

## Ensuring trans people in Wales receive dignified and inclusive health and social care in later life: The Trans Ageing and Care (TrAC) project, 2016-18

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### About the research

Stonewall estimates that around 1% of the population identify as trans, including people identifying as non-binary, though there are no accurate estimates of the number of trans people in the UK. The [recent UK survey](#) of over 108,000 LGB&T respondents commissioned by the UK Government (2018) indicates that trans respondents (13% of the sample) report lower life-satisfaction scores than the general population. Very little is known about trans people's health and social care needs in later life and not much attention has been given to issues associated with trans ageing. The objective of this two-year study was to better understand what the health and social care needs are of trans adults (50+ years of age) and to examine whether current health and social care services providers and professionals are meeting those needs in Wales.

#### What do we mean by the word 'trans'?

'Trans' is an umbrella term used to describe a range of gender diverse people whose gender identity and/or gender expression differ in some way from the gender assumptions made about them at birth and the biological sex assigned to them. This could include individuals who are seeking to transition from male to female and female to male through gender affirming treatments, but it includes a much wider group of people who may not be seeking gender reassignment. People may identify as transsexual, transgender, transvestite/cross-dressing, gender queer or non-binary amongst many other gender diverse identities.

#### Our aims and methods were:

- To identify the health and social care needs of trans people aged 50+ and their hopes, expectations and concerns about service provision in older age. We conducted interviews with 22 trans adults (50-74 years). Nineteen interviewees were seeking or had sought to transition from the sex assigned to them at birth to either male (4 interviewees) or female (15 interviewees). Two interviewees described themselves as crossdressers and one person as 'gender fluid'. Interviewees described their gender in a wide range of ways.*
- To examine attitudes and perceptions of health and social care professionals towards older trans people. 165 health and social care professionals across Wales completed an online questionnaire. This assessed respondents' knowledge about trans' legal and medical issues in later life, familiarity with trans individuals, levels of support for trans civil rights, and beliefs about gender diversity and trans issues.*
- To produce digital stories and guidelines for health and social care practitioners on supporting older trans people in later life. We held three engagement workshops with trans individuals and health and social care professionals (45 participants in total) across Wales and produced four digital films about older trans people's stories in Wales with film-makers Fox and Owl from <http://mygeneration.com/> My Generation.*

## Key findings

### Practitioners' knowledge and awareness of trans issues

- People responding to the questionnaire were mostly white and female from a wide range of professional roles including GPs, clinicians, mental health staff, social workers, and people in healthcare management and administration. Findings indicate respondents are trans-aware and familiar with trans issues (with the media being the most popular source) and are generally supportive of trans civil rights. There were identified gaps in respondents' knowledge about trans issues in later life (medical and legal knowledge) and a call for more education and training.
- GPs provide a crucial entry point to gender affirming treatments and pathways. Trans interviewees reported very mixed experiences of GPs; in the main GPs were inconsistent allies. Some patients had received highly positive responses to their requests for support with accessing treatments and pathways. Others had received transphobic responses (for example, being told they had to pay for hormone prescriptions because their GP did not agree). The most common theme was GP's lack of knowledge about treatments and pathways.
- Trans patients were reluctant educators in having to find out information for their GPs or having to chase up GPs continually to make referrals. Others reported being misgendered on their medical records and letters of correspondence (for example, use of incorrect gender pronouns) and receiving transphobic responses from healthcare staff, such as district nurses, that suggested they were not 'deserving' of NHS care and treatment. Others had received positive support from their local GP practices pre- and post-surgery.

*'I reported my GP down there, back about a year or so ago, two years ago probably now, because he made an [issue] about the kind of person I am. And then, because I was discussing hormones, and he said, 'Oh I'll have to read your notes if you go and wait outside, while I read your notes'. And then he comes out into the reception area and called me by my male name.'* (Louise, 58)

### The experience of ageing for trans people

- Not all interviewees were seeking to transition or access gender affirming treatments. For those seeking to transition, some had initiated this process earlier in their lives, while the majority had waited to later life-points – sometimes during their working career or, for others, post-retirement.

*I've had no qualifications, and um, even though when I tried, you know, when I came to my 50s and I decided I was going to transition and nothing was going to change my mind, and I was going to do that on my own, and then I thought, yes, and then I'll do a degree, you know* (Richard, 63)

- While most interviewees had not thought much about growing older, their reflections on later life wavered between older age bringing new beginnings or holding concerns about their future. For some, post-gender affirming treatment brought a new 'lease of life'. Others expressed regret about not seeking to transition earlier in life and a sense of running out of time as they were still pursuing gender affirming treatment in their 60s and 70s. Some individuals raised concerns about the unknown health risks associated with taking hormones in later life.

*You see yourself sort of ageing and you think, you know, where will I be in 10 years' time? I don't fear, um, the ageing process, I just feel a bit sad that I'm nearly 70 before, I will be probably 70 by the time I actually finish this process* (Barbara, 69)

- In relation to social care, some interviewees expressed worries about living with dementia and losing control over their appearance, dress and identity if they had to become reliant on social care staff to care for them. Others were worried about fitting into care home environments if they had to move into long-term care and how other staff and residents may treat them.

## Social and family life

- Within their social and familial circles, trans interviewees described the emotional labour of supporting their partners, spouses and other family members to adjust to their gender identity while seeking to manage the sharing of information about their trans status. Sometimes they had lost control of this information and were outed by family members to others as trans.
- In their family homes, local communities and the workplace some interviewees had experienced misgendering, deadnaming (for example, family members referring to them by the name and gender assigned to them at birth) and being outed to others (for example, by colleagues to other team members).

*'I still have huge problems with my family, on non-acceptance and misgendering me, and they will not use my new name, at all. Um, I am still working with them. ... So, I decided I'm not going to hide. I'm going to be out there, I'm going to be very visible.'* (Skogsra, 57)

## Trans people's journeys through the healthcare system

- The majority of interviewees described obstructed journeys through the healthcare system to access the gender identity clinic in London (where Welsh residents are currently referred to). They described the numerous hoops they had to jump through, lack of knowledge about trans needs at ground level and, once referred, the continual delays and cancellations they experienced in waiting for appointments. Individuals seeking gender affirming treatments relied heavily on the knowledge of trans peers (online and off-line) to know what questions to ask and how to navigate successfully through 'the system'. Interviewees noted variations in responses received across health boards with the onus falling on the individual to keep pushing against the system in order to move forward.



Members of the TrAC project team

- Once referred to the Gender Identity Clinic in London some individuals described 'superb care' and high-quality treatment. The majority reported long waiting times and appointment cancellations as the norm. There were often lengthy delays in communication between clinic staff and GPs back home. The distance between interviewees' homes and the clinic was a significant expense for a lot of individuals and their significant others, such as partners.
- A small number of interviewees had sought private treatment or were considering it. They had the financial means to exercise this choice and not everyone had this choice.
- When accessing the clinic, interviewees described the power imbalances and pressures to present the 'right way' as sufficiently feminine or masculine (including sufficiently gendered names) to be able to progress through the system. There were expectations placed on them to meet gendered norms about presentation and dress to be able to further access treatments and surgery.

## Policy implications

Recommendations for achieving change:

The following recommendations are based on our findings and from the engagement workshops with trans citizens and health and social care professionals held across Wales.

- The onus needs to shift from trans individuals educating GPs and other professionals to trans patients and service users being at the heart of good trans-inclusive care and their wishes being recognised and adhered to. GPs need to be informed routinely about pathways and services available to patients. This will enable Wales' newly proposed Interim Gender Identity (GI) Pathway to be more successful and truly trans inclusive.
- Pre- and post-qualifying training and education for health and social care professionals on trans-inclusive care is also essential for ensuring the above new pathway is successful. There is a need for compulsory education and training across Wales in a) primary and secondary care services and b) pre-qualifying professional programmes (for example, medicine, nursing, social work). Involvement of people with lived experience as trans is crucial. Part of this education includes raising awareness that not all trans individuals are seeking gender affirming treatment, but they still may need social support.
- Standards agencies (health and social care) in Wales need to agree and set a benchmark statement on the level of care and support trans and gender diverse individuals can expect from health and social care service providers. For example, by introducing a kitemark or accreditation scheme for ensuring good quality, trans-inclusive care.
- The Welsh Government and NHS Wales need to provide more information for older trans people about GI pathways and NHS-funded treatments available to them, regardless of their age, and make this information accessible in GP practices, libraries, community spaces and other outlets.
- Public bodies need to increase resourcing available for trans groups and networks across Wales in recognition of the power of peer support as important advocates for other trans individuals. Alongside this, health and social care services need to raise wider public awareness about the impact of anti-trans and cisnormative attitudes and actions on the wellbeing of trans citizens across their lifetime. [By cisnormative we mean assumptions made about a person's gender identity based on the sex assigned to them at birth].



## Further information and reading:

Age UK (2018). Factsheet 16: Transgender issues and later life. [www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs16\\_transgender\\_issues\\_and\\_later\\_life\\_fcs.pdf](http://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs16_transgender_issues_and_later_life_fcs.pdf)

Stonewall website: [The truth about Trans.](https://www.stonewall.org.uk/truth-about-trans)  
<https://www.stonewall.org.uk/truth-about-trans>

General Medical Council (no date). Trans healthcare - advice based on GMC guidance. <https://www.gmc-uk.org/ethical-guidance/ethical-hub/trans-healthcare---advice-based-on-gmc-guidance>

To learn more about the new Gender Identity Pathway commencing in Wales 2019, visit <http://www.genderdysphoria.wales.nhs.uk/gipg-updates>

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Visit the project website to view our digital stories and other resources: <http://trans-ageing.swan.ac.uk/>

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