Discussion Paper

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TESTING, WOMEN'S EMPOWERMENT AND UNIVERSAL HEALTH COVERAGE

> "This paper explores the potential of women as drivers of change in health systems to help close the testing gap that is holding back UHC."

Key Messages

- All countries have committed in the Sustainable Development Goals (SDGs) to deliver Universal Health Coverage (UHC) by 2030. Even before COVID-19, however, the greatest gap in disease management was in diagnosis, not in treatment – up to 65% of cases for some diseases are never diagnosed[ii]. **UHC will not be achieved without closing the testing gap.**
- For UHC to succeed it must meet the health needs of women and men throughout the life course, including the needs of women and adolescent girls in pregnancy and childbirth. **Gaps in access to testing threaten the health and lives of women and adolescent girls and in turn, undermine UHC.**
- Women drive health systems as 70% of the global health and social workforce but only hold 25% decision making roles[iii]. **Enabling women as self-carers, care-givers, health professionals and political decision-makers will help close the gap in testing and thereby, enable achievement of UHC for everyone.**

About this discussion paper

While development and access for drugs and vaccines have long been the focus of global health efforts, testing has often been an afterthought, particularly when it comes to primary healthcare services – that neglect has been laid bare by COVID-19. The historical lack of attention to and investment in testing means that for every person diagnosed with a disease, another goes undetected - 50% of patients get no care at all or get care too late.[iv]

Accurate diagnosis enables more accurate treatment. Testing is critical to UHC and this paper explores the potential of women as drivers of change in health systems to help close the testing gap that is holding back UHC.

This discussion paper, authored by FIND and Women in Global Health, addresses two questions critical to delivery of UHC:

- **Which barriers must be addressed to ensure testing reaches women who need it?**
- **How can the untapped potential of women be harnessed to drive testing for everyone who needs it?**

This paper will be followed by a consultation to gather data, research and case studies for a comprehensive report on Testing, Women's Empowerment and UHC to be launched later in 2020.

UHC will not be achieved without closing the testing gap

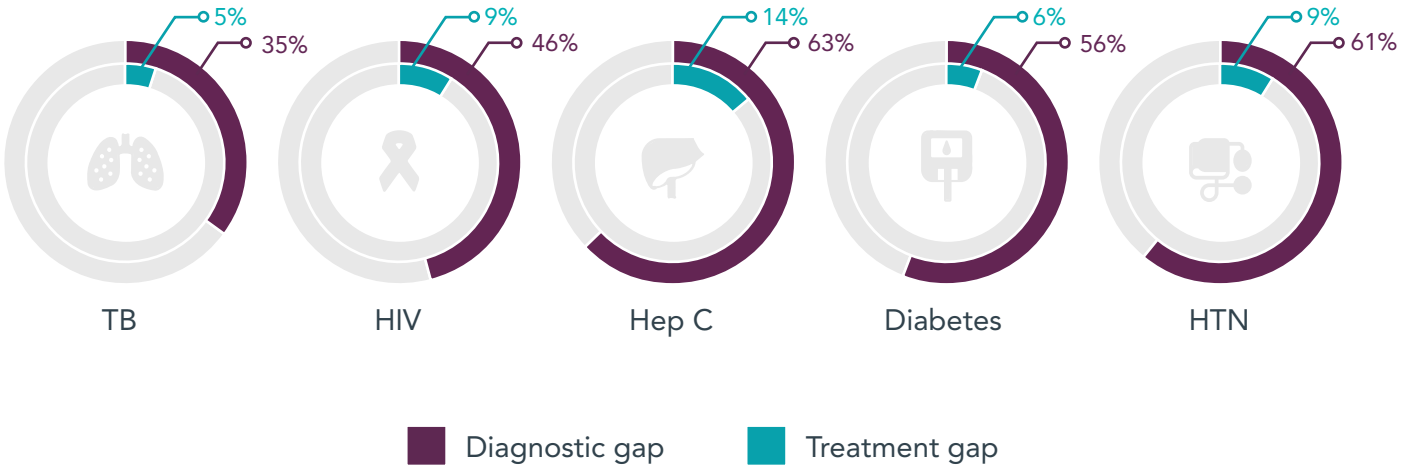
Diagnostics are tests and tools used to identify a medical condition. They are critical for identifying the presence and cause of disease and for determining an appropriate course of treatment. Results from diagnostic testing guide the majority of healthcare decisions and are therefore critical to improving global health and achieving UHC. Diagnostic testing also facilitates disease surveillance. Accurate diagnostics help reduce harm to the patient and create more cost effective and efficient treatments. Easy-to-use tools providing rapid diagnosis can allow therapy to start sooner. Testing is critical for patient safety.

"Up to 65% of cases for some diseases are never diagnosed."

However, as illustrated below, gaps in testing threaten progress in addressing all major diseases, from tuberculosis (TB) to malaria, hepatitis and diabetes, putting UHC at risk.

Testing Gaps are Larger Than Treatment Gaps

~50% patients not diagnosed



GBD = Global Burden of Disease; HTN = Hypertension; LMIC = low and middle-income country; PHC = primary healthcareSources: 1. Cascade of care analysis - estimated disgnostic and treatment gap for common CDs and NCDs in LMICs (Kholi et al, m/s in preparation).
2. Leslie et al. Bull World Health Organ 2017;95:738-748, http://dx.doi.org/10.2471/BLT.17.191916.
3. Global Burden of Disease forecasting (Pai et al, FIND data on file).

Testing enables:

- **Screening for asymptomatic infections in at risk populations, such as HIV, Hepatitis C, Syphilis, Chlamydia and in some instances, COVID-19**
- **Evidence-based patient management and greater patient safety (particularly for diseases with non-specific clinical symptoms and signs, such as fever)**
- **Disease surveillance and outbreak investigations, as seen currently in COVID-19**
- **Evaluation of the effectiveness of interventions and certification of disease elimination**
- **Detection and monitoring of drug resistance**
- **Facilitation of epidemiological studies to monitor disease burden and trends; and of clinical trials, such as drug and vaccine efficacy trials**
- **Self-management and better outcomes for Non Communicable Diseases, such as diabetes**

I. Gaps in access to testing threaten the health, lives and livelihoods of women and adolescent girls and undermine UHC

1) Women face barriers to accessing testing

+ tests are not available
+ tests are not affordable for women
+ women cannot access testing sites

2) Health systems may exclude women and adolescent girls, especially from marginalized groups

+ women are unaware of the benefits or availability of tests
+ stigma deters women from seeking testing

3) Women in humanitarian settings are particularly hard to reach

1) Women face barriers to accessing testing

> **"Countries with fragile health systems without strong laboratory networks are being left behind in testing, with serious impacts for women's health."**

+ Tests are not available

Tests that women need are not always available in low income countries because they are too complicated or expensive to use. An analysis of 8,000 health facilities across 10 low- and middle-income countries found that just 1% of primary healthcare facilities had access to essential diagnostics[v]. Only 14% of hospitals had adequate diagnostic capacity. Findings from 85 studies on women's take up of antenatal care in a range of country contexts showed women were more likely to attend if they believed medicines, tests and screening procedures (e.g. HIV tests and ultrasound) would be available.[vi] Women are unlikely to seek testing where the quality of health services is low, staff are absent or untrained and testing equipment and consumables are inadequate. Countries with fragile health systems without strong laboratory networks are being left behind in testing, with serious impacts for women's health.

+ Tests are not affordable for women

Women cannot always afford testing. At least half the world's population lacks full coverage for the most essential healthcare services, with women from marginalized groups often having least access. Over 930 million people spend at least 10 percent of their entire household budget on healthcare, plunging 100 million people worldwide into extreme poverty every year[vii]. UHC has the potential to change the health and lives of millions of people, the majority of them women. Women earn less than men, much of the work that women do is unpaid and the poorest women may have no financial autonomy within the family[viii]. Under such circumstances, women will often prioritize the health of their children above their own. Evidence from Ghana showed women choosing to give birth at home, rather than in safer hospital facilities because the 'informal costs' for services, that should have been free were therefore unaffordable for them[ix].A study in Senegal found that only 13% of women received the complete set of antenatal tests recommended in pregnancy.[x] Although the costs of delivery were free, most antenatal tests were not and were unaffordable for the majority of women. In the USA, despite rules that health insurance plans cannot charge more for a plan based on gender, women pay almost 70% more in out of pocket health expenses than men, partly because they have more preventative care than men, often connected to pregnancy.[xi] Testing is an excellent investment for national health systems as early diagnosis can often prevent more serious complications if undiagnosed and untreated. As countries implement their commitment to provide UHC, it will be critical that it covers diagnostics for all women, without imposing financial hardship and out of pocket expenses that will deter women from accessing testing.

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A study of [xii] the factors that enable or hinder women in Uganda from seeking and accessing cervical cancer screening, identified the following barriers and drivers:

Women don't seek screening due to:

- ✖ fear of the procedure and outcome
- ✖ embarrassment
- ✖ stigma
- ✖ living in rural or remote regions with limited access to screening services
- ✖ low levels of knowledge of cervical cancer
- ✖ low perceived risk

Women are more likely to attend screening if:

- ✔ encouraged to attend screening by other women or a health care worker
- ✔ they perceive their personal risk of cervical cancer is significant

"Special measures and innovations will be needed to reach women with testing in order to achieve UHC."

+ Women cannot access testing sites

Women cannot always access testing because services are not close to home. A study of Maasai women in Kenya who wanted to give birth at health facilities but had deliveries at home found they were unable to get there because "there was no means for a heavily pregnant woman to get to the health facility… a four-hour walk to the road and the nearest functioning dispensary, or a two-hour ride across rough terrain on a motorbike."[xiii] The poorest women may not come for testing even where it is low cost or no cost because they have a heavy workload of domestic, childcare and other paid or subsistence work. They may need to seek permission from male relatives to travel outside the home. Transport may be an added obstacle if it is unsafe for women or costly. Testing methods that enable women better access are therefore critical. A study in Mexico found a home test for cervical cancer picked up more cancers and pre-cancerous tests than tests conducted in a clinic and uptake was higher for the home test than test in a clinic.[xiv] For reasons including convenience, embarrassment, discomfort and inability to make the journey, women preferred to self-test at home. This result was confirmed by a meta-analysis[xv] that proved such self-sampling could be performed as effectively by users as health professionals, making it possible to extend testing to rural, marginalized and hard to reach women. The most marginalized women may not come for testing unless services can be taken to them at community or doorstep level, integrated into another health service they will be attending or accessed via self-testing. Special measures and innovations will be needed to reach women with testing in order to achieve UHC.

Self-testing

Self-sampling and home tests are now available in high income countries for a wide range of conditions, including HIV, sexually transmitted infections, stomach ulcers, Alzheimer's disease and some forms of cancer. As yet, few of these innovations are available in low-and middle-income countries but there are exceptions, including testing for HIV and cervical cancer. Self-testing gives patients more control over their health, can be more convenient (especially for women with work and family commitments), can be less intrusive, reduces the cost of travel and allows more privacy, especially for stigmatized conditions. Home testing kits enable patients with chronic conditions, such as diabetes, to monitor their conditions without attending a clinic. It is a more accessible and affordable option for obtaining a diagnosis efficiently, saving patients' time and money and easing the pressure on public health services.

Self-testing innovations in HIV

HIV self-testing has proved an important innovation in increasing uptake of testing. Instead of going to a clinical setting, the user may take their own sample and record the results or complete the test supervised by a counsellor, peer, nurse or educator. Over 65 countries have HIV self-testing protocols in place. As HIV self-testing was rolled out across sub-Saharan Africa, the number of people unaware of their HIV serostatus fell from 30-40% in 2015 to 20-25% in 2019[xvi]. Findings from 280 HIV self-test studies show the numbers of tests increased when this method was introduced, including amongst communities not traditionally screened, and amongst women. Women reported finding self-testing empowering and they acted as catalysts, extending testing to male partners.

"Gender responsive health services are needed to target the specific social circumstances of different genders and social groups if everyone is to be reached by UHC."

2) Health systems may exclude women, especially women from marginalized groups

Health systems may exclude women especially from marginalized groups. Gender responsive health services are needed to target the specific social circumstances of different genders and social groups if everyone is to be reached by UHC. The poorest women will be reluctant to attend any health facility where they are treated rudely or discriminated against due to their poverty, race, ethnicity, religion or other social characteristic. A study of low use of maternal health facilities in rural Uganda found that poor treatment by workers - said to be rude, poorly trained and unwilling to dispense prescribed drugs – was a primary barrier to access for women.[xvii] Women are more likely to attend if opening hours suit their schedules, waiting times are short and they can keep their children with them in relative comfort. Primary health care clinics will ideally be integrated as 'one stop shops' (not vertical programs) where women can go for a range of services without needing to travel to multiple facilities. Investment in more patient-empowering diagnostics, such as self-testing or self-sampling at home, testing in local pharmacies, or even self-testing in primary care clinics may help overcome some of the barriers to diagnosis and care for women and girls.

"Achieving UHC will require understanding the local context to identify the most effective and trusted ways of communicating information about testing to women."

+ Women are unaware of the benefits or availability of tests

Women do not always know tests are available or beneficial, especially if they are from vulnerable social groups in low and middle-income countries, are not literate or live in remote areas. Prevention and early diagnosis may not be a priority for women from lower socio-economic groups given the other demands on their time, particularly where a woman does not feel ill. The digital divide exacerbates inequalities and differences in health literacy between men and women and different social groups. Globally, around 327 million fewer women than men have a smartphone and can access mobile Internet. Women are, on average, 26% less likely than men to have a smartphone. In South Asia and Africa these proportions are 70% and 34%, respectively.[xviii] Gendered barriers to information will determine how news of testing reaches different groups of women who may have no regular contact with the health system. Radio may reach some more effectively than TV or social media. Religious or other social networks may reach women, depending on the context. Many health systems in low income countries have networks of community health workers and volunteers (generally women) whose role includes communicating health information to the local community. The impact, however, will depend on those frontline health workers themselves being empowered and informed. Achieving UHC will require understanding the local context to identify the most effective and trusted ways of communicating information about testing to women.

"Health systems must understand and address barriers to access for women and adolescent girls due to stigma if UHC is to leave no-one behind."

+ Stigma deters women from seeking testing

Social stigma prevents women from seeking testing for various conditions, even if assured of confidentiality. Social stigma associated with work women do, including sex work, may make certain groups of women less likely to seek testing. HIV/AIDS and sexually transmitted infections have been associated with stigma in many countries but depending on the context, women may be stigmatized for having a range of conditions. In South Asia and the Middle East[xix] Type 1 diabetes in girls and young women may be concealed due to social stigma and a fear they will be less marriageable if their condition is revealed. Girls with Type 1 diabetes may therefore not be regularly tested and monitored, with negative outcomes for their health. Solutions to addressing stigma include setting up targeted services for particular populations such as young people, education and health literacy campaigns, peer to peer counselling, self-testing and offering testing from non-clinical settings such as pharmacies. Health systems must understand and address barriers to access for women and adolescent girls due to stigma if UHC is to leave no-one behind.

Stigma: A review of barriers to cervical cancer testing in Uganda found studies mentioned stigma as a major reason for women avoiding testing. Women were reluctant to seek testing concerned that possible revelation of their HIV status would lead to stigma and societal rejection. Women were also concerned their spouses would leave them if testing identified they were ill.[xx]

"Diagnostic solutions must be tailored to fragile states and humanitarian settings if UHC is to reach the most vulnerable women and children."

3) Women in humanitarian settings are particularly hard to reach

Of more than 125 million people in need of humanitarian assistance worldwide, over 75% are women and children.[xxi] Women in humanitarian settings are some of the hardest to reach with testing and have some of the most complex needs and worst health outcomes. Sixty percent of maternal deaths globally occur in fragile states and humanitarian settings[xxii] where health services are often disrupted. Due to insecurity, lawlessness and destruction of health facilities, women are commonly prevented from accessing health services in emergency situations. Such disruption has also been seen in epidemics and pandemics, with increases in maternal deaths recorded during Ebola outbreaks.[xxiii] In complex political emergencies and conflicts, vulnerable populations may be internally displaced and hard to reach if they settle into the local population and are not located in one place. Providing quality, accessible health services and testing in humanitarian settings requires working with local communities, health providers, governments, civil society and women themselves to identify local risks and solutions. Similarly, refugees and migrants will be particularly hard to reach and vulnerable wherever they lack health service cover in the countries they are living in. Diagnostic solutions must be tailored to fragile states and humanitarian settings if UHC is to reach the most vulnerable women and children.

Testing for COVID-19 in humanitarian settings: Data collected by the International Rescue Committee (IRC)[xxiv] shows a high discrepancy between male and female confirmed COVID-19 cases in six conflict affected and fragile states (Afghanistan, Somalia, Yemen, Pakistan, Chad and Central African Republic). Less than 30% confirmed cases are in women. IRC report testing is extremely limited in general but the low level of confirmed infections in women points to less access to testing and healthcare for women. Since women make up the majority of primary caregivers and health workers in these countries, women's infection rates would be expected to be at least as high as men's. Lack of testing for women almost certainly results in lack of access to treatment for COVID-19 and greater community spread of the virus. IRC cite women's lack of mobility, low priority for women's health and discrimination as causes of lack of testing for women.

Data Gaps

Gaps in data and research on access to testing by gender have been identified from all regions. This is a major concern, since rapid progress in diagnostic testing is needed in low- and middle-income countries to reach the SDGs, attain UHC and achieve the health for all targets by 2030. Widespread gaps were found in the data about current diagnostic testing by sex, the impact of diagnostic testing, reaching different genders and social groups with testing and policy research on good practice in addressing testing, and health system deficiencies and gender equality. **The next stage of this FIND/WGH program will include a broad consultation to identify other data sources, case studies and research that may not be published. It will also identify critical data and research gaps that need to be addressed to achieve UHC.**

Data gaps and COVID-19. In June 2020, 130 countries reported sex disaggregated data on COVID-19 infections[xxv].The vast majority reported roughly equal numbers of infections in men and women. But 13 out of 130 countries reported that 70% or more of COVID-19 infections were in men. Nepal and Qatar, reported 91% infections were in men and only 9% were in women. Without further analysis, it is impossible to know whether this pattern of infection reflects exceptional circumstances where men in general were exposed to the infection in a way that women were not, or whether it reflects women's lack of access to COVID-19 testing. Those two possibilities have very different public health implications.

II. Enabling women as self-carers, care-givers, health professionals and political decision-makers will help close the gap in testing

1) Women health workers - if enabled - will deliver testing

2) Women are influencers in their communities and families for health and testing

3) Female political leaders are critical advocates for health budgets and gender responsive health services

1) Women health workers - if enabled - will deliver testing

Women are 70% of the health and social care workforce and critical to design and delivery of testing. Since women are over 80% of the global nursing and midwifery workforce and 90% of social care workers, they are central to the delivery of diagnostic testing at Primary Health Care level to women and all health service users. Women, however, hold only 25% of decision-making roles in health[xxvi] so have limited opportunity to drive the design of health systems to ensure testing is prioritized. One study[xxvii] concluded that women contribute over $3 trillion to the health sector annually, half in the form of unpaid work. There are serious gender inequities in the health sector, including its reliance on women's unpaid work, that undermine global health security. A global shortage of 40 million health workers is predicted by 2030, with 18 million additional health workers needed in low income countries to reach UHC.[xxviii] This health worker shortage impacts the capacity of most low-and middle-income health systems to deliver a full range of health services, including diagnostic testing. Investment in the health and social care workforce, particularly investment in decent jobs for women, will be critical to achieving both testing and UHC.[xxix] More research is needed on the most effective testing delivery models for reaching women in specific contexts. It will be critical to ensure that cadres of frontline health workers such as nurses, midwives, pharmacists, paramedics and community health workers (majority female) most able to reach women and vulnerable groups, are enabled to inform patients on testing and resourced and trained to deliver testing in all settings from community outreach to hospitals.

"Women are 70% of the health and social care workforce and critical to design and delivery of testing…… Women, however, hold only 25% of decision-making roles in health so have limited opportunity to drive the design of health systems to ensure testing is prioritized."

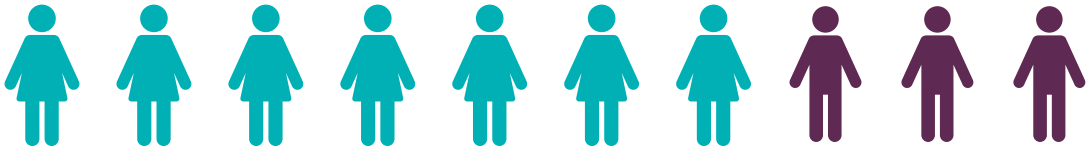
2) Women are influencers in their communities and families for health and testing

Health service delivery focused on women's access to timely and accurate testing will increase the decision-making power of women about their own health and the health of others. It is most often women who care for sick family members, encourage family members to visit healthcare professionals, make sure they take medicines and understand their treatment.[xxx] Women, as the main caregivers, can be powerful actors in health prevention and promotion within their families and communities. Health systems rely heavily on unpaid and informal work that disproportionally falls to women. A study of six African countries showed that 81% of informal caregivers were women.[xxxi] The roles women play vary according to gender roles and cultural norms within a society. Many countries have successfully engaged women's groups at community level to promote health. A meta-analysis of the impact of such groups found them associated with a 20% population-level reduction in neonatal mortality.[xxxii] Women can play a critical role in spreading accurate information within communities about testing, reducing fear and increasing take-up. Attacks by communities on health workers conducting community briefings, testing and treatment for Ebola led to suspension of programmes in the Democratic Republic of the Congo.[xxxiii] Attacks on health workers have been reported recently from a number of countries related to COVID-19.[xxxiv] Programs to influence take up of testing should engage the most influential groups of women in that context to both promote positive health information and combat misinformation and build trust.

"Programs to influence take up of testing should engage the most influential groups of women in that context to both promote positive health information and combat misinformation and resistance."

Global health; Delivered by Women, Led by Men[xxvi]

Women hold 70% of global health jobs



BUT
Women hold only 25% health senior leadership roles

"Female political leaders at national and local government levels can drive inclusion of testing in health budgets and gender responsive health services that prioritize diagnostic services needed by all genders."

3) Female political leaders are critical advocates for health budgets and gender responsive health services

Since just 1% of primary care clinics have basic diagnostic capacity, political mobilization will be needed to persuade governments to place greater priority on diagnostic testing as an essential component in delivering health for all. Female political leaders at national and local government levels can drive inclusion of testing in health budgets and gender responsive health services that prioritize diagnostic services needed by all genders. There is a growing body of evidence that women parliamentarians, when present in sufficient numbers, change the political agenda and prioritize health, particularly women's health. Research comparing the impact of an influx of women in parliaments in 22 countries following introduction of quotas, found a 9-12% decline in maternal mortality in low income countries.[xxxv] Moreover, they found the biggest falls in maternal mortality where gender quotas had been in place the longest. These results are consistent with a growing body of evidence that suggests female parliamentarians are effective in agenda-setting and coalition building, leading to greater parliamentary focus on women's health issues.[xxxvi] Women's movements and NGOs in health at global and local levels are also important advocates for change.

Women parliamentarians change the agenda: Research from 139 countries[xxxvii] 1995-2012 found that a large increase in women's parliamentary representation via quotas was followed by increased government expenditure on public health. Globally, however, women hold only 24.9% parliamentary seats and so in many countries, will have limited ability to exercise this positive impact upon health.[xxxviii]

Finally, please contribute to our work

We encourage feedback on this Discussion Paper and the key themes in it and ask you to complete a short survey accessed via this link. We are keen to hear from you about points we have missed, data, case studies, good practice examples and any other information and perspectives that would contribute to the FIND/WGH program on women, testing and Universal Health Coverage. Thank you. Email us on testing@womeningh.org.

Foundation for Innovative New Diagnostics (FIND)

FIND is a global non-profit organization that drives innovation in the development and delivery of diagnostics to combat major diseases affecting the world's poorest populations. Our work bridges R&D to access, overcoming scientific barriers to technology development; generating evidence for regulators and policy-makers; addressing market failures; and enabling accelerated uptake and access to diagnostics in low- and middle-income countries (LMICs).

Since 2003, we have been instrumental in the development of 24 new diagnostic tools. Over 50 million FIND-supported products have been provided to 150 LMICs since the start of 2015. A WHO Collaborating Centre, we work with more than 200 academic, industry, governmental, and civil society partners worldwide, on over 70 active projects that cross six priority disease areas. FIND is committed to a future in which diagnostics underpin treatment decisions and provide the foundation for disease surveillance, control, and prevention.

For more information: www.finddx.org **Follow us:** @FINDdx

Women in Global Health (WGH)

WGH, founded in 2015 and registered as a not for profit, is a global movement with more than 25,000 supporters across more than 90 countries and national chapters in around 15 countries. We bring together all genders and backgrounds to achieve gender equality in global health leadership. WGH's core leadership team is supported by a large network of volunteer fellows, advisors, coordinators and assistants, all virtually based in different parts of the world. The WGH movement challenges power and privilege in health by mobilizing a diverse group of emerging women leaders in health, engaging with existing global health leaders to transform their own institutions, and holding those leaders to account.

WGH co-chairs the WHO Gender Equity Hub for the Global Health Workforce Network, working with partners to catalyze gender equity and gender transformative change in the health workforce. WGH is one of the founders and co-convenors of the Alliance for Gender Equality and UHC, an alliance of over 100 national and global NGOs working for gender responsive UHC.

For more information: www.womeningh.org **Follow us:** @WomeninGH
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