2021, with a 6-month pause during the initial phases of the COVID-19 pandemic, from March to October 2020.

The educational materials stemming from the research take the form of open-access online learning materials. There are separate sets of learning materials for general practitioners (GPs), for mental health professionals and for members of the public. These are available from late 2023.

The research plan involved the extensive involvement of the Improving Care for Trans Adults (ICTA) patient and public involvement (PPI) group, of trans people. They were consulted about the content of the research instruments and participant information sheets, as well as on sampling priorities. They were involved in commenting on the analysis and draft reports throughout the project. The whole project was focused on health inequalities and equality, diversity and inclusion (EDI). The PPI group played an important role in keeping such concerns foregrounded.

The research design consisted of the following main elements:

- **Desk research on current arrangements across the UK** for providing transition-related care and for recognising the distinctive needs of trans people within general health care. This addressed RQ1. It also informed the selection of initiatives to improve care studied.
- **An investigation of factors associated with service use and non-use**. This addressed RQ2. An initial online and paper screening survey was used to gather data on demographics and service use across the UK, and received over 2056 responses, compared to a target of 500. It was promoted widely by the project partners and through LGBTQI+ networks and organisations. Response options included offering to be interviewed, with over 800 people putting themselves forward. Researchers used data on demographics and service use to construct five purposive subsamples, to be invited for individual qualitative interviews. The underlying rationale was to identify groups who were more likely to experience social exclusion or stigma in everyday life, and who were also more likely to experience difficulties in accessing and receiving health care. The experience of these groups would be an indication of the priorities for improving services to make them more inclusive and more effective in addressing health inequalities.

In discussion with the PPI group, the following five groups were identified as priorities for subsamples of trans service users:

1. older people and trans ‘elders’ (e.g. historic transitioners);
2. disabled or chronically ill people;
3. people with a low income or low educational qualifications;
4. people living in rural areas;
5. Black people and people of colour.

This gave rise to 65 interviews, most lasting between 1 and 3 hours, and all carried out online. An initiative to recruit more trans Black people and people of colour (TBPoC) resulted in a further 23 people attending focus groups to cover the same topics as in interviews. All of the interviews and focus groups were audio-recorded and transcribed, and then the transcriptions were anonymised.

Case studies of service experiences and initiatives to improve integration of care. This was to address RQ3 and contribute to answering RQ4. Six case studies were undertaken:

Case Study 1: third-sector gender-outreach workers attached to a GIC
Case Study 2: primary care liaison and psychology services within a GIC
Case Study 3: primary care training and accreditation for trans health care
Case Study 4: the Welsh Gender Service

Case Study 5: trans healthcare experiences in Northern Ireland
Case Study 6: healthcare experiences of trans people with mental health concerns or conditions

Fifty-five staff and 45 service users were interviewed across these case studies. The staff were invited to participate because of their role and experience relevant to the initiative being studied. The service users were invited to participate based on their having participated in the national screening survey of trans adults' healthcare experiences described above and indicated that they both had experience of the services being studied and were willing to be interviewed. Interviews were audio-recorded and transcribed, and then the transcriptions were anonymised.

Thematic analysis was used to analyse accounts of experiences of using services, and accounts of practices in delivering and improving them, the achievements and benefits resulting, and the issues or challenges encountered. This included the analyses and comparison of the six case studies and the five purposive subsamples. A 1-day online workshop attended by all project partners, an Advisory Group of NHS clinicians, third-sector organisations and representatives of trans communities, the PPI group and study steering group members was held in July 2021 to review the emerging findings.

Research findings

The analysis of the purposively sampled qualitative interviews and focus groups with trans service users revealed a significant body of experience of poor care, although there were also more positive experiences. Regardless of the extent to which these experiences represent those of the total UK population of service users, they allowed the identification of factors which undermine person-centred, co-ordinated care, make it difficult for trans people to access care, or which lead to problematic, unacceptable and even harmful experiences of care.

Poor experiences of care included:

- lack of understanding within GP practices of trans identities and respectful treatment of trans people, their health concerns and of the referral routes for transition-related care;
- waiting times of several years for GIC appointments once referrals have been made;
- the extended nature of GIC diagnostic assessments, which can seem to doubt that trans people know their own minds and be experienced as infantilising;
- breakdowns in collaboration between GICs and GP practices over the management of hormone therapy;
- difficulties of receiving psychological support within a GIC system that is experienced as seeing a mental health condition as a reason for delaying gender-affirming treatment;
- general mental health services that appear unwilling to treat trans people apparently simply because they are trans.

When experienced either separately or in combination, these factors can cause iatrogenic harm; that is, harm from the healthcare system itself.

Analysis of the initiatives to improve the integration of care revealed both benefits and unresolved issues.

- Training in trans health care for GPs can lead to trans people feeling welcomed and respected, to less stressful experiences of obtaining a GIC referral and more effective management of hormone therapy, when recommended by a GIC or, if needed prior to this, for harm reduction. However, the impact of training across the staff within a GP practice can be variable, often resulting in an uncertain quality of care.

- Third-sector peer-support workers attached to a gender service can deliver effective practical and emotional support to people awaiting assessment and also play an important role once gender-affirming treatment has begun. However, the long wait to access transition-related care remains the key issue for service users, over which peer workers have little or no influence. They must navigate a stressful 'dual belonging' to trans communities and a gender service. There is also a risk that relatively low-paid trans peer workers are expected to make up for gaps or shortages within the provision of other NHS services, such as mental health services.
- Gender service clinicians who pursue a collaborative approach to assessment for gender-affirming treatment, with the emphasis on clarifying the treatment options, potential benefits and risks, can lead to quicker, less stressful assessment experiences for service users. The practice of clinicians extending assessments for some people raises issues as to the most appropriate criteria to apply here, in order to avoid the danger of subjecting more stigmatised groups to a more extended process.
- Linking regional GP-led hormone therapy clinics to a gender service allows more rapid initiation of hormone therapy following assessment, with GP prescribers able to co-ordinate transition-related and general healthcare needs. There are, however, issues in finding an approach to electronic patient records that fully supports collaboration between a gender service, regional primary care hormone clinics and a trans person's own GP practice. Further problems persist in terms of the willingness of GP practices to take over hormone prescribing even after a period of stabilisation with the regional clinic.
- A psychologist team attached to a gender service, delivering individual and group sessions, can support trans people in working through problematic aspects of social transition or emotional reactions to their medical transition, as well as addressing experiences of isolation. However, tensions may exist between a therapeutic ethos and the role of a gender service in assessing people for access to gender-affirming treatment.

Conclusions

Learning from the national sample of interviews and the case studies of initiatives for improving care has implications for improving care within the established model of trans people accessing transition care through a tertiary GIC service. It also provides insight into how to improve the primary care gender services that were recently established by NHS England (NHSE). The findings suggest that a primary care gender service has great potential for integrating different aspects of transition-related care with each other and with other aspects of health care that a trans person needs.

Key directions for future practice include:

- mandatory trans healthcare standards and training for primary care, as well as for NHS services in general;
- peer support attached to gender services, with peer workers included within the professional team, able to answer questions from the service users on behalf of the service;
- psychological support made available to people using gender services, with the separation of therapeutic support from diagnostic assessment;
- further development of collaborative forms of assessment, including revisiting of the existing diagnostic guidelines in the light of how some areas of questioning can be experienced;
- fundamental reconsideration of the level of funding of trans health care, to address the egregiously long, damaging waiting times that trans people experience. Increased funding should, however, take account of the findings about effective models for delivering person-centred, co-ordinated care;
- greater involvement of trans staff in healthcare delivery, and of representatives of trans communities in the management and shaping of gender services and health services more generally.

Interviews with trans service users further indicated a widespread view that gender services should move, in the longer term, towards an informed consent model (ICM), which would dispense with the requirement for a psychological or psychiatric diagnosis before gender-affirming treatments can be accessed. Research on ICMs in the USA and Australia suggests ICMs have the potential to combine a person-centred focus on the goals of care with medical diligence and the authorisation of treatment.

The findings from our case studies suggest the benefits of care practices consistent with an ICM, as well as issues that would need to be resolved in order to implement one. These potential benefits and issues require further exploration by policy-makers and clinicians, working together with trans communities.

Limitations and further research

Drawing on over 160 qualitative interviews, this research sought to understand the dynamics underlying experiences of poor and better care. These findings are of broader relevance to helping a wide range of health services to improve the care they provide for trans people. However, some contexts of care and needs of particular groups of trans people could not be addressed sufficiently. There were some gaps in representation of people who are subjected to multiple forms of social stigma.

In particular, further research is needed regarding:

- The experiences of trans people at clinics that have adopted ICMs, using a similar level of qualitative detail as we were able to pursue during our ICTA interviews.
- What forms of assessment are appropriate for groups of trans people whom clinicians may regard as having an impaired ability to understand and consent to specific treatments, such as those with mental health conditions, those with learning difficulties, and some autistic people. These are groups who typically experience multiple forms of stigma across many settings, including health care. Research should also seek to explore what kinds of additional social and psychological support should be provided to accompany gender-affirming medical care for such groups.

Study registration

This study is registered as Research Registry, no. 5235.

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