# Title: Supplementary Appendix

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## Web Appendix 1: Shifting terminologies; indigenous identities

Transgender people identify in different ways. For example a transgender man may identify simply as a 'man', a 'trans man', a 'man of transgender experience', or 'a man with a transgender history'. Some transgender people prefer the term ‘transsexual’ rather than ‘transgender’. Others, particularly those who do not identify as being exclusively of one gender, prefer terms such as a 'non-binary', 'gender queer', 'bigender', 'pangender', 'agender' and 'neutrois'. Where their languages employ binary pronouns (such as 'he' and 'she' in English), they prefer that others avoid such pronouns, using non-binary alternatives (such as 'they' in English).

Historically, some clinicians and researchers in the field of gender identity have focused on birth-assigned sex when referring to transgender people. This has led, for example, to transgender women being described as ‘male transsexuals’, and transgender women attracted to men as a ‘homosexual male transsexuals’. Transgender people inevitably find these terms offensive denials of their identities. To their relief, as well as that of many contemporary clinicians and researchers, this practice appears to be abating.

The above terms originate from North America and Western Europe. Across much of the world many transgender people identify (and are identified by others) by way of more indigenous identity labels; sometimes traditional and carrying cultural and religious meaning, sometimes more contemporary. Asia and the Pacific region are rich in such categories. The 2012 UNDP 'Lost in Transition' report provides an illustrative list of over 40 identity terms for transgender women used in 20 countries across the region.[1] Some of the terms enjoy a national usage. Others are more regional. Some terms confer more respect and dignity than others.

Indigenous labels such as 'kathoey' (Thailand) and 'bakla' (Philippines) often reflect a traditional perspective in which sexuality (orientation and behaviour) and gender (identity and expression) were somewhat conflated in the cultures concerned. Some labels are echoes of cultures in which diversity was somewhat better accepted than in much of modern Western history, with some cultures displaying a 'gender pluralism' in which those we would nowadays call transgender people had important roles to play.[2] Modernising forces associated with colonisation, christianisation, industrialization, urbanization, and globalization have contributed to a weakening of these cultures, though vestiges of gender pluralism still remain in parts of the world, for example in South and Southeast Asia. For more on this see the 'Lost in Transition' report.

The indigenous identity terms available to transgender people are often imprecise, embracing other groups too. Some of the terms employed for transgender women are also used for effeminate and same-sex attracted men. Such broad terms are often ill-suited to the goals of transgender community activism (as well as to the task of identifying specific transgender health needs). Community groups are therefore developing their own identity vocabularies, with terms like 'transpinay' (= 'Filipina transgender woman') and 'transpinoy' (= 'Filipino transgender man'), or (for Thailand) 'khon (sao, phuchai) khaam phet' (= 'a person (woman, man) who has crossed sex'), 'khon (sao, phuchai) plaeng phet' (= 'a person (woman, man) who has changed sex'). Identity labels that convey both dignity and precision may be an important step for transgender people working to achieve recognition as a distinct community with specific needs and interests.

## Web Appendix 2: Estimating transgender populations from clinic records and other data bases

Zucker and Lawrence examined 25 transgender prevalence studies from 12 countries (USA, Canada, Denmark, Sweden, Germany, Netherlands, Belgium, Poland, Spain, Singapore, Australia and various parts of the UK).[3] The studies covered the period 1968 to 2007. The authors reported prevalence data from 12 of those studies (in 8 countries). The rates ranged from 1:2,900 and 1:8,300 (Singapore figures for transgender women and men respectively) to 1:100,000 and 1:400,000 (corresponding figures for the USA, albeit that these were from the oldest study they looked at). Zucker and Lawrence also reviewed incidence as reported in 8 studies (from 6 countries). The figures ranged from 0.15 referrals (a 1971 Swedish study) to 0.73 referrals (a 2006 Spanish study) per 100,000 persons in the general population per year. Zucker and Lawrence also presented sex ratio data, in this case from all 25 studies reviewed. The ratio (birth-assigned males versus birth-assigned females) ranged from 6.1:1 to 1:3.4. In fact the vast majority of studies showed a sex ratio in favour of birth-assigned males, with only two studies, both from Poland, showing a ratio in favour of birth-assigned females. The mean (unweighted) ratio was 2.2:1, implying a prevalence for transgender women possibly almost double of that for transgender men.

It remains unclear why so many studies derived from clinics report greater numbers of transgender women than transgender men. One possibility is that the numbers reflect perceptions (by prospective patients) of better outcomes associated with genital surgery for transgender women (as compared with transgender men), and consequently the latter's greater reluctance to seek it.

Arcelus et al have recently conducted a systematic review of research in this area that makes use of 12 studies providing prevalence data (or supplying information enabling it to be calculated).[4] The data came from different sources, but in every case concerned individuals who were intending to undergo, were undergoing, or had undergone gender affirming healthcare. While Arcelus et al included some of the studies reviewed by Zucker and Lawrence, others from that study were omitted on the grounds that they did not meet the inclusion criteria. Moreover, this more recent review was able to make use of several studies (in Belgium, Serbia, Sweden and Ireland) not available to the earlier reviewers. Arcelus et al reported prevalence figures of 4.6 transgender people in every 100,000 individuals (1 in every 21739 people), with 6.8 transgender women in every 100,000 birth-assigned males (1 in every 14706), and 2.6 transgender men in every 1000,000 birth-assigned females (1 in every 38461).

It should be noted that one recent study from Japan, included in neither of the reviews mentioned here, reported (like the two earlier Polish studies) a sex ratio in favour of transgender men, with estimated prevalence (again based on clinic data) of 3.97 transgender women and 8.20 transgender men per 100,000 people (1 in every 25,190 and 12,195 respectively); a ratio of 1:2.1.[5]

Clinic studies indicate increasing referral figures. A Swedish study by Djehne et al[6] (one of the studies reviewed by Arcelus et al) has reported a massive increase in applications for genital surgery (a procedure that has historically enabled legal gender recognition in that country) from 1960 to 2010, with applications rising for transgender women from 0.23 (mean 1972-80) to 0.73 (mean 2001-10) per year per 100,000 in the general population, and corresponding mean figures of 0.16 to 0.42 for transgender men. Interestingly, rates of regret regarding transition fell over the period examined. One may speculate that the rising referrals and falling regret rates may both be linked to improved experiences of surgery.

Growing numbers are evident elsewhere. Reed et al (2009) for GIRES (the Gender Identity Research and Education Society) report that in the UK there has been, around every six years, a doubling of the numbers of transgender people accessing UK gender clinics.[7] In a 2011 update GIRES suggested the upward trend was accelerating.[8].

The upward trend in referrals seems to apply to child and adolescent clinics too. Zucker et al (2008) and de Vries and Cohen-Kettenis (2012) indicated, over periods of several decades, a four to fivefold rise in referrals to their child and adolescent gender clinics in Canada and the Netherlands respectively.[9,10] In all three cases (the Swedish adult study, and the Canadian and Dutch child and adolescent research) the bulk of the increase occurred around 2000 and soon after.

Reasons for the rising figures are unclear, but may reflect in adults a growing willingness to live authentically (this willingness linked to more favourable social attitudes) and to approach clinics where they experience a need for gender affirming healthcare (this willingness perhaps linked to perceptions of improving healthcare).

A study by Veale in New Zealand, drew on a different kind of data base.[11] It made use of the opportunities in that country for transgender people who have not undergone gender affirming surgery to remove the sex marker on their passport, replacing it with an 'X' (conditional on evidence of lived experience congruent with their gender identity and, if appropriate, a name change). It should be noted that at the time the Veale study was being conducted the 'M' or 'F' option was only available in New Zealand to those transgender people who had undergone genital surgery. The study reported a prevalence estimate of 1:3639 for transgender women and 1:22714 for transgender men, noting that these figures should be regarded as underestimates for several reasons. For example transgender people who had undergone genital surgery had other gender options open to them, and may not have been represented in this figure. Alternatively, transgender people who had not undergone surgery might have declined the opportunity to have X on their passport, either because they did not want to be identified as a transgender person, or indeed because they did not identify as 'X'.

## Web Appendix 3: Estimating populations by way of population studies

Conron and co-workers asked participants in a Massachusetts USA general population sample the following question: "Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?" The researchers then supplied, for any participants expressing confusion, an explanation of the term 'transgender'. One in 200 people in their sample (0.5%) identified as transgender.[12] Clark et al, employed a similar methodology in a study of high school students in New Zealand. They asked students "Do you think you are transgender? This is a girl who feels like she should have been a boy, or a boy who feel like he should have been a girl." They then supplied examples of transgender identities, including some which are indigenous to that part of Oceania. They got an affirmative answer from 1.2% of the participants.[13] A further 2.5 % were unsure. Among the transgenderidentified students 27.3% reported that they had wondered about being transgender in early childhood (before the age of eight years).

Surveys asking people if they identify as transgender may risk underestimating of the size of the transgender population. Many gender incongruent people may be uncomfortable or unwilling to identify as transgender. In Western societies they may prefer to identify as 'bigender' (two genders), 'agender' (no gender), 'gender queer' or some other identity label. In others they may identify in other ways: for example 'kathoey' (Thailand), 'bakla' (Philippines), 'waria' (Indonesia) or 'hijra' (India). Regardless of where the research is being conducted gender incongruent people may simply identify as men or women.

For these reasons a two-question format has been developed for enabling a more accurate assessment of the size of the transgender population.[14] In this approach participants first of all indicate their gender identity (with as many options provided as is appropriate to the culture concerned). They then indicate the sex they were assigned at birth. Any discrepancy in the way the two questions are answered indicates a gender incongruence. Glen and Hurrell adapted this

method in a UK general population sample, asking participants first how they were described at birth (‘male’, ‘female’, ‘intersex’, 'prefer not to say') and then asking which word best described how they thought of themselves (‘male’, ‘female’ or ‘in another way').[15]

As indicated by the answers to these two questions, 0.5% indicated a gender incongruence; birth-assigned females identifying as male or in another way, and birth-assigned males identifying as female or in another way.

In passing we should note that Glen and Hurrell used the biological terms ‘male’ and ‘female’ in each question (rather than 'man' and 'woman'). Consequently, some transgender respondents may have referred to sex rather than gender in each question, thereby neglecting to reveal their gender incongruence. If so, Glen and Hurrell's 0.5% figure may actually underestimate the number of gender incongruent individuals. Support for this idea comes from a later question in the survey, as follows: 'Have you gone through any part of a process (including thoughts or actions) to change from the sex you were described at birth to the gender you identify with, or do you intend to? (This could include changing your name, wearing different clothes, taking hormones or having gender reassignment surgery).' A total of 1.0% of respondents answered yes to this question, indicating they had taken steps towards social or medical transition, or were considering doing so.

Two recent studies have allowed individuals the opportunity to identify themselves on a gender spectrum rather than in terms of two gender categories. In a representative Dutch population sample Kuyper and Wijsen examined participants’ degree of identification first as a man, then as a woman, each on a five point scale (from ‘not at all’ to ‘completely’).[16] Those more strongly identifying with the other gender were categorized as gender incongruent. They constituted 1.1 % of birthassigned males and 0.8 % of birth-assigned females. A Belgian study using a similar methodology reports figures only slightly lower; 0.7% of birth-assigned males and 0.6% of birth-assigned females.[17] The Dutch and Belgian studies also identified participants who were gender ambivalent (those expressing equal identification with each gender). In the Netherlands these constituted a further 4.6 % of birth-assigned males and 3.2 % of birth-assigned females. In Belgium the corresponding figures were 2.2% and 1.9%.

Kuyper and Wijsen note that, among individuals reporting incongruent identity, only a minority also reported a dislike for their sex anatomy, and, among these, even fewer indicated they wanted medical help to alter their bodies. That so few gender incongruent people express a desire for hormones and surgery perhaps goes some way to explaining the great discrepancies in prevalence figures when population-based and clinic-based samples are compared. It is tempting to assume that those not seeking hormones or surgery do not have health needs. In fact their experiences of stigma might mean they have needs for counselling and mental healthcare support as substantial as do those who undergo medical transition.

The population-based research reviewed here is from high-income societies. There are so far no corresponding studies from low- and middle-income countries. Still, it is worth noting population estimates for transgender communities in Asia that imply prevalences similar to those quoted above. Teh

estimates there to be 10-20,000 mak'nyah in Malaysia.[18] With around 10.7 million birth-assigned males aged 15 and above in the country,[19] this translates to a prevalence rate of around 0.1-0.2%.

In India, during the 2011 national census, a total of 490,000 transgender people chose to identify themselves publicly as 'third gender', the first time they had been given an opportunity to do so in an exercise of this sort.[20] Though large, the figure likely represents an underestimate of the actual numbers, the census preceding legislative and administrative decisions having the intention of reducing stigma for this highly marginalised group.

Sitipati (2009) earlier estimated that nationwide there are 1 million hijra (a major transgender community in India).[21] This would yield a prevalence rate of around 0.2% among birth-assigned males aged 15 and above. Curran (2009) estimates 400,000 hijra in Pakistan,[22] yielding a rate of around 0.6%. Finally, a simple observational study by Winter (2002) yielded a prevalence figure of around 0.6% for transgender people in Thailand.[23]

## Web Appendix 4: Reports detailing the effects of stigma upon transgender people's lives.

In recent years transgender stigma and its effects have been the focus of many recent regional, sub-regional and country reports. They cover North America,[24,25,26] Central and South America,[27,28,29] Europe,[30,31,32,33,34,35,36,37,38,39,40,41] Africa,[42,43,44,45,46] the Middle East,[47,48] and Asia and the Pacific.[49,50,51,52,53,54,55,56,57]

Within Asia and the Pacific there are a number of reports focusing on specific subregions and countries therein. Among sub-regions covered are: Central Asia,[58,59,60] South Asia,[61,62,63,64,65,66] South East Asia,[67,68,69,70,71,72] East Asia,[73,74,75,76,77] Australasia,[78,79,80,81,82] and Oceania.[83,84,85,86]

Many of these reports are available on the web.

While some regions are well researched, the samples are often weighted towards young transgender women living in cities. Moreover, there remain regions in which relatively little appears known about transgender people, their lived experiences or their healthcare needs. Among them is the Caribbean, and much of Africa and the Middle East.

## Web Appendix 5: Transgender people and HIV: the global pandemic

For much of the last 35 years of the response to the HIV/AIDS challenge, transgender people have found themselves largely invisibilised, with transgender women often conflated with MSM, and transgender men ignored altogether. Information on HIV prevalence has therefore been patchy at best. The available research, often localized and small-scale, was in the first years of this century indicating alarming HIV prevalence rates, revealing a pandemic among communities of transgender women worldwide, in Asia (for example 34%, reported in 2008 Jakarta);[87] South America (for example 37% in 2011 Buenos

Aires);[88] Africa (for example 57% in 2011 Cape Town);[89] and North America (for example 28% averaged across a review of US studies published in 2008).[90]

A recent meta analytic review published in Lancet Infectious Diseases revealed the scale of the problem for transgender women. The review incorporated 33 studies spread across fifteen countries and five continents, published over an eleven year period, and involving 11066 transgender women. The reviewers arrived at a pooled HIV prevalence estimate of around 19%, a figure around 49 times greater than that for adults of reproductive age in the countries involved. Rates were similar for low to middle income countries (around 18%) and high-income countries (around 22%). So were the odds ratios; 50 times greater than the underlying rate in low to middle income countries, around 46 in the high income countries).[91]

As may be expected, HIV infection is just part of the sexual health challenge facing transgender women. Scattered epidemiological research reveals high rates for other STIs. See for example studies in Pakistan,[92] Thailand,[93] and Indonesia.[94]

High HIV and other STI prevalence figures in transgender women appear related to stigma and consequent economic marginalisation and poverty, and high risk sexual practices. Involvement in sex work, often as a mean to survive, is a key factor, with transgender women involved in sex work showing higher prevalence rates than those not involved in sex work.[95]

Across the low and middle income countries of the global south and east, where healthcare services (including sexual healthcare) are often under-resourced, the situation justifies very great concern.[96] Internationally there are no statistics on the number of transgender people who have died of AIDS-related illness, or on what proportion of overall AIDS-related deaths are attributable to transgender people. Research on transgender men, including those involved in sex work, is lacking.

Recently steps have been taken to ensure that transgender people receive the sort of HIV/AIDS services they need. WHO has published consolidated guidelines for HIV prevention, diagnosis, treatment and care for key populations, including transgender people.[97] The United Nations Development Program (UNDP) and the International Reference Group for Transgender People (IRGT) have in the last months published the TRANSIT Guidelines, specifically to guide services for transgender people.[98]

## Web Appendix 6: Transgender people organising for health and rights

Over recent years transgender communities worldwide have increasingly organised themselves for social action, often working within broader LGBT communities to press for rights (including better access to health), but more recently forming their own groups exclusively concerned with transgender issues. Regional organisations include the Latin American and Caribbean Network of Transgender People (REDLACTRANS, established in 2004),[99] Transgender-Europe (TGEU, 2005),[100] Asia-Pacific Transgender Network (APTN, 2009),[101]

and Gender Dynamix (2005)[102] and Transgender and Intersex Africa (TIA, 2012),[103] both of which operate throughout Southern and East Africa.

At a more global level there are a number of community-based groups working for transgender rights and health. The International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) maintains a focus on transgender health and rights through its trans-secretariat (established 2006).[104] International Campaign Stop Trans Pathologisation (STP; established 2009)[105] works specifically for diagnostic reform. The Global Forum for MSM AND HIV (MSMGF) convenes an International Reference Group on Trans* and Gender Variant and HIV/AIDS Issues (IRGT), established in 2011.[106] However, Global Action for Trans* Equality (GATE; established 2010)[107] is perhaps the broadest and most active transgender-led organization working globally for transgender health and rights.

As for local and national groups, there are far too many to list here. For the UK alone the TranzWiki site developed by the Gender Identity Research and Education Society (GIRES) lists nearly 300 groups offering support to transgender people and their families, with around 60 of them in London.[108] ILGA and MSMGF maintain international directories of organisations and associations on their respective websites.[109]

At whatever level groups work in transgender rights and health, it appears that they tend to encounter problems attracting funding from donors, especially where the groups are led by the members of the transgender community.[110] Despite such difficulties, many community-led organisations manage to work effectively for transgender health and rights.[111]

## Web Appendix 7: Diagnoses in transition.

The current version of the World Health Organisation (WHO) diagnostic manual (ICD-10) describes *transsexualism* as '(A) desire to live and be accepted as a member of the opposite sex, usually accompanied by a sense of discomfort with, or inappropriateness of, one's anatomic sex and a wish to have hormonal treatment and surgery to make one's body as congruent as possible with the preferred sex'.[112] The diagnosis is one of a large number of diagnoses in a section called 'Disorders of Adult Personality and Behaviour', located within Chapter 5 (Mental and Behavioural Disorders).

The current American Psychiatric Association manual (DSM-5, published in 2013), has replaced the earlier DSM-IV diagnosis of *gender identity disorder* with *gender dysphoria,* focusing the diagnostic process upon the patients' distress and discomfort regarding their gender incongruence; the distress and discomfort that may prompt a transgender person to seek healthcare. For an adult a diagnosis of *gender dysphoria* necessitates '(a) marked incongruence between one's experienced/expressed gender and assigned gender, of at least six months duration,' as demonstrated by two of six criteria. In summary, these criteria focus on a felt incongruence between one's gender identity and sex characteristics (Criterion A1), a desire for bodily changes related to those characteristics (A2 and A3), a desire to live as and be treated as a member of another gender (A4 and A5), and a conviction that one has certain psychological and behavioural

characteristics associated with another gender (A6) (APA, p452). The gender incongruence must be accompanied by 'clinically significant distress or impairment in social, occupational, or other important areas of functioning' (Criterion B) (APA, p453). The name change from *gender identity disorder* (DSM-IV) to *gender dysphoria* (DSM-5) reflects the movement away from psycho-pathologising transgender people's identities, and towards a focus on the dysphoria that, for many transgender people, accompanies gender incongruence.

A "post-transition" specifier (included on the grounds that there may be a need for life-long hormonal treatment) arguably undermines the transgender person's possibility of exit from a mental disorder diagnosis.[113] Note also that a person's desire for medical care is listed as an indicator of the mental disorder.

More transformative moves are currently under way at WHO, where work proceeds on the next ICD revision (ICD-11 currently slated for approval in 2018). A key WHO Working Group on Sexual Disorders and Sexual Health has proposed reframing the old *transsexualism* and *gender identity disorder of childhood* diagnoses as *gender incongruence;* one diagnosis for adolescents and adults (GIAA), and one for pre-pubertal children (GIC). It has also proposed amended diagnostic criteria. The WHO Secretariat has now incorporated the recommendations into a Beta draft, and is field testing the diagnoses. At time of writing the diagnosis for GIAA is described in the ICD-11 beta draft as follows:

'Gender Incongruence of Adolescence and Adulthood is characterized by a marked and persistent incongruence between an individual's experienced gender and the assigned sex, generally including dislike or discomfort with primary and secondary sex characteristics of the assigned sex and a strong desire to have the primary or secondary sex characteristics of the experienced gender. The diagnosis cannot be assigned prior to the onset of puberty. Gender Incongruence of Adolescence and Adulthood often leads to a desire to 'transition', in order to live and be accepted as a person of the experienced gender. Establishing congruence may include hormonal treatment, surgery or other health care services to make the individual's body align, as much as desired and to the extent possible, with the experienced gender.'[114]

The WHO Working Group proposal (incorporated in WHO's Beta draft) is that these diagnoses should be located in a chapter called 'Conditions Related to Sexual Health'. The proposed relocation arises out of a growing understanding of the nature of the transgender experience, the healthcare needs of transgender people, and the adverse effects of psychopathologisation.[115] It takes into account recent scientific research, and evidence presented by professional associations like the World Professional Association for Transgender Health (WPATH), as well as advocacy organisations like Global Action for Trans* Equality (GATE) and the International Campaign Stop Trans Pathologisation (STP).

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