



# Im/moral healthcare: HIV and universal health coverage in Indonesia

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Abstract: In 2014, Indonesia reinvigorated its commitment to the provision of a universal health care system by introducing the National Health Insurance Program (Jaminan Kesehatan Nasional, JKN), with the aim of increasing access to health care for all sectors of society. A key question that emerges in the current climate is: how can Indonesia ensure people can access HIV health care? This question is critically important given Indonesia is on the verge of passing a law criminalising all sex outside of marriage. If passed, anyone presenting with HIV will be suspected ipso facto of involvement in criminal activity (e.g. them or their partner having sex outside of marriage and/or using intravenous drugs). In this environment, preventing transmission of HIV from mother to child becomes more difficult. In exploring these issues, we argue that, in a time of populist morality, Indonesia must give significant attention to how universal health coverage can prevent HIV transmission, particularly from mother to child. We offer three key strategies for Indonesia to implement in this regard: removing health care provision from a moral framework; de-idealising the category of woman; and repositioning shame and stigma around HIV. DOI: 10.1080/26410397.2020.1785377

**Keywords:** Indonesia, universal health coverage, HIV, Islam, sexual and reproductive health, populist morality, kinships of shame

#### Introduction

Indonesia's renewed commitment to providing all citizens with universal health coverage (UHC) is a laudable goal. With high health inequality, UHC has the potential to radically transform the well-being of not only Indonesians living in extreme poverty, but also those who go into debt to pay for health care. Indonesia faces significant challenges, though, in delivering UHC, particularly given its population size and geographic spread. With the scheme currently running in deficit, and more people expected to pay for services, it is timely to reflect on how UHC will assist people living with HIV, especially women of reproductive age. This reflection is particularly apt given moves in Indonesia to criminalise sex outside of marriage.

In 2018, there were an estimated 220,000 women living with HIV in Indonesia, and most of these women were of reproductive age (15–49 years). The HIV prevalence rate among women of reproductive age was 0.3%. Estimates suggest that in 2013, around 20,000 Indonesian women living

with HIV were pregnant.<sup>2</sup> Sadly, in 2016, just over 10% of these pregnant women accessed prevention of mother to child transmission (PMTCT) services.<sup>3</sup> PMTCT services, if started early in the pregnancy and continued through birth and subsequent months, can reduce the risk of a baby contracting HIV from 50% down to 5% or less.<sup>4</sup> Of all babies who contract HIV and who do not receive antiretroviral treatment, half will die before the age of two.<sup>4</sup> New HIV infections among women of reproductive age, who are outside key populations (e.g. not injecting drugs or working in the sex industry), are growing in Indonesia, in part because this group is erroneously considered not at risk of contracting HIV. Consideration is thus needed for how UHC will both prevent HIV transmission, especially from mother to child, and provide HIV health care more generally across Indonesia.

In this article, we use primary and secondary data to explore two seemingly irreconcilable developments in Indonesia. The first is Indonesian's endorsement of UHC. The second is the populist

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morality movement, which is making it increasingly dangerous, indeed in some places a criminal offence, to have sex outside of marriage, among other things. When sexuality is penalised, people can no longer safely access reproductive health care. Inability to access health care is particularly distressing for pregnant women living with HIV.

The article is divided into eight substantive sections, with an additional introduction and conclusion. We initially outline methods used to collect data, and then provide general discussion around UHC before introducing the country of focus, Indonesia, and examining the populist morality movement impacting sexual and reproductive health in the nation. Next, we explore the introduction and implementation of UHC in Indonesia. We then address HIV in the nation, with specific examination of the transmission of HIV from mother to child. In concluding we offer three strategies for Indonesia to implement in order to better provide HIV health care: remove HIV health care provision from a moral framework: de-idealise the category of "woman"; and reposition shame and stigma around HIV.

#### Materials and methods

The data collected for this article stem from two main sources. The first source is a literature review of extant material, in both English and Bahasa Indonesia, regarding three key issues in Indonesia: the development and implementation of UHC; the populist morality movement: and HIV. All secondary material was sourced via the internet. Given that revitalisation of UHC began only in 2014, there is limited secondary data on UHC in Indonesia. Nevertheless, we sourced material from vargovernmental and non-governmental ious organisations and numerous other reports and articles as identified. Similarly, regarding the populist morality movement, secondary data were sourced from policy releases, media and academic articles. In respect to HIV, there is a plethora of information about Indonesia and we sourced data from Ministry of Health reports, World Health Organization reports, UNAIDS reports, as well as academic publications. Here we note, though, that relying on statistics on HIV in Indonesia is problematic for various reasons, including that many people are never tested, and we stress that all figures must be assumed as estimates only.

We collected primary data on two key aspects for this article. All data were sourced following a feminist participatory action research framework. We chose this framework because it allows for consideration of multiple perspectives of women's lives, including consideration of gender, race and class.<sup>5</sup> Feminist participatory action research is a productive methodology to use for research into women's health. For instance, it emphasises the importance of creating partnerships for open dialogue. Building trust with participants is integral to this research to allow people to express their beliefs and understanding, something feminist participatory action research incorporates. Acknowledging people as the "real knowers" of their own situation, and the solution-makers for the challenges they face, are core values of this methodology.7

Both authors collected primary data to inform this article. The first source of primary data collected concerns Indonesia's populist morality movement (explained below). Through interviews and focus groups, material was gained about how particular moral issues, such as sex outside of marriage, are commonly perceived in Indonesia. Interviews and focus groups were also conducted with policewomen tasked with ensuring moral order, investigating their knowledge about various acts and the provision of health care for what is popularly framed as immoral behaviour (e.g. should access to antiretroviral medicine be provided if someone contracted HIV through criminalised activities?). We recognise the ownership of information among women and use "knowledge" here, rather than "perception", to reflect women's investment in their own knowing. These data were augmented by the collection and examination of social media content, such as postings on Facebook, Instagram and Twitter.8

The second source of primary data collected was from focus groups with 18 HIV-positive mothers who shared stories about their HIV journeys. Participants were provided space to discuss their experiences and to develop tools to enable access to prevention of mother to child transmission services. In addition to research with mothers, triangulation of data was undertaken with 26 health workers (12 midwives, 11 doctors, 2 obstetricians, and 1 paediatrician), and 9 NGO workers, as well as 12 HIV stakeholders. To collect data from these sources a combination of methods was used including informal interviews, focus group discussions, and participatory visual methods. Throughout research, pregnant women proved highly motivated to access services, but it was external factors, such as discrimination by healthcare professionals, that made it difficult for them to receive HIV care. In drawing together both the primary and secondary data, which were collected between 2014 and 2018, a powerful argument can be made compelling Indonesia to provide HIV care to mothers, especially considering the populist morality movement. While these data sources are integral to our analysis, given the scope and word limit of this article we only provide snapshots of this data. <sup>10</sup>

Full ethics approval was granted for this project. The Auckland University of Technology Ethics Committee gave permission on 7 March 2017 (Reference No. 17/22) and the Research Ethics Committee of the Faculty of Medicine, of Sriwijaya University gave permission on 15 March 2017 (Reference No. 39/keprsmhfkunsri/2017). Informed consent was obtained from each participant, and the authors have securely stored the signed consent forms. Further information is available regarding data collection methods.<sup>8, 11</sup>

# Universal health coverage

In efforts to address the enormous health inequalities evident across the globe, the United Nations passed a landmark resolution in 2012 endorsing universal health coverage (UHC). 12 UHC strives to provide everyone with health care regardless of their financial position. It aims to do this by having all those who can afford it, pay premiums (usually as part of general income tax), and this collective pool of money is used to pay for health care for those too poor to pay premiums. As the World Health Organization (WHO) further explains, UHC aims to provide people and communities with the "promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship". 13 WHO also notes that UHC will address three aims: ensuring equity in access to health services whereby everyone who needs services can receive them, not only those who can pay: ensuring that health services are of good enough quality to improve the health of those receiving them; and protecting people against financial risk, ensuring the cost of using services does not put people at risk of financial harm. 13

UHC is a good idea not just because almost four billion people globally do not receive the essential

health care they need, but because another 100 million people fall into extreme poverty each year trying to access it. 14 In Southeast Asia, nearly one-third of households have to borrow money or sell assets to afford health care. 15 Investing in health care makes good economic sense. Indeed, health improvements drove a quarter of full income growth in developing countries between 2000 and 2011. 16 At this rate of return, every US \$1 invested in health would produce US\$9-US \$20 of growth in full income over the 20 years from 2013. 16 Reducing or eliminating out-ofpocket spending is critically important to promote access to health services and to health workers. and to prevent impoverishment for vulnerable populations, including those affected by HIV. 17, 18

Of relevance to this article is the importance of UHC vis-à-vis sexual and reproductive health. Sexual and reproductive health services need to be accessible and of high quality, and available without discrimination, coercion or violence. Investing in comprehensive sexual and reproductive health services through UHC enables women and girls, who are often are the most marginalised members of a community, to lead fulfilling and healthy lives. Maternal, new-born and child survival improve rapidly with equitable health financing through UHC. In particular, UHC is needed to address HIV, including the prevention of transmission from mother to child.

While countries such as Indonesia have vocally supported UHC and put measures in place to enact it, challenges loom. Countries are grappling with issues such as how to ensure coverage of the informal sector to make UHC truly universal, and how to develop a financially feasible benefit package responsive and appropriate to diverse health challenges. Public financing is essential for UHC to cover people who cannot contribute financially, but nations often struggle to increase government resource generation and allocation to health, and to enact efficient spending. At 3.1% of GDP. Indonesia's total health expenditure levels are among the lowest in the world, <sup>20</sup> meaning significant shortfalls are inevitable. Some countries, though, have managed improvements. For example, Mexico moved toward UHC by increasing public spending on health by an average of 5% annually from 2000 to 2006.<sup>21</sup> A further challenge, particularly for lower-income countries, is to ensure that healthcare services can be provided. For instance, even if there is enough funding, it is often uncertain if there are sufficient highly trained doctors, midwives, and indeed hospitals, to provide health care.<sup>22</sup> For these reasons and more, Indonesia is facing significant challenges in implementing UHC. Before specifically examining UHC in Indonesia, we provide some context with regard to the country itself.

### Indonesia in context

Indonesia has a population of 264 million people, with a rapidly growing middle-class. There are 633 ethnic groups, speaking 580 languages, living across more than 6000 inhabited islands.<sup>23, 24</sup> There are also six recognised religions, with almost 88% of the population adhering to Islam. While these numbers are impressive, they mean implementing a universal health coverage system is challenging.

It is not just the sheer expanse and diversity of the country that makes health care delivery difficult. High levels of poverty persist, with around 43% of Indonesians living on less than US\$2 a day.<sup>25</sup> Poverty means people cannot pay taxes, reducing further the budget the government has to provide health care. Moreover, in a decentralised, highly bureaucratic country, there are few penalties for people outside the public sector who are financially able but unwilling to contribute to a health care scheme. 26–28 Further, while in theory a decentralised system might make a country responsive to culture-specific health care needs, this has not been the case. In Indonesia, decentralisation has resulted in challenges in the relationship between citizens and state, leading to negative implications for health financing and service provision. 26, 27

Following democratic reform in 1998, decentralisation became a tool for the government to quell long-standing seccessionist movements. In 2002, East Timor was granted full independence. In 2005, Aceh received special autonomy, allowing it to enact *sharia* laws, which we discuss below. Continuing separatist movements are occurring in Indonesia, notably in Papua. <sup>29</sup> With Indonesia battling such movements, the provision of health care in such places is woeful. HIV prevalence had risen in Papua to 2.3% of the population by 2013, compared with 0.4% for the rest of Indonesia. <sup>30</sup> Inequality and decentralisation are two primary reasons why implementing universal health care is difficult in Indonesia.

Indonesia has successfully tackled enormous social challenges before, though. In 1945, as

President Sukarno declared Indonesia's independence. less than 1% of the population was literate.<sup>31</sup> By 1980, this percentage had risen to 70%, due in large part to the implementation of a national education system.31 In 2019, around 95% of the population had some level of literacy.<sup>32</sup> In life expectancy, too, Indonesia has made dramatic progress. When President Sukarno was forced to resign in the mid-1960s, average life expectancy was just 52.33 By 2015, average life expectancy was 67 for men and 71 for women.<sup>34</sup> Indonesia thus has experience in dramatic social change, and with solid political will, it could achieve UHC. There is, however, an additional challenge making the adoption of UHC difficult, and this is the current populist morality movement driving the criminalisation of behaviours such as sex outside of marriage.

# Populist morality in Indonesia

One of the factors making UHC difficult to implement in Indonesia in relation to sexual and reproductive health is the increasing populist morality movement taking hold of the country. As such, it is important to understand this dynamic in Indonesia in order to push for UHC and the provision of HIV health care. Populist morality is a term developed to frame current events in Indonesia driving the criminalisation of all sorts of activities, including private consenting sexual activities, on the basis of morality. There is such widespread support for moves to criminalise moral issues (e.g. blasphemy, adultery), that there are laws to this effect currently as of July 2020 before the courts. The sexual activities are laws to this effect currently as of July 2020 before the courts.

Morality has always been of concern in Indonesia, as elsewhere. However, for much of the twentieth-century sexuality was not of primary focus for either government or the security sector. Due to its Dutch colonial legacy, homosexuality was never made illegal in Indonesia, unlike in Singapore and Malaysia where British colonial law was adopted.<sup>37</sup> Homosexuality was removed from the register of mental health disorders in 1993,<sup>38</sup> and to this day homosexuality is not a criminal offence.<sup>39</sup> While lack of criminalisation did not mean homosexuality was supported, it did mean that it was easier to provide healthcare services to key groups, particularly in response to the HIV epidemic.

When Indonesia introduced democracy as its political system in 1998, foreign NGOs increased

their involvement in health care issues such as HIV. 40 Democracy also enabled lesbian, gay, bisexual and transgender (LGBT) activists and allies to focus attention on the need for HIV health care. 40 New laws were ratified providing sexual rights for women. For instance, marital rape became an offence in 2004. 41 But all this progress started coming undone in 2008, and increasingly so from 2016.

After a decade of democratic reform, conservative elements in Indonesia grew progressively anxious about what they framed as the liberalisation and Westernisation of Indonesian values and morals. There were increasing calls for the criminalisation of sexuality in its broadest sense. The first major tangible effort to criminalise private consenting adult sexuality was the ratification of an anti-pornography law in 2008. This law frames pornography as

"pictures, sketches, illustrations, photos, writing, voice, sound, moving pictures, animation, cartoons, conversations, movements of the body, or other forms through a variety of communication media and/or performances in public which contain obscenity or sexual exploitation which violates the moral norms in society".<sup>44</sup>

The law has been liberally used, including being exploited by the government and police to harass and persecute sex workers and the LGBT community. 45–47

With the anti-pornography law paving the way, in 2016 more overt moves were made to criminalise sexuality, in particular LGBT sexuality. Precipitating what became known as the "LGBT Crises", government minister Muhammad Nasir publicly stated in January 2016 that universities must uphold standards of "values and morals" and should not support organisations promoting LGBT activities. 38, 48 This statement was shortly followed by Indonesia's then vice-president Jusuf Kalla rejecting UN funding earmarked to support work on ending stigma, discrimination and violence towards LGBT people. 38 In effect, funding for HIV prevention was radically reduced.

By 2019, the increasing persecution of LGBT people had widened to include moves to criminalise all sex outside of marriage. Currently before the courts (July 2020) is a bill that will criminalise all sex outside marriage, alongside other draconian changes. <sup>49</sup> In addition, the populist morality movement has caused a delay in passing a law criminalising sexual violence. <sup>35</sup> In a letter sent to President

Widodo in August 2019, signed by Vice President Ma'ruf Amin in his capacity as Chair of the Indonesian *Ulama* Council, the President was told that if the bill to criminalise non-marital sex passes, "your name will be written in history with golden ink". The *Ulama* Council, an umbrella organisation for many Islamic groups, has issued various *fatwa* (religious rulings) against homosexuality, claiming "homosexuality, whether lesbian or gay, and sodomy is legally *haram* [forbidden] and a form of crime [sic]". Ma'ruf's dual role is no coincidence; his appointment as vice-president was precisely because of his Islamic credentials. As Ma'ruf's homophobia reveals, Indonesia's populist morality movement is intimately linked to the country's increasing Islamisation. The Indonesia's populist morality increasing Islamisation.

As Indonesia moves towards a more conservative form of Islam,<sup>53</sup> the provision of health care is constricted for many groups. For instance, during our research we heard of numerous people denied access to the national health insurance scheme on the basis of addiction. While we could not find any specific policy to this effect, people told us that if hospital staff knew or suspected they were using intravenous drugs they were disqualified from accessing treatment. A cited reason for this disqualification was that it was their own fault they contracted HIV and therefore the limited medical resources should be reserved for "innocent victims". We also met people living with HIV who were denied access to medication because medical professionals blamed them for their "immoral" behaviour. A further example of constriction is seen at Tangerang District Hospital. south of Jakarta, which has become the first hospital outside of Aceh to formally implement Islamic sharia legal principles. 54, 55 This hospital recommends that in order to receive care, female patients be veiled and accompanied by a mahram (male relative).<sup>55</sup> Placing moral conditions on who receives care detrimentally impacts those deemed immoral; we see this precisely in the fact that people who contract HIV through sex work or intravenous drug use are often denied care because medical practitioners consider it their fault that they contracted HIV. Indonesians living with HIV are positioned ipso facto as immoral and populist morality thus makes accessing health care difficult. Given that sex outside of marriage may soon be criminalised, it is difficult to envisage how Indonesia will provide universal health coverage, especially in relation to sexual and reproductive health, in such an environment. If sex outside of marriage is criminalised, unmarried people will not, or will be not be able to, purchase condoms, thus increasing the risk of contracting HIV.

# Universal health coverage in Indonesia

The need for universal health coverage in Indonesia cannot be overstated. <sup>56, 57</sup> Each day, 50 women die from cervical cancer. <sup>58</sup> More than 10 million people are living with diabetes, giving Indonesia a diabetes prevalence rate of 6.2%. <sup>59</sup> Of all Indonesian men, 65% smoke, making it unsurprising that cardiovascular disease was responsible for 37% of deaths in Indonesia in 2016, with stroke the leading cause, followed by coronary heart disease. <sup>34</sup> Furthermore, the maternal mortality rate in Indonesia is around 126 deaths per 100,000 live births, higher than other Southeast Asian countries such as Thailand (40 deaths) and Malaysia (20 deaths). <sup>60, 61</sup> To improve these health statistics, Indonesia introduced a revamped universal health care system.

In January 2014, Indonesia reinvigorated its commitment to the provision of health care by introducing the National Health Insurance Program (Jaminan Kesehatan Nasional, JKN). JKN is a contribution-based social protection mechanism whereby some people contribute for their own coverage and other people's contributions are covered by the state. <sup>62, 63</sup> As with any universal health care scheme, Indonesia must focus on ensuring equal access, <sup>64</sup> especially for marginalised communities.<sup>21</sup> IKN crystallised efforts made by various unions and other groups over the previous five decades to introduce universal health care.<sup>27</sup> JKN aims to keep some healthcare services with strong public health benefits, such as vaccinations, "free". meaning that people who are not able to regularly pay contributions will still be entitled to these services. IKN must focus on accommodating cultural and religious diversity with flexible and adaptive implementation features and quick evidence-driven decisions based on changing needs. It has been suggested that IKN has moderately reduced inequality in access to health care in Indonesia.<sup>65</sup>

JKN has grown rapidly in Indonesia and now ostensibly covers more than 203 million people, the largest single-payer scheme in the world. There are gaps in provision, however. The informal sector dominates Indonesia's workforce (58%, or a total of 74 million workers). With only 31 million JKN members from this segment, an estimated 40 million people working in the informal sector

are missing from JKN enrolment.<sup>65</sup> Overall coverage is still low for children aged less than 9 years, especially those younger than 4 years, for whom coverage is less than 30% for the poorest groups.<sup>65</sup> There is an urgent need to accelerate treatment for children, especially children living with HIV.<sup>66</sup>

Given the inability of the government to collect premiums from those who can afford them, and the inability of many to pay premiums, financing IKN in Indonesia is difficult and the scheme is running in debt.<sup>67</sup> Indeed, due to low incomes, more than 96 million Indonesians are currently beneficiaries of the Premiums Assistance Recipient scheme (Penerima Bantuan Iuran). These recipients have their healthcare premiums covered by the state budget. But even for people who can afford to pay, due to various inefficiencies, 40% of all JKN non-state contributions remain uncollected. There are no mechanisms in place compelling people to pay premiums if they are not employed by the state.<sup>28</sup> If Indonesia does not increase collection of premiums, the government may place a further cap on how much health care is covered.<sup>68</sup> raise premiums, and/or cut services.<sup>69</sup> Research suggests that out-of-pocket payments are the most regressive way of financing the health system, placing particular burdens on the most marginalised. 70, 71 Whatever option is taken, the most vulnerable will likely be negatively impacted, and this includes people living with HIV.

# HIV in Indonesia

Indonesia currently has the fastest growing HIV epidemic in Southeast Asia, and there is low retention in care.<sup>72</sup> In 2018, it was estimated that almost 640,000 Indonesians were living with HIV, giving Indonesia an HIV prevalence rate of 0.4%. In 2018, 46,000 people were newly infected with HIV, and 38,000 died from HIV-related causes.1 Indonesia's first case of HIV was reported in 1983.<sup>73-75</sup> During the 1990s, prevalence remained low but grew amongst certain groups. Amongst waria (transwomen) 76 sex workers, prevalence grew from near 0% in 1991 to 8% by 1995.<sup>77</sup> From around 2000, there was a marked increase in HIV rates among injecting drug users, with one in every two testing positive for HIV.<sup>78</sup> By 2016, prevalence amongst *waria* sex workers had grown to 25%.<sup>79</sup>

HIV has remained concentrated in key groups in Indonesia. In 2016, HIV prevalence was 29% among people who inject drugs, and 5% among

female sex workers.<sup>79</sup> In 2019, it was estimated that 50% of men who have sex with men in Jakarta were living with HIV.<sup>80</sup> In areas such as Papua, the general prevalence rate is around 2.3%,<sup>30</sup> with some estimates suggesting 56% of female sex workers in the central highlands of Papua are living with HIV.<sup>30</sup> Worryingly, in 2018, only 51% of people living with HIV in Indonesia knew their status.<sup>1</sup>

In 2018, 17% of people living with HIV in Indonesia were on antiretroviral therapy (ART). In other words, of the estimated almost 640,000 people living with HIV, half a million people were not receiving the medical care they needed. ART figures were slightly higher for children, with 22% on treatment. 81 In Indonesia, ART is theoretically free, but patients are supposed to pay a registration fee and hospitalisation costs when needed.<sup>82</sup> More problematic is the lack of services. Clinics are often located far from people's homes, and clinics frequently run out of medicine.83 Further, viral load testing is not widely available and CD4 testing, which counts a type of white blood cell, is not always conducted among those on ART. 10, 84 Without these services, health care for people living with HIV remains unsatisfactory.

In addition to a lack of services, other challenges to providing HIV care in Indonesia remain. A first challenge is the decentralisation of government, discussed above, which means there is no clear, efficient overarching framework for addressing HIV. A second challenge is that very little money is channelled into HIV health care. In 2016. Indonesia allocated only 3.1% of GDP towards total health care, 20 far below Japan at 10.1% and Vietnam at 6.6%. 63 In 2014, all money spent on HIV in Indonesia was US\$107 million, just under half (43%) of this coming from international sources, and only 1% of the total was spent on key population prevention.<sup>56</sup> Despite JKN including the provision of integrated HIV programmes,<sup>78, 85</sup> and the Global Fund offering a new funding model to help finance HIV prevention and treatment, 86 funding shortfalls remain significant. Over half of useable funding comes from private and foreign sources. 79 However, given the populist morality movement explored above, foreign funding ear-marked for HIV prevention has reduced.87

A third challenge facing Indonesia is the lack of HIV awareness, and indeed awareness of sexual health in general. Sex education is not part of the school curriculum in Indonesia, <sup>88–90</sup> which explains why only around 10% of 15–24-year-olds

have comprehensive knowledge of HIV prevention and treatment.<sup>3, 91</sup> Lack of understanding is further compounded by ignorance at the highest levels. In 2015, a senior Indonesian Minister said second-hand clothes could spread HIV.<sup>92</sup>

A fourth challenge in providing HIV health care in Indonesia relates to cultural barriers. HIV is often seen as something people contract as punishment for acting immorally. Within this framework, it is hard to elicit support from the community for HIV prevention and treatment. In addition, there are potential negative consequences for people doing precisely the things that would reduce HIV transmission. For instance, in many provinces. sex work is a criminal activity and during our fieldwork we heard of cases where a condom was admissible in court as proof of a sexual transaction. Such cases provide a disincentive to using condoms. Despite these challenges, Indonesia must prioritise HIV prevention and care, not least among pregnant women living with HIV.

# HIV, mothers and children in Indonesia

The Indonesian Ministry of Health estimated that around 20,000 pregnant women were living with HIV at any one time between 2013 and 2017. This number represents a 25% increase from 2012, when it is estimated that 12,000 pregnant women were living with HIV. This figure excludes Papua, where it is estimated that in 2013, 3% of all pregnant women were living with HIV. 4

Pregnant women have a high chance of passing HIV on to their baby through vertical transmission during pregnancy, childbirth and breastfeeding.<sup>95</sup> Without treatment, if a pregnant woman is living with HIV the likelihood of the virus passing to her child ranges from 15% to 45%. 96 However, antiretroviral treatment and other interventions can reduce this risk to below 5%.96 Treatment must continue after birth but it is often out of reach for new mothers. For instance, poor women may not be enrolled in public health schemes and thus they will not be able to pay for a caesarean delivery, which would reduce the chance of HIV transmission to the child.<sup>97</sup> Caesarean delivery is expensive, especially when combined with postdelivery recovery. The cost of caesarean delivery in Indonesia is around US\$1000, while vaginal delivery is around US\$200.98 In addition, milk formula, which is recommended for mothers living with HIV, substantially increases the economic burden.<sup>97, 99</sup>

To prevent transmission, pregnant women should be tested for HIV. Unfortunately, in Indonesia only around 28% of pregnant women receive an HIV test. If the HIV test is positive, women must receive antiretroviral treatment. However, in 2018 only 15%, or 1818 pregnant women, received antiretroviral treatment to prevent the transmission of HIV to their child. In 2018, only 1% of HIV-exposed infants in Indonesia were tested for HIV before eight weeks of age. In Indonesia

In 2018, 18,000 children aged 0-14 were living with HIV in Indonesia. The cohort of children under 4 years old accounted for 2% of all Indonesians living with HIV. 100 Of these children living with HIV, only 22% were receiving antiretroviral treatment. To add to their trauma, many of these children will become orphans. In 2018. 310,000 children aged 0-17 were living as orphans due to HIV. In order to reduce the number of orphans, and to prevent the transmission of HIV from mother to child, Indonesia has a lot of work to do. Given reinvigorated efforts to ensure UHC. and the restrictions populist morality is having on health care efforts, what strategies should Indonesia implement to ensure UHC can effectively prioritise HIV prevention and care?

# Strategies for HIV prevention and care through UHC

Integrating HIV prevention and care into UHC presents significant challenges in Indonesia. 101 To guide Indonesia through this process we offer three strategies to promote inclusion of HIV through UHC. In particular, we focus on strategies that will help prevent transmission of HIV from mother to child and provide HIV care to both. Further, we offer strategies not based on provision of care or funding per se. Rather, we recognise the centrality of culture and the wider socio-political context; all the condoms in the world are of little benefit in preventing HIV if people refuse to wear them for fear of criminal repercussions. Culture and the political environment shaping it are crucial considerations. The strategies we propose are: removing health care provision from a moral framework; de-idealising the category of "woman"; and reframing shame and stigma around HIV.

# Removing health care provision from a moral framework

Indonesia's health care provision is currently contingent on a moral framework. Indeed, during

fieldwork, we were told by people with addiction that they were prevented from accessing the national health insurance scheme on morality grounds. The moral framework is implemented even within the police service, where policewomen must undergo a virginity test to prove their fidelity and hence morality.8 This moral framework has been particularly detrimental to HIV care. While statistics show that in 2014, men who have sex with men registered the highest incidence rate (23%) of all groups, they received only 0.05% of total HIV funding allocation. 56 While HIV care receives limited funding in general, it can be surmised that an additional reason men who have sex with men receive limited consideration is because they are deemed to participate in immoral behaviour.

The level of social and political persecution and harassment has increased dramatically for Indonesia's LGBT community since 2014. Indeed, at the peak of the LGBT crises in early 2016, people were avoiding outreach clinics for fear of being targeted, and this meant they could not access essential antiretroviral medicine. Some research has even found that involvement with an HIV-related organisation is associated negatively with retention in care for HIV-positive men who have sex with men, and transgender women. In consideration of the bill currently under debate that would criminalise all sex outside of marriage, Indonesia must consider the detrimental impact this bill will have on HIV transmission and care.

People with HIV are positioned in Indonesia as being ipso facto immoral (e.g. they have likely participated in sex outside marriage and/or intravenous drug use). This positioning needs to be reframed. There are many levels where reframing is desirable. HIV must be seen as a health issue, not a moral issue. Behaviours, such as sex outside marriage and drug use, must be seen as precisely that, behaviours, not issues of morality to be criminalised. Living with HIV must be removed from moral connotations. Such removal can be started by showing that everyone is susceptible to HIV, for instance through blood transfusions, doctors reusing syringes, vertical transmission, and from a spouse. Normalising HIV transmission away from high risk activities can help destigmatise HIV.

Our first strategy, then, for ensuring HIV health care through UHC is uncoupling HIV health care from morality. More broadly, Indonesia must take a harm reduction approach to HIV care. In order for UHC to deliver HIV health care, there

must be no criminalisation of consenting adult sexuality. What this will look like in practice needs further research, but Indonesia must ensure people are able to access HIV care without moral penalties.

### De-idealising the category of "woman"

Risky heterosexual sex was thought to cause 47% of new HIV infections in 2016. 103 Through this mode, new HIV infections increased from 6623 people living with HIV in 2010, to 17,754 people living with HIV in 2016. 100 Women of reproductive age from non-key populations were thought to be the largest cohort of new HIV infections in Indonesia between 2016 and 2019. 104 Why are rates among this group growing? An answer to this question was revealed in our research: women are considered, and often consider themselves, impossible recipients of HIV. This impossibility comes from the idealisation of women in Indonesia. Women are conceptualised, as indeed women are largely conceptualised globally, as primarily concerned with being good wives and mothers, perpetually nurturing and innocent of all bad deeds in the world (c.f. Najmah<sup>11</sup>). In Indonesia the most common way to refer to women is as Ibu Rumah Tangga (housewife). This appellation implies their first duty is as manager of the household, providing for the welfare of husband and children. As Ibu Rumah Tangga, women cease to exist as individuals who may have sex outside marriage and/ or use drugs. Further, Ibu Rumah Tangga are imagined to be married to faithful husbands.

In de-idealising the category of "woman": Indonesia can earnestly address HIV prevention, especially prevention of mother-to-child transmission. Indonesia can also provide effective HIV care. What our research has shown is that while part of the issue is the inability of mothers to see themselves as recipients of HIV, a bigger issue in the increasing prevalence of HIV among mothers is the inability of society in general, and the medical industry in particular, to see mothers as recipients of HIV. Many mothers in our research are in fact empowered to demand HIV tests, safe delivery of their babies, and antiretroviral medication. The difficulty is that doctors and nurses refuse to treat them. 105, 106 Part of this refusal is lack of knowledge about HIV among medical personnel, and part of it is a lack of facilities to provide care. But part of this refusal is that testing pregnant women for HIV appears unnecessary; the assumption made by many medical staff is that pregnant housewives cannot possibly have HIV. A further part of this refusal stems from medical staff feeling that offering an HIV test suggests that the mother has acted immorally. This "face saving" will become more acute if sex outside of marriage is criminalised.

Our second strategy, then, is a de-idealisation of the category of "woman", including as wife and mother. This de-idealisation will enable women to be full participants in their HIV health care. This de-idealisation will also remove the insinuation of immorality, enabling doctors to ask difficult, embarrassing questions. This de-idealisation may also empower women to demand men wear condoms during sexual intercourse (cf. Davies<sup>108</sup>). Acknowledging women as recipients of HIV, and acknowledging women as empowered to undertake their own HIV care if resources are available, are important steps in ensuring UHC can provide HIV health care. We can further extend this deidealisation of women to enable them to be precisely good wives and mothers. For instance, a de-idealisation does not mean that women stop being good wives and mothers. On the contrary. in order for them to be such, they need to be able to demand HIV tests, demand medication, demand HIV care for their children, and demand knowledge about a husband's infidelities.

#### Repositioning shame and stigma around HIV

It has been estimated that over 50% of vertical HIV transmissions globally can be attributed to the cumulative effect of shame and stigma. <sup>66</sup> But can we reposition these affects to make them driving forces for HIV health care provision? Shame, in particular, we think has real potential for invigorating HIV health care provision through UHC.

Shame is a key organisational principle in Indonesian society. 109 Shame has profound power to pull people into its remit and direct action accordingly. One way of understanding shame's pull is through the notion of kinships of shame. To draw on Benedict Anderson, 110 kinships of shame are a way of thinking about shame as something that not only impacts the person in question, but all those within a kin relationship, be that direct familial relationship or as citizens in an imagined community. We can illustrate kinships of shame through the following example. In 2014, then Indonesian President Susilo Bambang Yudhoyono trended globally on Twitter for several days after he announced moves to eliminate direct elections for all lower levels of government.<sup>111</sup> The initial Twitter hashtag was #ShameOnYou, calling the President out for his disregard for Indonesia's democratic political system. Of note, though, was the fact that the hashtag quickly changed to #ShamedByYou. What the semantic change reflects is that Indonesians felt the President had not shamed himself only, but importantly shamed all Indonesians. All connected people were brought into the orbit of shame.

Given the organisational force of shame, we suggest as our third strategy the utilisation of shame to ensure UHC can provide HIV health care across Indonesia. To be sure, shame is debilitating, making it particularly hard, for instance, for women to report sexual violence. 112 Associated with shame is humiliation, which can leave residues of bitterness and irrationality. But we think shame can be repositioned as a proactive force. Examples of this repositioning of shame sprinkle our fieldwork. For instance, pregnant women living with HIV loudly declared their status upon arrival at the maternity ward, showing that good mothers demand a caesarean section. To their shame, hospitals turned many such women away, either out of vocalised fear that they would contract HIV, or because they said they lacked facilities to care for pregnant women with HIV. 10 This shame must be attached solely to the medical profession, not to women being good mothers. Such a repositioning of shame can be effective for mandating hospitals to provide quality HIV care, insisting on broadscale HIV education with gender-sensitive and non-discriminatory approaches, and demanding that government prioritise HIV health care through UHC. It is possible that through this repositioning of shame, its flipside can be developed. This flipside is dignity. If women are empowered through demonstrating they are sourcing care for their family, resulting senses of dignity can be used to encourage other women to demand HIV care.

# **Conclusion**

In this article, we have argued for the culturally sensitive implementation of universal health coverage (UHC) across Indonesia to address the country's growing HIV epidemic. While material resources are needed to implement UHC, we have shown that without sufficient detail to cultural aspects, HIV prevalence will continue to grow in Indonesia. We have thus made a case for Indonesia to implement three strategies to ensure UHC can attend to the challenges of HIV prevention

and care: removing health care provision from a moral framework; de-idealising the category of "woman", which can empower women to claim the ideal wife and mother role by accessing HIV care; and repositioning shame and stigma around HIV.

Sexual and reproductive health and rights are included in every nation's UHC package and Indonesia is no exception. These health services must be available to all, and no one should be excluded. especially those who are marginalised and/or criminalised. 113 A key recommendation the 2017 review of the national health sector response to HIV in Indonesia by the World Health Organization states that collaborative engagement with, and support from, key populations is needed to support government efforts to prevent and treat HIV. 114 In short, governments must work with communities to set priorities. 115 Sadly, however, Indonesia is currently approaching health care from a populist morality base, which is increasing, rather than decreasing, HIV harm.

If Indonesia proceeds with the current populist morality movement that is shaping health policy. HIV prevalence will continue to grow. Criminalising sex outside of marriage will not stop people having sex, but it will stop people seeking health care. People who are at higher risk of HIV or living with HIV, and who are criminalised and stigmatised, already face significant social and legal barriers when it comes to accessing health services. 116 Moreover, Indonesia's National AIDS Commission was dissolved in 2017 and all its activities incorporated into the Ministry of Health, making care less available. Added to this, civil society support for HIV prevention and treatment has become irregular. Civil society is no longer a key partner when it comes to shaping the national health agenda. Indonesia's populist morality movement is making it difficult to reduce HIV-harm through universal health coverage, and the current morality-based health care provision will result in increasing HIV prevalence. Basing health care on morality is immoral, we argue, and we thus end with a plea for Indonesia not to criminalise consenting adult sexuality, but rather to ensure its provision of UHC can work towards an HIV-free Indonesia.

Further research should investigate tangible ways Indonesia can work toward providing universal health coverage for HIV. A first limitation of this article, then, is that it does not provide a road map in this respect. With Indonesia's turn to morality, whereby ethical behaviour is prescribed as the

way to achieving a better life, moralised decisionmaking prioritises health care for some and not others. Unpacking how morality can be used to access health care could be one way forward, if morality cannot be removed from health care provision. A second limitation of this article is that it does not discuss financing models, and these are crucial to both the development and implementation of any strategy aimed at improving HIV health care. We hope further research will thus explore financing models. A third limitation of the article is that it does not detail specific strategies for de-idealising the category of "woman". Future research should develop evidence in support of such a de-idealisation strategy, including reference to the intersectionality of women vis-à-vis HIV health care.

### Acknowledgements

Thank you to all the participants who engaged with our research. Thank you also to the anonymous reviewers who made incredibly helpful and insightful comments. And finally thank you to Lisa Melville.

#### Disclosure statement

No potential conflict of interest was reported by the author(s).

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#### Résumé

En 2014. l'Indonésie a relancé sa volonté de mettre en œuvre un système universel de soins de santé en introduisant le programme national d'assurance maladie (Jaminan Kesehatan Nasional, IKN), dans le but d'élargir l'accès de tous les secteurs de la société aux soins de santé. Une question clé qui apparaît dans le climat actuel est de savoir comment l'Indonésie peut garantir l'accès des personnes aux soins du VIH ? Cette question est essentielle puisque le pays est sur le point d'adopter une loi pénalisant toutes les relations sexuelles en dehors du mariage. Si cette législation est promulguée, quiconque se présentant avec le VIH sera soupçonné automatiquement de participation à une activité criminelle (par exemple des rapports sexuels de cette personne ou de son partenaire en dehors du mariage et/ ou l'usage de drogues intraveineuses). Dans ce contexte, prévenir la transmission du VIH de la mère à l'enfant devient plus difficile. En étudiant ces questions nous avançons que, à un moment de moralité populiste, l'Indonésie doit accorder une grande attention à la manière dont la couverture santé universelle peut prévenir la transmission du VIH, en particulier de la mère à l'enfant. Nous proposons trois stratégies clés que

#### Resumen

En el año 2014. Indonesia revitalizó su compromiso de establecer un sistema de cobertura universal de salud al introducir el Programa de Seguro Médico Nacional (Jaminan Kesehatan Nasional, JKN), con la finalidad de ampliar el acceso a los servicios de salud para todos los sectores de la sociedad. Una interrogante clave que surge en el clima actual es: ¿cómo puede Indonesia garantizar que las personas puedan acceder a los servicios de salud relacionados con el VIH? Esta pregunta es de importancia fundamental dado que Indonesia está a punto de aprobar una ley que penalizará todas las relaciones sexuales fuera del matrimonio. Si la ley es aprobada, toda persona que se presente con VIH será sospechada ipso facto de estar involucrada en actividad criminal (es decir, que ella o su pareja tiene relaciones sexuales fuera del matrimonio y/o consume drogas intravenosas). En este entorno, resulta más difícil prevenir la transmisión materno-infantil del VIH. Al explorar estos temas, argumentamos que, en tiempos de moralidad populista, Indonesia debe prestar atención significativa a cómo la cobertura universal de salud puede prevenir la transmisión del VIH, en particular de madre a l'Indonésie pourrait mettre en œuvre à cette fin : retirer la prestation des soins de santé d'un cadre moral ; désidéaliser la catégorie de la femme ; et repositionner la honte et la stigmatisation qui entourent le VIH.

hijo. Ofrecemos tres estrategias clave al respecto a ser aplicadas por Indonesia: eliminar la prestación de servicios de salud del marco moral; desidealizar la categoría de mujer; y reposicionar la humillación y el estigma en torno al VIH.