

# HEALTH IN THEIR HANDS:

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## Testing & Women's Empowerment Means Better Health For All

NOVEMBER 2020



# Executive Summary

## ***Testing empowers women by putting their health in their own hands***

In 2019, at a landmark UN High-Level Meeting on Universal Health Coverage (UHC), the world's governments committed to achieving UHC as part of the Sustainable Development Goals (SDGs) by 2030. The World Health Organization (WHO) estimates that around half the world's population, mostly in low- and middle-income countries, lacks full coverage for essential health services.<sup>1</sup> UHC therefore has the potential to change the health and lives of millions of people, the majority of them women, who cannot currently access quality health services, including essential diagnostic testing.

Global health initiatives have focused on development of and access to drugs and vaccines, with diagnostic testing often an afterthought – 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.<sup>2</sup> Testing is critical to UHC and therefore to the health of everyone, especially women.

Men and women are all likely to need diagnostic tests at some time in their lives, and some of the barriers identified in this report may be common to both sexes. In some areas of health there may be a greater testing gap for men than women because social norms encourage men to take greater health risks and focus less on prevention. Women need tests for conditions and diseases common to both sexes (e.g. HIV/AIDS, COVID-19) and they also require tests for conditions unique to women (e.g. antenatal tests related to pregnancy). Women's reproductive role means the average woman will be likely to need more diagnostic tests during her lifetime than the average man.

The Foundation for Innovative Diagnostics (FIND) and Women in Global Health (WGH) have joined forces to gather the evidence on women's access to testing and explore the potential of women as drivers of change in health systems, to help close the testing gap that is holding back UHC and health for all. The conclusions of a comprehensive data gathering process are contained in this report. An important caveat, however, is that there is very little sex-disaggregated data, research or policy analysis on this subject, particularly from low- and middle-income countries. It will be impossible to close the testing gap if we do not have the evidence upon which to base policy solutions.

Although some of the obstacles described in this report are experienced by women in all countries, the focus of this report is on women in low- and middle-income countries, who face the greatest burden of infectious, non-communicable diseases and maternal mortality and have least access to diagnostic testing.

We hope this report will start a global conversation that leads to investment in women's health through reaching women with diagnostic testing. We also hope this report will lead to a new focus on the role women play as drivers of diagnostic testing for the whole of society.

## Testing empowers women: putting health in their hands

### KEY MESSAGES

1. Testing and knowing their health status empowers women to better manage their health and plan their lives.
2. Universal health coverage (UHC) cannot be achieved without closing the testing gap and must address the barriers that impede women's access to testing.
3. Action on testing is most urgent in low- and middle-income countries, where women face the greatest burden of disease but have least access to diagnostic testing.
4. There is lack of investment in and limited data, research and evidence on women's health and testing.
5. When empowered, female healthcare workers will scale up testing for everyone
6. Women's leadership - at community, health system and political levels - can drive access to testing

**BACKGROUND:** Global health initiatives have focused on development of and access to drugs and vaccines, with diagnostic testing often an afterthought – 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. Testing is critical to UHC and therefore to the health of everyone, especially women. However, there has been a lack of investment in women's health diagnostics, and there is a lack of data and research on the issues women face in accessing testing in low and middle-income countries, where the testing gaps are greatest.

Women in Global Health conducts consultation and synthesizes evidence gathered

### KEY FINDINGS: Women can drive testing for all

- The tests women need are often not available in health systems.
- Gender inequality creates information, financial and cultural barriers for women to access testing.
- Women lack trust in testing services, and may fear procedures, diagnosis, and stigma.
- Barriers to testing are compounded for marginalized women, especially in humanitarian contexts.
- Female health workers can scale up testing for everyone, if enabled with training, resources, and decent work.
- Taking testing to women at home and work and self-testing can expand testing to more women.

### RECOMMENDATIONS

1. **Prioritize and invest in diagnostic testing** as an essential component of UHC. Include access to testing as a commitment in the Political Declaration for the 2023 UN High-Level Meeting on UHC.
2. **Collect data and conduct research on access and barriers to testing**, including cost effectiveness studies to track the return to investment on testing and early, accurate diagnoses.
3. **All countries should adopt Essential Diagnostic Lists** that include a package of essential diagnostics for conditions specific to women.
4. **Invest in innovation for low cost, quality self-testing methods and point-of-care testing devices** to meet the demands of a large and underserved market.
5. **Integrate testing into health systems at primary health care level and take testing as close to women's homes and places of work as possible** through female community health workers and self-testing, and in pharmacies.
6. **Understand and address cultural contexts for women.** Engage peer mentors, women health workers, and address women's mobility and security concerns. Respect women's privacy and cultural norms. Prevent and reduce stigma.
7. **Reach the most marginalized women, ensuring that lack of information and affordability are not barriers to testing.** Engage trusted channels to inform women about testing. Provide free services to the least able to pay.
8. **Build community trust in testing.** Ensure all health facilities maintain community trust by eradicating stock outs of essential testing components and have enough staff trained to carry out essential diagnostic tests.
9. **Engage with men at community level through peer mentors** to increase understanding of, and priority given, to routine screening and testing for women's health and their own health.
10. **Enable women primary health care workers (community health workers, nurses, midwives) through training and resourcing** to deliver testing in homes and communities. Invest in decent work and conditions to attract and retain female health workers.
11. **Engage women community leaders and women led community-based organizations to promote health literacy on testing** and support women to attend. Women are more likely to take up testing if encouraged by women they trust.
12. **Support women political leaders to be testing champions** within their countries and communities to promote investment in health to ensure all women can access testing and treatment.

# Key Findings From The Report

**1. The tests women need are often not available:** The overall picture in low- and middle- income countries shows poor availability of diagnostic tests in general, whether for men or for women. The sole study on availability in low- and middle-income countries found only 1% of primary healthcare facilities had access to essential diagnostics.<sup>3</sup> In addition, there is evidence from some countries that tests specifically needed by women, such as antenatal tests, are not available to all women: a study in Senegal found that only 13% of women received the complete set of antenatal tests recommended in pregnancy.<sup>4</sup>

**2. Very few countries have Essential Diagnostic Lists (EDLs):** National EDLs in line with WHO recommended best practice, enable countries to establish national lists of effective and safe tests appropriate for the critical health needs of their populations. Without national EDLs countries have no national standards on tests women should be entitled to receive. Countries with EDLs in development are not currently using a gender-responsive approach but there is an opportunity to change this.

**3. Gender inequality creates information barriers for women to access testing:** Too many girls still lack quality education and have poor health literacy, which limits demand for testing. Women cannot always access accurate information about testing and tend not to prioritize their own health.

*“...for every person diagnosed with a disease, another goes undetected.”*

**4. Gender inequality within households and societies limits women’s access:** Within households, women often lack financial and decision-making power and the cost of tests and transport to reach health facilities may prevent access to services. In addition to money, women may also need consent from relatives to access testing. In a study of pregnant women in South West Nigeria, 97% reported relying on their husbands for money to access antenatal testing and care.<sup>5</sup> The time required for testing also limits access for women balancing the double burden of domestic and economic labour, even when tests are available.

**5. Women lack trust in testing services, and fear procedures and diagnosis:** Women may fear testing procedures, especially when they lack information from trusted sources and tests are carried out by male health workers. Gendered cultural stigma around some diseases means women may fear the stigma of diagnosis. In a study examining TB-related stigma in India, 40% of women were uncertain that their spouses would support them after a positive diagnosis.<sup>6</sup>

**6. Barriers to testing are compounded for the most marginalized women:** The gendered barriers women face to access testing are compounded for women living in humanitarian settings and those marginalized through geographic location, ethnicity, disability and occupation. For example, only 40% of female factory workers in Myanmar sought testing for TB symptoms because they were not allowed to take time off work.<sup>7</sup> Due to security challenges in North East Nigeria, only 30% of camps for people displaced by conflict had HIV testing services for women living there.<sup>8</sup>

**7. Lack of investment in women's health diagnostics:** There has been a systematic underinvestment in all areas of research and development on women's health globally. Only 1% of Australia's Medical Research Council's annual budget has been allocated for endometriosis research, although the condition affects 10% of women of childbearing age.<sup>9</sup> Research and development of medicines and diagnostic tests have often been based on clinical trials with only male subjects, resulting in some medicines and diagnostics that do not work as effectively for women.

**8. Gender bias hinders accurate diagnosis for women:** TB kills more women annually than all causes of maternal mortality combined yet in many cultural contexts TB is considered a 'male disease' and women are not actively targeted for screening. For example, in a Swaziland study, a screening tool missed 85% of active TB cases.<sup>10</sup> For chronic conditions like heart disease, clinical diagnostic definitions have historically been based on symptoms reported in men, meaning warning signs that are different in women have been ignored, unrecognized or misdiagnosed.

**9. Lack of data and research on women's access to testing is a serious deficiency:** Lack of data is a widespread challenge limiting our understanding of women's access to testing. For example, in October 2020 only 8 countries were reporting sex-disaggregated COVID-19 testing data despite the fact that there is higher male mortality from COVID-19 in almost all age groups. In June 2020, 13 countries reported over 70% infections in men,<sup>11</sup> an implausible result since men and women are likely to be exposed in roughly equal numbers or exposure higher in women due to their work in health and social care. Without routine collection and analysis of sex-disaggregated data key research questions remain unanswered on barriers to access for both women and men.

**10. If empowered, female healthcare workers can scale up testing for everyone:** Women are 70% of the global health workforce, 90% nurses and midwives and the majority of health workers at primary care level.<sup>12</sup> Despite global health worker shortages, women are driving testing and there is potential to scale up diagnostic testing through enabling women with training and resources. In many low- and middle-income countries, pharmacies are the first point of call for healthcare needs and an important community location for some diagnostic testing. It is projected that women will be around 72% of pharmacists by 2030.<sup>13</sup>

In Zambia, when female community health workers were trained on testing for malaria, there was an increase in the numbers tested, especially children and women.<sup>14</sup> However, **women are not always enabled to deliver testing** – they are not paid fairly or adequately trained or resourced. Large numbers of female frontline community health workers are unpaid or paid only incentives and stipends, which may disincentivize health screening and testing. The work of nurses in Sri Lanka includes screening for non-communicable diseases (NCDs) but because the service is offered free of charge, nurses are expected to conduct screening in their own time.<sup>15</sup>

### **11. Self-testing has the potential to expand testing to more women, and men:**

Research suggests women may prefer to self-test at home for conditions such as pregnancy and cervical cancer. A pilot human papillomavirus (HPV) screening study in Uganda found 93% of women chose to provide a self-collected sample rather than attend a local clinic to have a sample taken by a health provider.<sup>16</sup> However, self-testing innovations are not widely available in low- and middle-income countries. Unmarried women, who may be subject to stigma if pregnant, could benefit from access to affordable pregnancy self-tests but they are not available through health systems. Learning from HIV self-testing programmes in southern Africa has demonstrated how women, including female sex workers, can reach men and other high-risk populations using secondary distribution of self-test kits.<sup>17</sup>

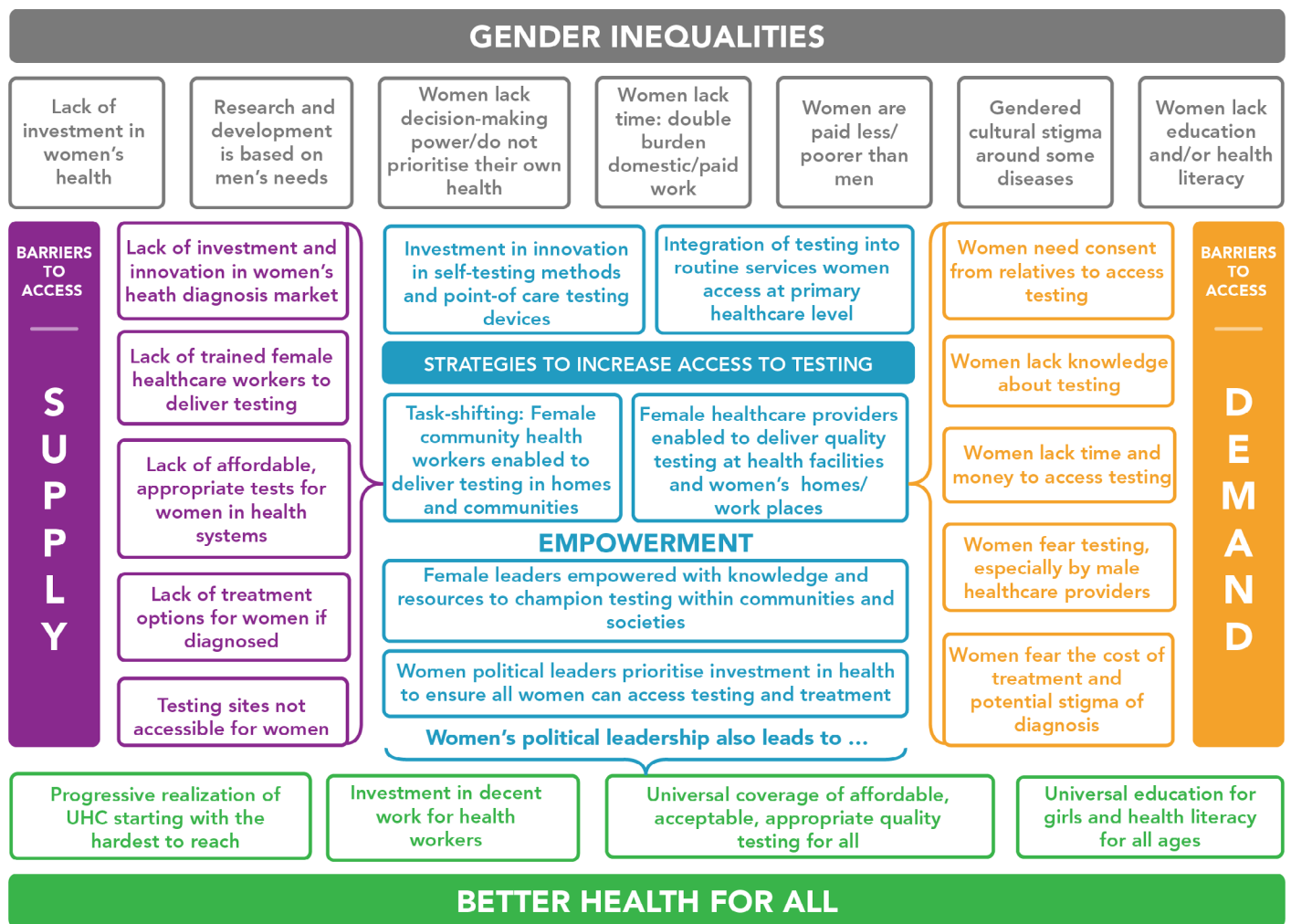
*“....a study in Senegal found that only 13% of women received the complete set of antenatal tests recommended in pregnancy.”*

**12. Women’s leadership and influence - at community, health system and political levels - has the potential to drive access to testing:** Globally, women are at the heart of the diagnostics delivery chain in health systems. In their role as wives, mothers and community influencers, women also have a key role in promoting testing for family and community members. In Nigeria, there is compelling evidence that engaging influential traditional birth attendants in health delivery helps prevent mother-to-child transmission of HIV by improving screening and diagnostics services.<sup>18</sup> Female pharmacists are in an ideal position to support women’s health literacy, and enable them to influence others.<sup>19</sup> There is a growing body of evidence that women parliamentarians change the political

*“.....women parliamentarians change the political agenda and prioritize health”*

agenda and prioritize health, particularly women’s health. Initial analysis suggests COVID-19 deaths were six times lower in female-led countries due to early, decisive action.<sup>20</sup>

# Graphic: From gender inequality to better health for all: strategies to empower women and close the testing gap



# Key messages

**1. Testing empowers women by putting their health in their own hands.** When women have access to screening and accurate diagnosis through testing, they have more control over both their health and their lives. It gives women the information they need to manage their health and increases their trust in health systems.

**2. Lack of diagnostic testing is a major issue for low- and middle-income country health systems and a major barrier to achievement of universal health coverage for all genders.** National Essential Diagnostics Lists are needed to clarify the tests people can expect from national health systems, and to strengthen the social contract between people and countries in terms of the right to health.

**3. Action on testing is urgent in low- and middle-income countries, where women face the greatest burden of disease but have least access to diagnostic testing.** Women in lower income countries are facing a high burden of infectious diseases, a growing burden of NCDs and maternal mortality and morbidity. In 2020 all countries are affected by the COVID-19 pandemic but the impacts could be felt harder on health systems in low- and middle-income countries, especially those still recovering from Ebola and other disease outbreaks.

**4. Universal health coverage must address the social and financial barriers linked to gender inequality that impede women's access to testing.** UHC must target the hardest to reach women with testing services if it is to be universal.

**5. Health systems must enable women's access to the tests needed by both men and women and enable women's access to the tests needed uniquely by women.** Women's reproductive role increases women's need to access testing.

**6. Testing services brought to women and self-testing are most likely to reach women.** Self-testing can also overcome stigma and cultural barriers.

**7. Women must be engaged equally with men across research, political decision making and in the delivery of testing.** It is essential to incorporate the perspectives, experience, and expertise of women to fully meet their health and social needs.

**8. Testing must be targeted to reach all women and girls, including the most vulnerable and marginalized.** Special measures will be needed to overcome security and other barriers for women in humanitarian settings.

**9. Women are drivers of diagnostics and critical to building trust in testing.** From pharmacists to nurses, and community healthcare workers, women are the majority of the diagnostics delivery chain and essential to delivering testing in health systems. Severe health worker shortages in low-and middle-income countries especially undermine health service delivery. In their role as wives, mothers and community influencers, women have a key role in promoting testing for all and building trust in testing at community level.

**10. Women parliamentarians change the agenda and prioritize health.** 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.



# Key recommendations

- 1. Give global priority to and invest in diagnostic testing** as an essential component of UHC. Include access to testing, for women and men, as a political commitment in the Political Declaration for the 2023 UN High-Level Meeting on UHC.
- 2. Collect data and conduct research on access and barriers to testing for women and men**, including cost effectiveness studies to track the return to investment on testing and early, accurate diagnoses.
- 3. All countries to adopt Essential Diagnostic Lists** that include essential tests for all priority conditions and also a package of essential diagnostics for conditions specific to women.
- 4. Invest in innovation for low cost, quality self-testing methods and point-of-care testing devices** to meet the demands of a large and underserved market.
- 5. Integrate testing into health systems at primary health care level and take testing as close to women's homes and places of work as possible** through female community health workers, pharmacies and self-testing.
- 6. Understand and address cultural contexts for women.** Engage peer mentors, women health workers, and address mobility and security concerns. Respect women's privacy and cultural norms and prevent stigmatization.
- 7. Reach the most marginalized women, ensuring that lack of information and affordability are not barriers to testing.** Work with trusted channels to reach women with accurate information. Provide free services to the least able to pay.
- 8. Build community trust in testing.** Ensure all health facilities maintain community trust by eradicating stock-outs of essential testing components and have enough staff trained to carry out essential diagnostic tests.
- 9. Engage with men at community level through peer mentors** to increase understanding of, and priority given, to routine screening and testing for women's health and their own health.
- 10. Enable women community health workers, nurses, midwives at primary health care level through training and resourcing** to deliver testing in homes and communities. Invest in decent work and conditions for female health workers.
- 11. Engage women community leaders and women led community-based organizations to promote health literacy on testing** and support women to attend. Women are more likely to take up testing if encouraged by women they trust.
- 12. Women political leaders to be testing champions** within their countries and communities and champion investment in health to ensure all women can access testing and treatment.

# Final Word

This report documents a neglect of diagnostic testing for women that has devastating health consequences and loss of life for women in low- and middle-income countries (and many in high-income countries) when curable conditions are not diagnosed, diagnosed too late, misdiagnosed and therefore untreated or wrongly treated. Since data and research are so scarce, the true scale of this unacceptable cost for women is unknown.

Beyond the unacceptable cost for women, is the cost to economies and societies of the preventable spread of infectious diseases and also emerging threats such as antimicrobial resistance (AMR) driven by wrong diagnosis and wrong treatment. It is clear from this report that UHC will not be achieved until the testing gap has been closed.

The current COVID-19 pandemic is a stark reminder of the health, human and economic costs of failure to invest in health security. Investment in diagnostic testing for all, especially women, is an excellent investment with high returns, not least in resilience of health systems and communities for future shocks and pandemics.

Having detailed the challenges of the serious testing gap for women, this report also outlines three areas for hope.

***“UHC will not be achieved until the testing gap has been closed.”***



**A female health worker draws blood from a woman in a syphilis test during her antenatal visit at a primary health care facility in Zambia (credit: WGH Zambia)**

***“Women must be engaged equally with men across research, political decision making and in the delivery of testing.”***

First, that testing empowers women by putting their health in their own hands. Second, that there is a global army of women in the diagnostics delivery chain, who can scale up testing for women and men and work towards closing the gap. And third, there is a growing number of women political leaders from community level to national Parliaments able to champion investment in testing that meets the needs of women and that, in turn, will enable the women in diagnostics delivery to meet the testing needs of everyone.

***“Globally, women are at the heart of the diagnostics delivery chain.”***

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