

# Submission on Pharmac's proposal to fund testosterone gel

Te Ngākau Kahukura is a national initiative that works to change systems and environments around rainbow<sup>1</sup> people to make sure they are affirming, welcoming and non-discriminatory. We work with professionals, organisations and wider systems that provide health, social and education support to people in Aotearoa. We provide advice, best practice guidance and learning opportunities to support systems change.

Our vision is an Aotearoa where rainbow people grow up feeling safe, valued and like they belong in the places where they live, learn and access healthcare and social support. As part of this vision, we advocate for wider access to gender-affirming healthcare that is guided by trans people's autonomy and mana motuhake, based on informed consent, depathologised, holistic, developed and led by and with trans communities, and in solidarity with intersex healthcare needs and aspirations<sup>2</sup>.

Thank you for the opportunity to comment on these proposals. We would like to note that our comments relate to ensuring that rainbow people have equitable access to medicines. Our backgrounds are as public health advocates, not as prescribing doctors.

## **Testosterone gel**

We support the proposal to fully fund testosterone gel without restrictions. We have no comment to make about the proposal to award Principal Supply Status to Testogel.

As is noted in the proposal, one of the current uses of testosterone medicines is as part of gender-affirming healthcare – that is, healthcare that people access to affirm their gender and increase congruence between their body and their gender or sense of self<sup>3</sup>.

Best-practice gender-affirming healthcare does not prescribe two standard treatment pathways. Each trans person has their own healthcare needs and transition goals, and a range of publically-funded healthcare options are needed to respond to these.

### Testosterone gel should be available as an option for gender-affirming hormone therapy

Internationally, gel is recognised as a method of administering testosterone for gender-affirming hormone therapy<sup>4</sup>. It is a commonly-used option in other countries, including in the US<sup>5,6</sup> and Australia<sup>7</sup>. In an informal community-based survey of gender-affirming testosterone use led by a US-based artist, testosterone gel was the

<sup>&</sup>lt;sup>1</sup> We use *rainbow* as an umbrella term to describe people whose sexual orientation, gender identity, gender expression and/or sex characteristics differ from majority, binary norms. This include people who identify with terms like takatāpui, lesbian, gay, bisexual, intersex, transgender, queer, non-binary or fa'afafine, as well as people who don't use specific words for their identity, people whose identity changes over time, and people who are in the process of understanding their own identity and may not have 'come out' to themselves or others. <sup>2</sup> Te Ngākau Kahukura. (2023). *Key topics: Gender-affirming healthcare.* Retrieved from: https://www.tengakaukahukura.nz/gender-affirming-healthcare

<sup>&</sup>lt;sup>3</sup> Professional Association for Transgender Health Aotearoa. (2020). *Transgender Health: Briefing to the Incoming Minister of Health 2020*. Retrieved from: https://patha.nz/2020-briefing

<sup>&</sup>lt;sup>4</sup> Coleman, E., et. al. (2022). Standards of care for the health of transgender and gender diverse people, version 8. International Journal of Transgender Health, 23(sup1), S1-S259.

<sup>&</sup>lt;sup>5</sup> Mayo Clinic. (2023). Masculinizing hormone therapy. Retrieved from: https://www.mayoclinic.org/tests-procedures/masculinizing-hormone-therapy/about/pac-20385099

<sup>&</sup>lt;sup>6</sup> FOLX Health. (2022). *Testosterone Gel for Gender-affirming Hormone Therapy: What, Where, and How.* Retrieved from: https://folxhealth.com/library/testosterone-gel-hrt-what-where-how

<sup>&</sup>lt;sup>7</sup> Nolan, B. J., Zwickl, S., Wong, A. F., Locke, P., Simpson, S., Li, L., Zajac, J. D., & Cheung, A. S. (2022). Testosterone concentrations and prescription patterns of 1% testosterone gel in transgender and gender diverse individuals. *Therapeutic Advances in Endocrinology and Metabolism*, *13*, 20420188221083512.

second most common method of administration among the survey's 389 participants<sup>8</sup>. Research suggests that there is no difference in safety or efficacy in testosterone gel compared with the injectable testosterone that is most commonly used in New Zealand<sup>9</sup>.

Gels may be preferred over other testosterone administration methods because applying gel may be a more tolerable experience than injections (which do not suit those with a fear of needles<sup>10,11</sup>), or patches (which cause skin irritation for some<sup>12</sup>). They may also be preferred by people who prefer to take a lower dose than those typically administered through other methods, have more day-to-day control over dosing<sup>13</sup>, and see body changes potentially happen over a longer time period<sup>14,15</sup>. For these reasons, gels may be used by preferred by some people who are non-binary<sup>16</sup>, or have gender embodiment goals that are different to the typical binary patterns that have historically been associated with gender-affirming healthcare.

## Funding testosterone gel will support choice, autonomy and health equity

The proposal to fully fund testosterone gel will mean that trans people are more able to access testosterone in a form that works for them through an 'informed consent' process, that is, by making their own supported decision with a prescribing doctor, given clear information about the known risks and benefits<sup>17</sup>. Where a trans person is working with a doctor who supports this informed consent approach, they will have more ready access to a medication that may better suit their gender and embodiment goals.

The cost of medications is an important health equity issue for trans people, who on average have significantly lower disposable income than cisgender people<sup>18</sup>. Two large local surveys have validated that cost of hormone medications is a major barrier to trans people accessing the gender-affirming healthcare they need. Among *Counting Ourselves* participants (which surveyed trans and non-binary people aged 14 to 83), 28% of those who had an unmet need for gender-affirming hormones indicated that they could not afford to access these. In the *Identify* survey of rainbow young people and allies (aged 14-26), 41% of those who wanted but could not access gender–affirming medications indicated that one of the reasons was that accessing medications cost too much.

The current cost of testosterone gel is prohibitive for many (for example, one local transdermal cream product currently costs around \$150 for a less than two month supply<sup>19</sup>.) Fully funding testosterone gel would broaden access to essential medicine for many transgender people. While injectable and patch-based testosterone medications are currently funded, this proposal would provide access to a medication that may better suit many people's gender and embodiment goals.

In addition to the direct cost of prescriptions, the current pharmaceutical funding situation creates barriers to trans people accessing gel. Current medical guidelines do not acknowledge testosterone gel because it is not PHARMAC-funded<sup>20</sup>. Doctors will not typically offer non-funded medications as a first option, and may be reluctant to

<sup>&</sup>lt;sup>8</sup> Newman, R. Y. (2022). *The Testosterone Survey Zine: A Community Health Art Project*. Retrieved from:

https://renayehuda.gumroad.com/I/TestosteroneSurveyZine

<sup>&</sup>lt;sup>9</sup> Pelusi, C., et al. (2014). Effects of three different testosterone formulations in female-to-male transsexual persons. The journal of sexual medicine, 11(12), 3002-3011.

<sup>&</sup>lt;sup>10</sup> Newman, 2022, as above.

<sup>&</sup>lt;sup>11</sup> FOLX Health, 2022, as above.

<sup>&</sup>lt;sup>12</sup> Gooren, L. J., & Bunck, M. C. (2003). Transdermal testosterone delivery: testosterone patch and gel. *World Journal of Urology, 21*, 316-319.

<sup>&</sup>lt;sup>13</sup> Newman, 2022, as above.

<sup>&</sup>lt;sup>14</sup> Nolan et al, 2022, as above.

<sup>&</sup>lt;sup>15</sup> FOLX Health, 2022, as above.

<sup>&</sup>lt;sup>16</sup> Nolan et al, 2022, as above.

<sup>&</sup>lt;sup>17</sup> Oliphant, J., Veale, J., Macdonald, J., Carroll, R., Johnson, R., Harte, M., Stephenson, C. ,& Bullock, J. (2018). *Guidelines for gender affirming healthcare for gender diverse and transgender children, young people and adults in Aotearoa New Zealand*. Transgender Health Research Lab, University of Waikato, 2018.

<sup>&</sup>lt;sup>18</sup> Stats NZ. (2022). *LGBT+ population of Aotearoa: Year ended June 2021*. Retrieved from: https://www.stats.govt.nz/information-releases/lgbt-plus-population-of-aotearoa-year-ended-june-2021/

 <sup>&</sup>lt;sup>19</sup> Bays Health Pharmacy. (2023). AndroFeme/Androforte. Retrieved from: https://www.bayshealthpharmacy.co.nz/lawley-pharmaceuticals
<sup>20</sup> Carroll, R., Nicholls, R., Carroll, R. W., Bullock, J. Reid, D., Shields, J., Johnson, R., Oliphant, J., McElrea, E., Whitfield, P., and Veale, J. (2023).
*Primary Care Gender Affirming Hormone Therapy Initiation Guidelines: Aotearoa New Zealand guidelines for commencing GAHT for adults in*

prescribe options they are less familiar with. This means that trans people seeking to use testosterone gel often need to self-advocate, and may face additional appointments or waiting time while their doctor learns about the benefits and risks of this formulation.

#### Funding testosterone gel should be supplemented with supporting trans-led community education

Your proposal asks for comments on what implementation activities would be required to support the funding of testosterone gel, for patients (including Māori, Pacific peoples, those using testosterone gel as part of gender affirming hormone therapy and other populations experiencing health disparities), doctors and pharmacists.

Given that testosterone gel has not been widely used in New Zealand as part of gender-affirming hormone therapy, it would be useful to produce an information resource specifically for transgender and non-binary patients and for doctors and nurses who prescribe gender-affirming hormone therapy. This resource could outline the differences from other testosterone formulations, and outline practical considerations for using testosterone gel (for example, the most effective methods of application, how to manage dosages, and caution about physical contact with other people or animals while gel is drying). This could be provided along with existing information about the effects and risks of testosterone therapies (as are available for example in the recently-published primary care guidelines<sup>21</sup>), and much of the information could be transferrable from the Testogel New Zealand Data Sheet<sup>22</sup> (which is currently written with hypogonadal cisgender men in mind).

We suggest that this resource be co-developed with trans communities, and supported by community-based education (for example, website content and online video) to introduce trans communities to the availability of this medication and advise how to access it.

Further, we suggest that this resource could be incorporated into the national primary care workforce training currently in development<sup>23</sup>, so that primary care providers are more knowledgeable and confident about prescribing testosterone gel.

primary care. Retrieved from University of Otago: https://blogs.otago.ac.nz/rainbow/files/2023/03/Primary-Care-GAHT-Guidelines\_Web\_29-Mar.pdf

<sup>&</sup>lt;sup>21</sup> Carroll et al, 2023, as above

<sup>&</sup>lt;sup>22</sup> New Zealand Data Sheet: Testogel. Retrieved from MedSafe https://www.medsafe.govt.nz/profs/datasheet/t/testogelGel.pdf

<sup>&</sup>lt;sup>23</sup> Verrall, A. (2022). *Rainbow health gets funding boost*. Retrieved from: https://www.beehive.govt.nz/release/rainbow-health-gets-funding-boost