HEALTH IN THEIR HANDS:

Testing & Women's Empowerment Means Better Health For All

NOVEMBER 2020

FIND
Because diagnosis matters

WGH
WOMEN IN GLOBAL HEALTH

WPL
Women Political Leaders

Contents

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Foreword

Dr Aminata Touré, former Prime Minister and former President of the Economic, Social and Environmental Council, Senegal; founder and CEO of AT-Consulting International & FIND Goodwill Ambassador for Affordable Testing

Achievement of Universal Health Coverage and the Sustainable Development Goals will not happen without increased access to testing, particularly in the light of the unprecedented disruption resulting from COVID-19.

The pandemic has demonstrated not only the importance of testing in the absence of a cure or vaccine, but also just how much we rely on women for healthcare. Around the world we have seen demonstrations of appreciation for the healthcare workers who put their lives on the line for our collective health, yet we continue to underinvest in these same healthcare workers in terms of providing them with the tools, training, and resources they need to undertake their work effectively.

Access to testing is vital for women to take control of their own health and that of their families and communities. This report is the first to highlight some of the many barriers women face in accessing testing, including inadequate testing infrastructure, information barriers, and cultural barriers. It highlights the many areas where research and investment are needed and it inspires us with compelling actions that can be taken by all of us to create the change we need.

I am pleased this report highlights the vital role of political leadership to bring greater attention to the need to empower women as leaders in our communities, health systems, and countries. This report is a call to action for governments to ensure that women's testing needs are met, that they are engaged actively in the process, and that they are drivers in the quest to increase access to testing.

I commend FIND and Women in Global Health for identifying the barriers preventing women from fully participating in the benefits of access to testing and for articulating a range of approaches that will help shape the agenda, providing us all with actionable recommendations that we can take forward.

Foreword: Dr Roopa Dhatt, Executive Director, Women in Global Health

On behalf of Women in Global Health (WGH), I am delighted to present this joint report from WGH and FIND, significant in being the first comprehensive evidence review and analysis of diagnostic testing and women in low- and middle-income countries. WGH are pleased to work in the vanguard with FIND, to catalyse gender transformative change in diagnostic testing, a critical area of global health.

I am grateful to the many expert partners and specialists who contributed time, evidence and ideas to strengthen our analysis, and to WGH chapters and FIND staff who grounded this analysis in the reality of women's lives and health systems in low- and middle-income countries.

Here are four things we know:

- **universal health coverage will never be universal until it includes the hardest to reach**, particularly women and girls, who can face extraordinary barriers accessing quality health services, including diagnostic testing, which should be theirs by right.
- **universal health coverage, including critical diagnostic testing, will be delivered by women** – often undervalued and under-resourced - who form the vast majority of the health and social care workforce.
- **women political leaders, when present in sufficient numbers, change the agenda and prioritize health**, especially women's health. We also know that women are critical health influencers in families and communities.
- **finally, information is power**: with knowledge of their own health status and those around them, women can plan their lives and ensure their families and communities thrive. Testing empowers women with critical health information that improves lives and increases prosperity for all.

Diagnostic testing has been the 'Cinderella' of global health, often overlooked and underfunded, despite its critical impact for health, lives and societies. The COVID-19 pandemic has led to a new focus on testing but has also had devastating impacts on many health systems and economies. Our aims for this report are to present the evidence that will put testing higher up global and national health agendas; recognize and empower the women in the diagnostics delivery chain who will make it happen; engage women political leaders and other influential women to champion testing for women; and above all, to empower women by putting their health in their own hands.

Glossary and acronyms

'Testing' in this report is used to cover all types of diagnostic services including disease identification (e.g. screening for cancer), determining cure after treatment, disease monitoring, and testing for conditions that do not fall under disease categories (e.g. pregnancy).

Asymptomatic: A person is asymptomatic if they have recovered from an illness or condition and no longer has symptoms, or has an illness or condition but does not have symptoms.

Gender: The socially constructed characteristics of women and men, such as norms, roles and relationships of and between groups of women and men. While the majority of people are born male or female, and display characteristics and behaviours associated with their sex, they are taught norms and ways of conducting themselves, including how they should interact with others of the same or opposite sex within households, communities and workplaces.

Health security: The activities required to minimize the danger and impact of acute public health events that endanger people's health across geographical regions and international boundaries.

Primary health care (PHC): Addresses a person's health needs throughout their lifetime within their community, including physical, mental and social well-being. It is a whole-of-society approach that includes health promotion, disease prevention, treatment, rehabilitation and palliative care.

Screening: The presumptive identification of unrecognized disease in an apparently healthy, asymptomatic population by means of tests, examinations, or other procedures that can be applied rapidly and easily to a target population.

Self-sampling: When a person collects their own specimen or sample and sends the sample for analysis by a laboratory.

Self-testing: When a person collects their own specimen and then performs a test and interprets the result, often in a private setting, either alone or with someone they trust.

Sex: The biological and physiological characteristics that define men and women.

Surveillance: An ongoing, systematic collection, analysis and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice.

Testing gap: The percentage of the population with the condition who are undiagnosed.

Universal health coverage (UHC): The assurance that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services.

Women's empowerment: The process by which women who have been denied the ability to make strategic life choices acquire such an ability.

Acronyms

AMR: Anti-microbial resistance

CHW: Community health worker

FIND: Foundation for Innovative New Diagnostics

HIV: Human immunodeficiency disease

HPV: Human papillomavirus

NCDs: Non-communicable disease

PHC: Primary health care

SDGs: Sustainable Development Goals

STI: Sexually transmitted infection

TB: Tuberculosis

UHC: Universal health coverage

WGH: Women in Global Health

WHO: World Health Organization

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.[1] 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.[2] 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.[3] 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.[4]

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.[5] 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.[6]

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.[7] 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.[8]

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.[9] 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.[10] 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,[11] 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.[12] 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.[13]

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.[14] 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.[15]

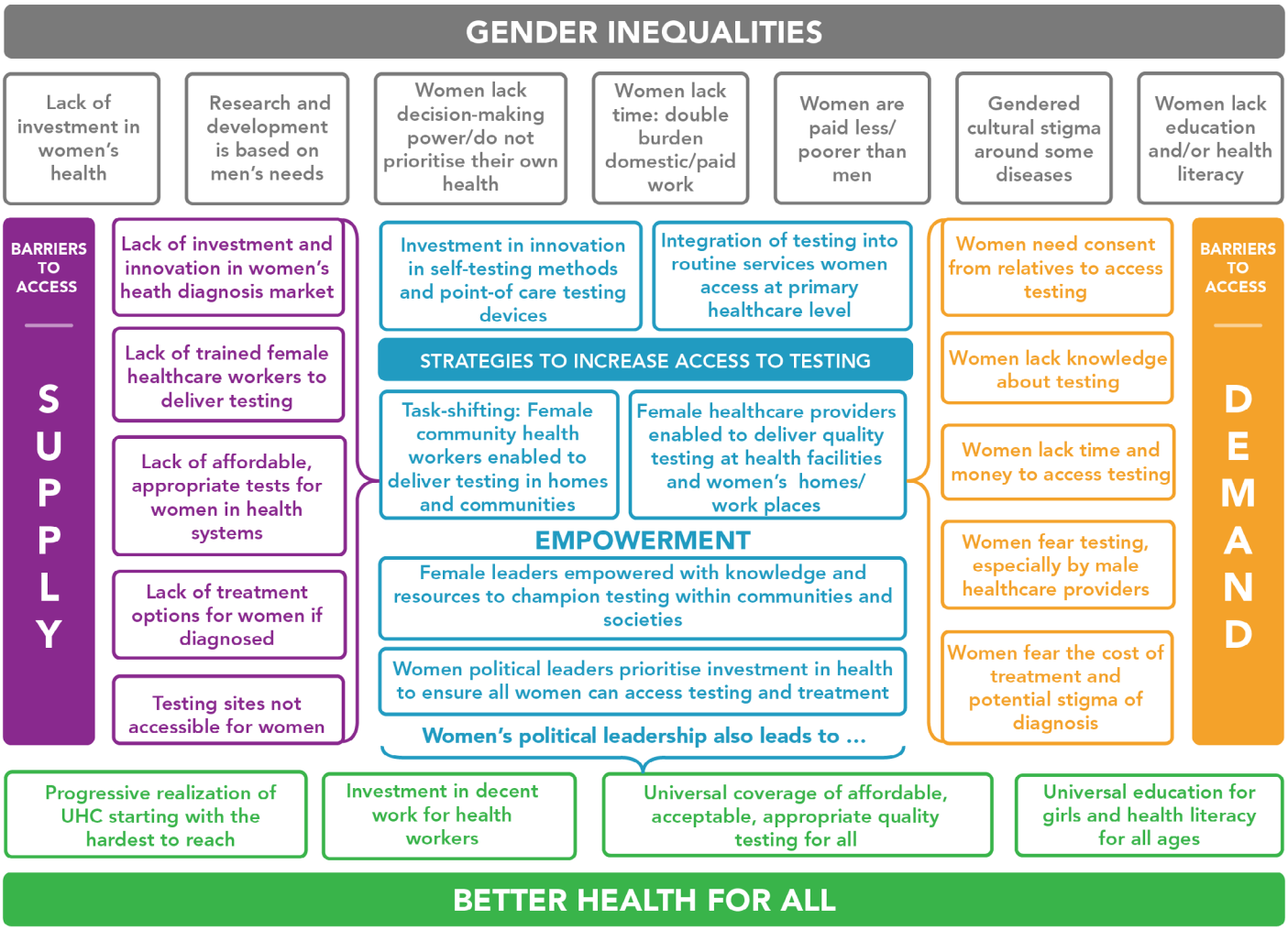
11. Self-testing has the potential to expand testing to more women, and men: Research suggests women may prefer to self-test at home for conditions such as pregnancy and cervical cancer. A pilot human papillomavirus (HPV) screening study in Uganda found 93% of women chose to provide a self-collected sample rather than attend a local clinic to have a sample taken by a health provider.[16] 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.[17]

> ***"....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.[18] Female pharmacists are in an ideal position to support women's health literacy, and enable them to influence others.[19] There is a growing body of evidence that women parliamentarians change the political 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.[20]

> ***".....women parliamentarians change the political agenda and prioritize health"***

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.

"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)

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.

"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."

Introduction

This report is part of an ongoing initiative between the Foundation for New and Innovative Diagnostics (FIND) and Women in Global Health (WGH) 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 universal health coverage (UHC) and health for all. FIND, in its strategy review for 2021-2023 has brought a greater focus to the gendered aspects of testing, the role of women in models for delivery of testing in communities, the potential for self-testing to reduce stigma and other barriers to care.

Recognizing that both men and women are affected by the testing gap, this report focuses on the issues women face in accessing the tests they need throughout the life course, and consider how pervasive gender inequality across medicine, households and societies compounds health system challenges and prevents UHC for women. Although many of the obstacles described in this report are experienced by women in all countries, the focus is on women in low- and middle-income countries, who face the greatest burden of infectious, non-communicable diseases (NCDs) and maternal mortality and have least access to diagnostic testing.

> ***"…many of the obstacles described in this report are experienced by women in all countries"***

The report is in two parts: the first part explores the barriers women face to accessing testing, which synthesizes the findings of our research process. In the second part, we present 'snapshots' from a range of different contexts to highlight the gap in services women in the diagnostics delivery chain are able to deliver and what they could deliver, if enabled, to drive testing for all. Again, the focus is on low- and middle-income countries, where the untapped potential is greatest, especially at community level.

Report objectives:

- To analyse the barriers women face in accessing testing, which are undermining UHC and women's health and empowerment;
- To highlight priority gaps in resources, data and research;
- To make recommendations on how women can drive testing efforts, to help achieve UHC and advance empowerment;
- To inspire investment in women as testing champions across health and political systems.

Background to the report

The project began in May 2020 with a literature review of key global health databases to explore two questions:

- 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?

Few health systems collect sex-disaggregated data on testing and women's access to testing is not well researched or documented in low- and middle-income countries. Although a small number of studies help answer the research questions, the current evidence base is sparse, and it is a challenge to generalize from limited data. To promote investment in testing and women's empowerment within UHC, WGH and FIND initiated a process outlined below and detailed in the Methodology (see Annex I), to help close this evidence gap, generate political will, and inspire action.

> ***"Few health systems collect sex-disaggregated data on testing"***

The first step in the process was to scope the issues in a joint FIND and WGH Discussion Paper[21], which fed into a high-level roundtable on testing, women's empowerment and UHC in July 2020. The roundtable included participants from civil society, health workers, global health leaders and UN agencies who shared insights and recommendations on the themes raised in the discussion paper.

Key messages from the roundtable:

- **Deficiencies in diagnostic testing seriously undermine women's health and autonomy** in many low- and middle-income countries, particularly for women in humanitarian emergencies;
- **It is critical to bring more testing services to women,** rather than assume women will be able to access and afford services provided in a more distant location;
- Women may need spousal consent to access health care, thus education and **improving health literacy amongst both women and men is critical;**
- **Culturally appropriate language and communication** are crucial to informing communities, reaching the most marginalized and building trust in testing for women;
- **Task shifting, bringing health services including testing to community level**, has proven effective in increasing access for HIV/AIDS testing in low- and middle-income countries;
- **Engaging a range of healthcare workers** including midwives, pharmacists, and community health workers (majority women), to inform women and communities about testing expands access, decreases stigma and removes misconceptions surrounding diagnostics;
- **Women political leaders can best champion testing for women** if enabled with evidence and arguments.

Following the roundtable, a global consultation was conducted with global health organizations, non-governmental organizations (NGOs), health worker professional associations and other relevant stakeholders. Through a targeted online survey, we received information from organizations working on testing and health systems globally, including in Brazil, Ecuador, Peru and Sub-Saharan Africa. Concurrently, open-ended interviews with NGOs, UN agencies and researchers working on testing were conducted. Information was also collected through WGH chapters and FIND in-country networks. The evidence from the literature review was synthesized with grey literature, qualitative data and information gathered during the consultation process to produce this report.

The report will be complemented by a digital policy bank, a compilation of research and policy sources, to be launched in early 2021.

Consultation on women's access to testing in Cameroon. Source WGH Cameroon

PART 1:

WOMEN FACE BARRIERS TO ACCESSING TESTING

The testing gap

Access to testing in low- and middle-income countries is poor for men and women of all ages. The lack of widely available, rapid, accurate, and affordable tests is a major challenge hindering both the COVID-19 response and UHC progress. The majority of tests require healthcare facilities with clinical laboratories; but the majority of healthcare facilities in low- and middle-income countries do not have functioning laboratories (see table in Annex II).

Diagnostics influence about 70% of healthcare decisions, and yet only 3–5% of healthcare budgets are spent on tests.[22] When health systems do not sufficiently plan for or fund diagnostic services, health workers must rely on empirical evidence or their experience to decide a diagnosis, leading to both missed cases and unnecessary treatments including the mis/over-use of antibiotics[23]. The problem of inadequate testing is a contributing factor to global anti-microbial resistance (AMR).

Testing for all is crucial because it enables detection, diagnosis and monitoring of diseases. Testing data enables informed referrals within health systems and forms the basis of data required throughout the health system.

Testing for all is important because it enables…

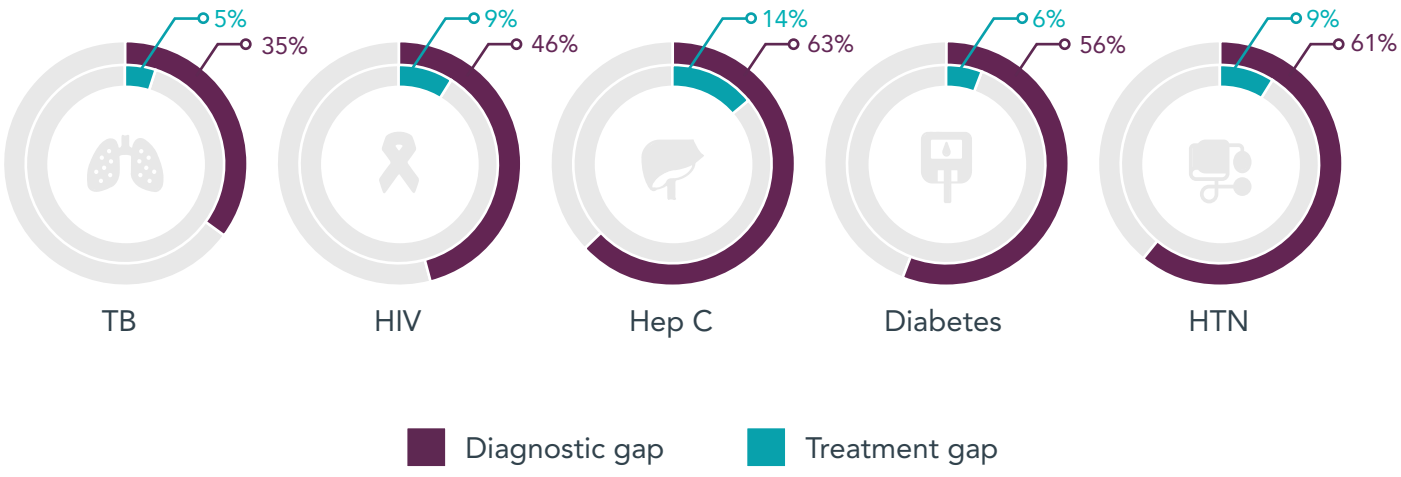
- Screening for asymptomatic infections and diseases that may progress but remain symptomless for years
- Greater reproductive choice
- Better outcomes for non-communicable diseases such as heart disease, which are often missed in women due to gender- biased perceptions
- Antenatal testing that ensures women remain healthy during pregnancy and labour to reduce risk of maternal mortality
- Women to be empowered with the information they need to manage their own health

Even before COVID-19, the greatest gap in disease management was in diagnosis, not in treatment. The historical lack of attention to and investment in testing means that for every person diagnosed with a disease, another goes undetected; the 'testing gap' results in up to 50% of patients getting no care at all or getting care too late, with up to 65% of cases for some diseases never diagnosed.[24] Hepatitis C virus affects over 71 million people worldwide, but it is estimated that only 20% have been diagnosed.[25] Testing gaps also exist for NCDs; for example, nearly one in two people in India with diabetes are unaware that they have the disease.[26] Across Africa more than 50 million people were estimated to be living with diabetes in 2017, however, this is likely to be an underestimate and the majority are aware they have the disease.[27]

GRAPHIC: The testing gap in global health

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).

COVID-19: a challenge and opportunity to elevate testing

COVID-19 has focused political attention on testing, a neglected yet essential component of health systems and health security globally. However, while COVID-19 has increased public and political awareness about the importance of testing, on the ground, the pandemic's disruption to routine health services has resulted in reduced access to testing for other conditions. According to a WHO survey in May 2020, 46% of countries reported closure of population level NCD screening programmes.[28] Chronic diseases such as heart disease, diabetes, kidney disease and breast cancer dominate the Global Burden of Disease top 10 causes of mortality for women and screening is essential to save lives. In 2018, cervical cancer was the leading cause of cancer-related death in women in sub-Saharan Africa and many women are at risk; yet even in high-income countries screening has been impacted by COVID-19.[29]

"Women are critical to ensuring access to testing - a vital tool for meeting health challenges. We must protect, support and empower women to deliver testing where needed to achieve health goals or risk collapse of our health systems."

Dr Catharina Boehme,
CEO, Foundation for Innovative New Diagnostics (FIND)

In June 2020, a survey of Global Fund-supported programmes across 106 countries found widespread disruptions to HIV, TB and malaria service delivery as a result of the COVID-19 pandemic, impacting approximately three-quarters of programmes. There are challenges to testing and case identification for HIV, TB and malaria, with medical and laboratory staff reassigned to the fight against COVID-19.[30]

As documented in previous health emergencies such as Ebola, the COVID-19 pandemic has also disrupted access to critical sexual and reproductive health services and lock downs requiring people to stay at home has increased gender-based violence, at a time when women and girls need services most.[31] Of particular concern is disruption to pregnant women's access to antenatal tests, which are crucial for detecting issues that may increase the risk of maternal mortality, still a major cause of death for women in many low resource settings. Using the Lives Saved Tool to model the additional maternal deaths under different scenarios in 118 low-income and middle-income countries, researchers have estimated that reduced coverage of four childbirth interventions due to COVID-19, in the most severe scenario, could result in 56,700 additional maternal deaths.[32]

"Reaching Universal Health Coverage will not happen unless we address the inherent bottlenecks that drive the inequalities in access and utilization of diagnostics and health services, particularly for women, youth, children and the elderly."

Dr Prosper Tumusiime, Acting Director, Universal Health Coverage & Life Cycle Cluster, WHO Regional Office for Africa

Gender inequality undermines testing

Gaps in access to testing threaten the health, lives and livelihoods of women and adolescent girls and undermine UHC efforts. Women face barriers in accessing testing related to both demand and supply side issues. Many of the barriers discussed are not unique to testing and reflect the literature on barriers to access to healthcare for women in low- and middle-income countries more broadly. When considering barriers to healthcare access for women, it is important to recognize that different groups of women have different needs and will face different challenges. For example, with HIV testing, adolescent women and sex workers may be the hardest to reach but are also the most important to reach, requiring specific initiatives.

In this section, we present an overview of the spectrum of challenges that affect women's access to testing, for a range of different conditions, as evidenced by research and experiences in diverse low- and middle-income contexts. We outline the different and interacting gendered barriers that need to be addressed to ensure women have access to acceptable, appropriate and affordable testing.

> "Gender disparities in diagnostic testing underlie gender disparities in health care. Testing means proper diagnosis means proper treatment - women should not be denied this health right."
>
> *Dr Michelle Gayer,*
> *Director of Emergency Health, International Rescue Committee*

CHALLENGE 1:
Gender inequalities within households and societies hinder access to testing

Where women lack decision making power within their family, consent from husbands or other relatives can be a major barrier to accessing testing, especially for asymptomatic conditions.[33] Sexually transmitted infections (STIs) like chlamydia and gonorrhoea are more likely to be asymptomatic in women than in men, but the resulting health impacts if untreated (including infertility) can be more severe. The time required to undertake testing is a barrier for busy women juggling economic and domestic labour, especially as tests can be time consuming and may need to be repeated.[34] Women may not come

for testing, even where it is low cost or free, because they have a heavy workload of domestic, childcare and other paid or subsistence work.[35] Transport may be an added obstacle if it is unsafe for women or costly.[36]

Gendered financial barriers stand out as a common challenge across contexts, as the snapshots below highlight. On the other hand, where testing services are provided free at the point of delivery, especially when integrated into primary health care, women may be more likely to access them. For example, the Kingdom of Eswatini provides free TB screening and testing for everybody who accesses any public healthcare facility, which has reportedly led to dramatic increases in TB care access for all, but notably for women who access TB testing while attending reproductive health services.[37]

Financial barriers to TB testing for some of the poorest women in Peru[38]

Research in Peru has found that, despite women having greater knowledge about tuberculosis care than men, financial barriers prevented women accessing available TB testing. Women's lack of financial independence and the low prioritization of their health by family members were underlying issues. Difficulties meeting the cost of healthcare contributed to delays in seeking testing. Although TB care is free, women reported that the patient must still pay the cost of the initial consultation at the clinic and all analyses prior to the sputum test. In addition, there may be hidden or indirect costs, such as the cost of a chest radiograph, lost income whilst unable to work and the cost of travel to the health establishment. There was a common perception that women's TB care was of secondary importance to that of men. This reflected societal gender values and occurred despite apparent gender equality in care provision. In Peru, the greatest opportunities for improving women's access to TB services appear to be in improving social, political and economic gender inequality, and less in programme modification.

Financial barriers to maternal diagnostics in Senegal[39]

In Senegal, research on the barriers to uptake of antenatal maternal screening tests revealed that the complete set of six antenatal screening tests were only available from the health centre level and above. This proved a major barrier to access because most women

access antenatal care in health posts close to their homes. Although laboratories in Senegal are generally well equipped and staff trained, the intermittent stock-out of reagents and breakdown of machines pose barriers to uptake of antenatal testing. Financial issues were identified as barriers, especially for the poorest women: two thirds of women struggled to afford tests. Less than 10% of women had some of the costs covered by health insurance, showing how much progress will be needed to achieve UHC. The high price of tests and the need for multiple trips, combined with poverty constitute major barriers to women taking up antenatal testing in Senegal.

Examples of barriers women in Nigeria face to access testing

Summary of evidence compiled by WGH Nigeria Chapter

Testing sites are not accessible: For many rural women in Nigeria, testing sites are not accessible. Factors affecting accessibility include poor roads, difficulty with transportation, long distances, and facilities not always being open when needed.[40]

Tests are not available: Local studies have reported a dearth of available testing and diagnostics at primary care level, which is a greater challenge in Northern Nigeria compared to the South, and greater in rural areas than urban centres.

Tests are not affordable: Breast and cervical cancers are responsible for more deaths than any other cancers in Nigeria, in part due to their late diagnoses. Health care is not affordable for all in Nigeria and one study estimated that over 72% of breast cancer patients in Nigeria pay out-of-pocket for their treatment due to poor social health insurance coverage; as elsewhere, finances are often in the hands of a husband or male relative, who may not wish to pay for testing or treatment.[41] In a study of pregnant women in South West Nigeria, 97% reported relying on their husbands for financial support to access antenatal testing and care.[42] The high costs of services, women's inability to pay for services even when costs are not excessive, and the introduction of informal payments by staff discourage many rural women from using primary care services including testing.[43]

Women are unaware of the benefits or availability of tests: In a study of women in Lagos, the major barriers to the uptake of cervical cancer screening were lack of awareness of screening methods (64% of participants) and lack of adequate information on screening methods (43%).[44]

Stigma deters women from seeking testing: In a review study, stigmatizing behaviour by healthcare workers was found to be worst against women; a reflection of power imbalances which manifest as financial inequality and low levels of authority, were noted to discourage women from seeking diagnostic and treatment services.[45]

Women in humanitarian settings are particularly hard to reach: Rural women in conflict affected Northern Nigeria face the greatest barriers to accessing healthcare including testing.[46] In a 2015 assessment of HIV/AIDS services in camps for internally displaced people in North East Nigeria, 60% of the camps had reported residents living with HIV/AIDS in the camps. However, only 30% of the camps had some form of HIV testing services, which was not standardized.[47]

CHALLENGE 2:
Gender inequalities create information barriers, and produce fear and stigma around diagnosis

Health literacy is not universal. Even where testing is available, women often lack information about what testing is, why it is important, and where they can access services.[48] Poor literacy among women and girls is reflected in poor health literacy. This highlights the imperative for quality girls' education as a key pathway to increase uptake of health services like testing. Sadly, due to cultural practices such as early marriage, teen pregnancy and son preference, many girls in low- and middle-income countries do not complete school and may struggle to comprehend health information and messages throughout their lives.[49] While literacy barriers can be overcome using radio and community mobilisation activities, information barriers are compounded for women from ethnic groups whose language or dialect may not be covered by national programmes.[50]

Information barriers to cervical cancer screening in the Caribbean[51]

Trinidad and Tobago has one of the highest cervical cancer mortality rates in the region. WHO has estimated that 549,000 women over the age of 15 are at risk of developing cervical cancer in Trinidad and Tobago. Barriers to screening uptake identified from qualitative research include lack of awareness and fear. There is lack of awareness about the importance of screening: many women are not

aware of cervical cancer, screening procedures and the importance and benefits of periodic pap smears. There are cases where women come for their first pap smear after experiencing discomfort and find they have advanced cancer. These experiences deter other women from coming. Some women dismiss the importance of the cervical cancer screening pap smear and fail to attend regular screening because they believe they do not have a "genetic" predisposition or risk factors, or think it is not needed because they are not sexually active. Alongside these attitudes, fear was one of the main barriers to having a pap smear. Women who have never had a test reported being afraid of the process and possible pain. Others who intended to have the smear were put off by other women´s negative experience with a doctor or of the procedure. Women may also fear the results.

The 'digital divide' exacerbates inequalities and differences in health literacy between men and women and different social groups. Gendered barriers to information will determine how news of testing services reaches marginalized women who may have no regular contact with the health system. Mhealth – the use of mobile and wireless technologies to support the achievement of health objectives - may be a solution to reaching women with testing information in high-income countries; however, globally around 327 million fewer women than men have a smartphone and can access mobile Internet and women are, on average, 26% less likely than men to have a smartphone, which means Mhealth solutions are not applicable for all contexts.[52]

Testing, prevention and early diagnosis of disease may not be a priority for women who lack information and have heavy demands on their time, particularly where a woman does not feel ill. In Palestine, 90% of women in one study were willing to have mammograms where they had a specific concern, but only 27% were willing to have screening mammograms otherwise.[53] Migrant women in Turkey lacked knowledge about breast cancer symptoms, risk factors, and screening, citing "feeling healthy" and "small breasts" as their reasons for refusing testing.[54] More research is needed to understand how to incentivize women in low income contexts to participate in screening programmes and how availability of treatment may influence demand for testing.

Even within the formal health system, information barriers exist. For example, in Trinidad and Tobago cervical cancer screening recommendations are not standardized and health personnel can be confused about who needs to get screened, at what age they should start, how often should it be done, and where should it be conducted.[55] If health providers are confused then mixed messages are likely to reach women and reduce attendance.

The evidence from other health areas - most notably, vaccine hesitancy (also known as the 'anti-vax' movement) - demonstrates the power of misinformation to undermine public health goals. Women's health is particularly plagued by rumours; health information may be manipulated by leaders to perpetuate control over women's bodies. For example, there have been allegations by religious leaders in some contexts that family planning or even vaccinations are strategies by donor countries to control population growth in low income societies or amongst particular social groups.[56] Religious leaders may prohibit its use, reducing reproductive choice for women and having negative impacts on their health. Working with trusted community influencers, especially trusted women, is thus vital to ensure women have universal access to the health information they need to promote health seeking behaviours including testing.

Research on modern contraceptive uptake among young women finds myths and misconceptions are important barriers to access.[57] Especially when a woman has no symptoms, the importance of testing is not immediately obvious, and she may be susceptible to misinformation. Women do not make decisions to use services such as testing in isolation, but in consultation with others in their social networks. Both information and misinformation are spread through social networks, which must be engaged to ensure correct and appropriate information on testing reaches women, thus creating trust in testing.

Myths and misconceptions about testing often stem from stories involving negative experiences when women have accessed services. Such stories can impact demand and service utilisation. For example, in Uganda, a qualitative study on cervical cancer screening found mistreatment of women by health workers at health facilities: women noted some health workers were rude to women and women therefore stopped attending and went instead to traditional herbalists; other women expressed concerns and fears about testing methods, heightened by previous poor treatment by health workers.[58]

Compounding practical issues, gender related stigma prevents women from seeking testing for some conditions. In South Asia and the Middle East Type 1 diabetes in girls and young women is sometimes concealed due to social stigma and a fear they will be less marriageable if their condition is revealed.[59] In countries affected by HIV/AIDS, women are reluctant to seek testing concerned that possible revelation of their HIV status would lead to stigma and societal rejection.[60] Social stigma associated with work women do, including sex work, may make certain groups of women less likely to seek testing.[61] Global evidence shows the burden of TB stigma falls more heavily on women than men: a woman who is found to have TB may be divorced by her husband or, if unmarried, may have difficulty in finding a husband[62]. In a stigma study examining community perceptions of TB-related stigma in Western Maharashtra, India, 40% of women were uncertain that their spouses would support them after positive diagnosis.[63]

Gendered biased perceptions matter too: TB kills more women annually than all causes of maternal mortality combined, yet TB is considered a 'male disease'. The fact that globally men are more at risk of contracting and dying from TB than women (in 2017 close to 6 million men contracted TB compared to an estimated 3.2 million women[64]) means women are often not targeted with screening in the same way.[65] For example, in a Swaziland study among women, the screening tool was found to miss 85% of the active TB cases.[66]

CHALLENGE 3:
Reaching the most vulnerable women

Lack of accessible, acceptable and quality testing threatens the health and lives of women and adolescent girls and undermines UHC. Although barriers to testing exist for all women in all countries, special attention – and innovation – is required to reach the most vulnerable groups. In many low-income countries, where investment in health has focused on maternal and child health, pregnant women and mothers may have better access to HIV testing, for example, than adolescent girls, women who are not mothers, and older women. Women left behind from UHC efforts – including migrants, women displaced by conflict, those living in humanitarian settings, women from ethnic minorities, and disabled women – face barriers to accessing healthcare including testing. Female sex workers and gender-based violence (GBV) survivors are especially vulnerable groups with additional testing needs.

Women in humanitarian settings are some of the hardest to reach for testing and have some of the most complex needs and worst health outcomes. Diagnostic approaches must be tailored to fragile states and humanitarian settings if UHC is to reach the most vulnerable women and children.[67] Reaching women with testing in these settings requires task-shifting so community-based healthcare workers are equipped to reach women with testing who may be unable to access services due to cultural norms or insecurity. The lack of affordable and field-applicable tests is a challenge for humanitarian organizations; for example, rapid diagnostic tests that do not require laboratory infrastructure are urgently needed for COVID-19 and other conditions in humanitarian settings.[68]

Wherever they live, the most marginalized women may not come for testing unless services can be taken to them at community or doorstep level, integrated with other health services they will be attending or through self-testing. To manage health campaigns, spread awareness about diseases, testing and prevention and support the response to health related emergencies, Pakistan depends on a cadre of 100,000 Lady Health Workers, who provide door-to-door services to women in areas without access to comprehensive healthcare. Each Lady Health Worker oversees 150-200 households, reaching women in a highly conservative social context where women's mobility can be severely constrained, even to seek health services.[69]

Testing and women IDPs in Cameroon

As a result of ongoing political crises, Cameroon has nearly one million internally displaced persons (IDPs). WGH Cameroon conducted research in the South West region, an area where long term political crisis has weakened the health system and limited access to testing for almost half a million IDPs. Interviews and focus group discussions with health workers were conducted to explore the challenges for testing in this humanitarian setting.

The main challenge reported was financial, as women are not able to pay for the tests needed to diagnose their conditions. This is particularly true for STIs whose infection rate seems to have increased since the beginning of the crisis: a nurse noted "every week we are noticing an increase in the number of new HIV cases and STIs". Women willingly take tests that are offered for free but cannot afford the ones that require payment. There is a need to subsidize tests for Hepatitis B and C that are still very expensive for pregnant women. Waiting times are also a challenge: "women need to wait for a long time for a test result. They either leave and do not return for the results or avoid doing the test".

Insecurity is a serious issue in the region, limiting access to health facilities for all. Communities have relocated to "the bushes", beyond reach of the health system. To avoid getting ambushed by armed groups they seek care at local clinics, which have proliferated in conflict affected areas, but offer substandard care and do not conduct testing before treatment. The misinformation around the COVID-19 pandemic has further reduced attendance at health facilities as the community fears they will be infected with COVID-19 through vaccination. As a result, people do not only refuse to vaccinate their children, but also are very reluctant to attend the hospital for primary care, including diagnosis services.

Health workers in this area believe the limited access to testing has serious consequences for individuals as well as for the community as a whole. Symptomatic treatment without testing leads to increased treatment costs and longer hospital stays. Patients often present at the hospital too late with life threatening conditions, for example uterine rupture among pregnant women who did not attend antenatal checkups. The spread of infection due to late diagnosis is also a grave concern, particularly for STIs.

"I remember a case where HIV was spread to at least three members of the community in the same day. An HIV positive woman delivered a baby but she did not know her status because she had not done antenatal testing. Someone came from the village to see the baby and got wounded on the way. To help fix his wound they pressed the liquid from the baby's umbilical cord on the wound. After testing a couple months later, it turned out they had all become infected."

Community health worker

Some innovations to improve access to testing have been trialled, for example, community health workers have been trained to perform basic tests including using malaria rapid diagnostic tests (RDTs). Another intervention piloted was the "Mother-mentors" concept, where women are selected in the community to follow-up HIV positive women and conduct contact tracing. Although this project proved effective in a pilot phase, limited funding has prevented scale up. Health workers report lack of resources (including poor supply of tests) as a key challenge: ***"If we had more, we would do more"*** *said one nurse from Kumba.*

Health workers believe women have great potential to reduce the gap in testing. Discussions confirmed that ***"women are best understood by women"****, women feel more comfortable explaining their health problems to women health providers. To harness the potential of women to drive testing they recommend training of women leaders, subsidizing unaffordable tests, and empowering women to improve their socioeconomic status.*

CHALLENGE 4:
Shortage of female healthcare workers empowered to deliver testing

The testing gap data described above shows the scale and scope of the challenge remaining to ensure universal access to testing. While both men and women are affected by overall poor availability of testing in low- and middle-income countries, women face an additional barrier where sensitive tests are delivered by a male healthcare worker. Indeed, in many studies, women were hesitant about seeking tests and examinations from male health professionals.[70] Research into health systems and societal barriers for gestational diabetes mellitus (GDM) services found that "*it is not so much the number of available health care providers, but more an issue of not having enough female health care providers, especially female doctors, as many women do not want to discuss issues related to reproductive health with male doctors*".[71]

Research on NCDs has found differences in the way both symptomatic and asymptomatic women with NCDs are treated compared with men. Researchers found the gender of a patient significantly influenced doctors' diagnostic and management in a study that controlled for these variables: women were asked fewer questions, received fewer examinations, and fewer diagnostic tests were ordered for women for coronary heart disease.[72] These differences are considered to reflect gender bias against equitable prevention and treatment and have serious health implications for women.

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.[73] 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. It will be critical to ensure that cadres of frontline health workers such as nurses, midwives, pharmacists, paramedics and community health workers (the vast majority of whom are 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 communities to hospitals. In the second part of this report we explore the untapped potential of women to drive testing and create better health for all.

CHALLENGE 5:
The tests women need are not available in health systems

Lack of availability of tests in low- and middle-income country health systems is a major challenge for UHC, and one that affects both men and women. However, the tests women need during their life course as girls, mothers and older women will differ from those needed by men; women and men have different biology and are affected by health conditions unique to their sex. As with all areas of health, a gender sensitive approach to testing provision is essential to ensure care is accessible and appropriate for all genders.

An analysis of 8,000 health facilities across 10 countries found that just 1% of primary healthcare facilities had access to essential diagnostics and only 14% of hospitals had adequate diagnostic capacity.[74] Lack of supply may impact demand: findings from studies on women's take up of antenatal care in 85 countries showed women were more likely to attend if they believed medicines, tests and screening procedures would be available.[75] However, overall, the evidence base on how supply affects demand for testing is limited.

While access to essential medicines is explicit in UHC, access to essential diagnostics has received little attention. Despite the recent Ebola outbreaks, laboratory capacity in Sub-Saharan Africa remains woefully inadequate. Yet most tests (usually designed for high resource settings) required to respond to the evolving burden of disease faced by women in low- and middle-income countries rely on this infrastructure, including trained laboratory workers (see table in Annex II). Innovation is required.

The role of National Essential Diagnostic Lists

The diagnostic ecosystem is marked by a highly fragmented industry landscape, including numerous small start-ups seeking to maximize their return on investment, a lack of incentives to invest in product development, and vague regulatory pathways for approval of quality products and there has been a historic lack of guidance on essential diagnostics.[76]

In May 2018, the World Health Organization (WHO) published the first Essential Diagnostics List (EDL) and declared its commitment to give equal importance to diagnostic tests and essential medicines. The EDL serves as core guidance to help countries prioritize and formulate demand for tests that should be widely available and affordable within health systems.

The current WHO EDL has 46 general tests for routine patient care, and 69 for detection and monitoring of specific conditions. The EDL is intended to be a model for countries to develop their own lists based on their burden of disease and healthcare structure, and to plan the laboratory and other infrastructure needed to support testing. WHO's EDL offers countries a benchmark that they can use to measure and improve diagnostic services.[77] It also provides an important accountability tool for local

and global civil society advocating for UHC. India is one of the few countries to have an official national EDL, which is a positive first step as it details transparently the diagnostic tests that should be available. However, preliminary data from a pilot study shows limited access to those essential tests at the primary care level – greater investment is needed.[78]

Currently, lists are not being designed with women's specific health needs in mind, or with a gender-responsive approach, however, there is an opportunity to change this. To achieve UHC and to enhance global health security, national diagnostic strategies that take into account the needs of all genders are required.

Our consultation revealed many of the routine tests women need are not available, accessible or affordable in low- and middle-income countries. However, there is limited data to back up anecdotal evidence and field reports. Studies looking at baseline EDL availability in India and South Africa are planned, but these have not been designed to consider the different testing needs of men and women. Research is needed to understand the scale of the problem, as well as to evaluate pilot programmes in low resource settings. For example, in Nigeria, a project on cervical cancer prevention through screening using visual inspection with acetic acid has enabled the Nigerian government to facilitate the extension of cancer screening services.[79] As well as resources, innovation will also be required to adapt and develop the tests needed to help prevent premature mortality among women, however, such innovation has been hampered by a lack of investment and neglect for women's health in global health R&D.

CHALLENGE 6:
Lack of investment in women's health diagnostics

Gender inequality in testing begins in R&D. Many common pharmaceuticals have been deemed safe despite clinical trials only using men.[80] A US Government Accountability study revealed that 80% of the medicines withdrawn from the market were due to side-effects in women.[81] There has been a systematic underinvestment in research and development for women's health: in 2017/18 the UK Medical Research Council allocated less than 3% of its research expenditure on women's health, despite the fact that a third of women experience severe reproductive health problems.[82] If left undiagnosed and untreated, endometriosis can cause infertility yet in Australia only 1% of the National Health and Medical Research Council's annual budget was allocated for endometriosis research in 2015, despite endometriosis affecting 10% of women of childbearing age and is reported to cost Australian society $9.7 billion annually.[83]

Where clinical diagnostic definitions are based on symptoms reported from men, warning signs in women are often ignored, unrecognized or misdiagnosed, ultimately leading to undertreatment.[84] A recent systematic review of chronic

obstructive pulmonary disease (COPD) found that women with the condition were generally younger, smoked less, had a lower body mass index, and were more likely to be of lower socioeconomic status than men; in addition, women were more likely to exhibit small airway disease (bronchiolitis), whereas men are prone to develop emphysematous - these differences could potentially result in delays in diagnosis or misdiagnosis among women.[85] Regrettably, such research is all too rare and most diagnostic devices are designed without gender considerations.

There are however positive signs that the global women's health diagnostics market is being taken seriously. Industry research estimates that the market is projected to reach USD 36.64 billion by 2021 from USD 25.03 billion in 2016, at an annual growth rate of around 7.9% during the forecast period. However, it is also noted that shortage of skilled laboratory technicians and high costs of diagnostic devices, tests, and procedures are hindering the growth of the women's health diagnostics market.[86]

CHALLENGE 7:
Lack of research, data and evidence

As in all aspects of global health, gender considerations are crucial to enable the most effective and appropriate testing interventions. While some differences are linked to biology (for example, only women require testing for pregnancy or screening for cervical cancer), testing interventions for most conditions must consider how gender differences impact both demand for and access to appropriate testing. Yet how gender inequalities impact women's access to and experience of testing is poorly understood due to lack of data and research. In academia, our consultation revealed research has focused mainly on men's lack of access to testing, under the assumption that women (especially mothers) interact more with the health system and thus have more access to testing.

Without comprehensive and comparable sex-disaggregated and gender data, we cannot take a truly gender-responsive approach to men and women's relative access to testing. The lack of disaggregated data on testing for COVID-19 is, for example, a major issue. The COVID-19 Sex-Disaggregated Data Tracker is produced by Global Health 50/50, the African Population and Health Research Center and the International Center for Research on Women to study and expose data gaps. Their analysis (as of October 2020) finds only eight nations are reporting sex-disaggregated COVID-19 testing data.[87]

> "Sex-disaggregated testing data can provide a window into gender inequalities in access to health services. In many settings, women have less access to health care and health insurance than men, and are not allowed to make decisions about their own health care. These realities may be behind the disproportionately lower numbers of positive cases (of COVID-19) among women compared to men in some places."
>
> *Global Health 50/50*

Data collected by the International Rescue Committee (IRC) has shown a large 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. IRC cite women's lack of mobility, low priority for women's health and discrimination as causes of lack of testing for women.[88]

Unanswered research questions – time for a new gender-responsive research agenda

Lack of data is a widespread challenge limiting our understanding of women's access to testing and how a more gender-responsive research agenda can contribute to more effective testing for men and women. Many research questions remain unanswered and additional analysis is needed to better understand women's experience of testing and their specific barriers to access. While more quantitative data is also needed, re-analysing existing datasets such as those collected in Demographic and Health Surveys (DHS) could offer new insights. Standardized patient surveys offer a unique opportunity to compare testing access for men and women who seek care at facilities where testing is available.[89] In the private sector, manufacturers of tests may have sex-disaggregated data on consumers that could reveal, for example, the proportion of women versus men who purchase tests. This report scratches the surface of a large and important, currently underdeveloped, research agenda.

PART 2:

WOMEN AS DRIVERS OF TESTING

Rather than seeing women solely as passive users of health services, this report celebrates the women who drive health and diagnostic systems - 70% of the global health and social workforce are women.[90] We set out a vision for how enabling women as self-carers, care-givers, and health professionals will help close the gap in testing and thereby enable achievement of UHC and more effective global health security. However, although women drive health systems, they only hold 25% decision making roles. Empowering women political leaders to be health and testing champions will also be essential.

> "A world in which women have control and influence over health decisions, actions and management at all levels will help close the gap in testing and enable an environment of UHC for everyone."
>
> *Dr Anna Versfeld, StopTB Partnership*

Women are the non-professional caregivers closest to healthcare professionals and are often the ones who visit pharmacies and assume responsibility for health in the household. It is often a woman who encourages family members to visit a healthcare professional and who makes sure they test, take medicines and understand their health management.[91]

Highlighting evidence and examples from low- and middle-income countries across Africa, Asia, and Latin America, we explore the potential of women as drivers of change in health systems to help close the testing gap that is holding back UHC and global health security.

Nurses in Sri Lanka provide diagnostic health services at the heart of communities[92]

As part of a multidisciplinary team, nurses from the National Hospital of Sri Lanka provide outreach services to improve access to essential services closer to where people live. This includes homes, schools, working environments and community centres. Using a mobile clinic, they are able to reach the community, identify their health needs and provide access to health services accordingly. The services that

are offered include: physical assessment, blood pressure monitoring, blood sugar testing, height and weight, blood and urinalysis; health education for disease prevention and early detection. Historically, a key challenge in Sri Lanka is the limited availability of community–based services to provide diagnostic, investigation and screening within the community and hospitals are filled to capacity with a large number of avoidable admissions. A high proportion of the population is unaware of their health status and there are many undiagnosed NCDs. As a result of the nurses' work, over 350 consultations are offered free of charge each day. Over the last three years, over 300,000 people have been seen in their screening clinics. The mobile clinics reach people within the community that would otherwise not receive services and are well respected and appreciated. The key to the service is that there is community engagement and involvement in how care is provided. However, because nurses must use their personal time to support the clinics, sustainability is not guaranteed. Women are not empowered in their capacity as qualified health professionals and this situation perpetuates gender inequalities around fair pay.

Traditional Birth Attendants deliver HIV testing in Nigeria[93]

In Nigeria, the Traditional Birth Attendant (TBA) and PHC centre Integration (TAP-In) model has been trialled in two states as part of a quasi-experimental study. TBAs were mapped, evaluated, and upskilled to increase HCT (HIV counselling and testing services) to pregnant women to increase their likelihood to take up HIV screening and diagnosis. TBAs buy-in into the intervention was secured, before they were integrated into selected PHC facilities with referral linkages for their clients. In less than one year, the TAP-In programme contributed 20% to the overall total number of pregnant women counselled, tested and who received their results in the two states. More importantly the outreach contributed 12% to the total number of women diagnosed with HIV infection in the two states. Evaluation of the TAP-In intervention found that intervention facilities more than doubled the number of pregnant women who received HCT in their catchment area, compared with the control. This provides

compelling evidence that engaging TBAs in health delivery has the potential to help prevent mother-to-child transmission by improving screening and diagnostics services. Empowering trusted women like TBAs in the health system can improve testing reach and uptake by their female clients. The environment of trust and respect shared by women helped contribute towards closing the testing gap in women's health.

Community health workers deliver malaria testing in Zambia[94]

Community health workers (CHWs) are nominated by their own communities to provide health care at the household level. Individuals receive a modest set of incentives after their initial training. However, these volunteers receive no ongoing monetary compensation for their work. In Zambia, CHWs are effective delivery points for prompt and effective malaria case management at community level. When CHWs were trained on testing for malaria and administering treatment to malaria positive cases, there was an increase in the number of individuals tested, especially children and women. In this study, all the 20 severe malaria cases were referred to the health facility. At the end of the study no severe malaria cases were reported in patients initially diagnosed as uncomplicated malaria at all the sites, demonstrating the competency of the CHWs to use rapid diagnostic tests as well as other healthcare professionals. Unfortunately, progress to sustain and scale up has been hampered by lack of supplies to enable the initiative to continue; the success of such initiatives depends on the government's commitment to ensure availability and sustainability of the testing programmes.

Community health workers provide free pregnancy tests in Madagascar[95]

Not having access to affordable pregnancy tests profoundly affects women's lives. Without access to these tests, women are not able to confirm if they are pregnant. This leads to delays in getting prenatal

care services. Complications related to pregnancy as well as mother and infant deaths are all too common in low-resource countries. Pregnancy tests now cost only 10 US cents wholesale, but are not universally available. In Madagascar, a solution has been trialled: researchers used a randomized controlled trial to allocate community health workers to receive (or not) free pregnancy tests for distribution in their community. After following these health workers for a period of four months, it was found that offering free pregnancy tests through community health workers led to an increase in the number women seeking general health services: a 50% relative increase from the control-group was observed. Importantly, this intervention also led to significantly more women receiving antenatal care. Urine pregnancy tests are one example of a hugely under-appreciated health technology for improving women's health. Providing pregnancy tests through community-based programmes is cost effective. Introducing free home pregnancy tests as part of community-based health services can enable more women to confirm they are pregnant and receive antenatal counselling and care.

Spotlight on female pharmacists

In many low- and middle-income countries, pharmacies are the first point of call for healthcare needs.[96] When women do not have time to visit healthcare facilities - where waits may be long, medicines may be short and tests are rarely available – pharmacies represent an important and untapped part of the diagnostics delivery chain. Behind the counter, the pharmacy workforce is already predominantly female and the proportion of women is set to reach around 72% by 2030.[97]

Research by The International Pharmaceutical Federation (FIP)[98] has found that pharmacists, as often the most accessible healthcare professionals, are in an ideal position to:

- Empower women in their role as informal caregivers
- Communicate to women about their health and testing needs
- Support women's health literacy, to enable them to manage their own health and influence others

However, as in all areas of global health, the sector is 'delivered by women, led by men'.[99] The International Pharmaceutical Federation has started to address this through its work on gender equity in the industry.

"Having the leadership of women limited in the profession is detrimental and concerning because women are recognised as agents of change globally. Having leadership that is gender-diverse has far-reaching benefits in all spheres of society."[100]

Nsovo Mayimele, South Africa

"Women are frequent visitors to pharmacies. Pharmacists are therefore in an ideal position to educate women about medicines and health, to build an alliance with women, and empower and support women to better care for the health of their families. You can view this as empowering women as well as "training the trainers."[101]

Parisa Aslani, Australia

Spotlight on self-testing

In this report we use self-testing to cover, self sampling and self-testing.

Why self-testing benefits women

- It can be done without women needing to gain consent to access services that may be unaffordable
- It allows women privacy and control over the process and information
- **Self-testing empowers women: putting health in their hands**

However, self-testing must be accompanied by access to follow up counselling and care in the event of a positive result.

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, however, few of these innovations are available in low - and middle-income countries, although 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. Self-testing 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. However, it is crucial that self-testing is linked to care pathways; for example, if a woman uses a pregnancy self-test to learn about an unplanned pregnancy, it is vital she has access to counselling and abortion services if required.

Self-testing for pregnancy is something most women in high-income countries take for granted. However, this is not the case in much of sub-Saharan Africa. For example, in Zambia, the problem is one of availability and affordability. Pregnancy self-tests are not readily available in PHC facilities, and this may mean only those who can afford to buy them from private pharmacies can access them. In particular, unmarried young women, who may be subject to stigma if pregnant, could benefit from access to pregnancy self-tests but these women are least likely to be able to afford them from pharmacies.[102]

HIV self-testing (HIVST) – where a person collects their own sample (oral fluid or blood) and then performs the HIV test (with or without supervision), interpreting the result

often in private – is a discrete, empowering and innovative way to increase HIV testing among people who are harder to reach with 'classical' testing and counselling strategies. A recent meta-analysis of five randomized control trials found HIVST to increase uptake and frequency of HIV testing.[103] Many of the studies among women have focused on pregnant or post-partum women and female sex workers, finding that women have been successful in giving HIV test kits to partners.[104]

As the snapshots below show, women can both benefit from self-testing, and also play an important role in increasing access for others.

Young women and female sex workers benefit from HIV self-testing in South Africa[105]

South Africa has the most adolescent girls and young women aged 15- 24 years living with HIV in the world. Despite this, HIV testing and linkage to care remains inadequate in this population; fewer than 50% of all 15-19 year olds reported ever testing in 2016, and only 14% of HIV-positive adolescents are on antiretroviral therapy (ART). In addition, young men aged 18-35, the partners of many of these young women, are some of the least likely to test for HIV. Novel strategies to get young people to test for HIV are needed. A recent study in South Africa found, when given a choice between clinic-based HIV testing and HIV oral self-testing, the overwhelming majority of young women chose self-testing. In addition, those offered a choice of HIV testing modality were much more likely to test, distribute test kits to peers and partners, and to have peers and partners who reported testing compared to women not given a choice. Self-testing offers an important opportunity to increase testing rates significantly among young women and their peers and partners.

Female sex workers and HIV self-testing[106]

Despite reduction in HIV infections in the general population of affected countries, the prevalence and incidence of HIV among female sex workers (FSWs) remain extremely high. Self-testing for HIV may be particularly appropriate for female sex workers who need frequent re-testing. HIV self-testing has been shown to be acceptable to and feasible for female sex workers and increases the uptake of testing. Modelling studies in Zimbabwe demonstrated that increasing HIV testing among female sex workers could be one of the most cost–effective uses of HIV self-testing.

"You don't wait for anyone to tell you your status. You know your own status therefore it's more private and it's up to you whether you tell someone or not." *– female sex worker*

Lessons learnt from programme with FSWs in Malawi and Zimbabwe:

- *Participation: female sex workers must be involved at all stages of planning and implementation.*
- *Female sex workers can test themselves accurately if adequately supported, but this may depend on the context or on women's levels of education and literacy.*
- *Acceptability of HIV self-testing by female sex workers is high, mainly because it overcomes some of the barriers they face, or perceive they face, when testing through general population or targeted services.*
- *Female sex workers have the potential to reach other hidden, high-risk populations using secondary distribution.*

AideSmart! an app for antenatal screening of rural Indian women[107]

In rural India pregnant women missed multiple antenatal screening opportunities due to inadequate public health facility-based screening, resulting in undiagnosed HIV and sexually transmitted bloodborne infections (STBBIs) and conditions (anaemia). Additionally, a shortage of trained doctors, rural women's preference for home delivery and health illiteracy affect health service delivery. To address these issues, researchers developed AideSmart!, an innovative, app-based, cloud-connected, rapid screening strategy that offers screening for STBBIs and anaemia at the point-of-care. A feasibility study of 510 women found women preferred the app-based system and that 95% stayed with the programme throughout their pregnancies. In conclusion, the AideSmart! strategy was deemed feasible to operationalise by health workers. It was accepted and preferred by participants, resulting in timely screening and treatment of HIV/STIs and anaemia, preventing mother-to-child transmission. The strategy could also be reverse-innovated to any context to maximize its health impact.

Self-sampling for cervical cancer

Around the world, self-sampling for cervical cancer is being scaled up to increase access. A study in Mexico found a home test for cervical cancer picked up more cancers and pre-cancers than tests conducted in a clinic and uptake was higher for the home test than for a test in a clinic.[108] 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 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.[109] A global study on the acceptability of self-collection sampling for HPV-DNA testing in low-resource setting found self-and vaginal-sampling are widely acceptable among women in low-resource settings.[110]

Community health workers (CHWs) can help inform women about and enable self-testing. In a pilot study in Uganda, CHWs went door-to door in their catchment areas to educate women about cervical screening and offered the option to self-sample for HPV testing or follow up with a health provider at their local clinic. Among participants, 93% of women chose to provide a self-collected sample over a provider-collected sample at a local clinic, indicating a strong preference for this screening option.[111]

To capture the benefits of any form of self-testing, the rapid linkage to care is paramount. A positive diagnosis must directly point to a range of affordable treatment options. For example, if a woman tests positive for pregnancy at home with a urine dipstick, it is vital she then has access to family planning options. HIV self-testing has the potential to improve test access and uptake, but counselling and support during and after HIV self-testing are a *sine qua non* to such forms of testing. Clear and accessible instructions for administering a self-test must be unequivocal, and thus may require adaptation where this is not the case.[112] In addition, many testers desire in-person support during the test process or need encouragement and reassurance from those providing pre-test counselling in order to proceed with testing.[113] There are contextual and individual nuances in the self-testing process and a balance must be struck between the need for privacy and the need for support.[114] Finally, quality assurance and market regulation, the linchpin of a developing market for self-testing in low- and-middle income countries,[115] will be key to ensuring uptake and building the community and health system trust in self-testing.

Women influence testing uptake in their communities

> "Women are not only primary health caregivers, but they also shape the health beliefs and behaviours of their communities. Their voice and engagement in leadership in the health sector is critical to achieving UHC."
>
> *Dr. Amina Jama,*
> *Project Director, Save the Children International, Somalia*

Women, as the main caregivers, can be powerful actors in health prevention and promotion within their families and communities. Women can thus play a critical role in spreading accurate information within communities about testing, reducing fear and increasing uptake. Programmes to influence uptake 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. Health literacy training for women's groups has been found to improve uptake of maternal and child services. Women's groups have also improved screening for HIV, especially among internally displaced communities, and worked actively towards reducing stigma.[116]

In Somalia, women's role as influencers is used to improve health:[117]

- To reduce maternal mortality in Somalia, traditional "cutters", whose role was to conduct female genital mutilation on girls, were engaged with financial incentives and retrained as health promoters to reduce female genital mutilation.

- Traditional Birth Attendants (TBAs) have been absorbed into community health committees and retrained to act as a bridge between the community and health facilities, referring women to clinics to increase antenatal visits.

- Midwives command huge respect with families and have been trained as health communicators to help bridge the relationship between the community and district health committees.

Women political leaders can drive investment in testing

> "We can influence the inclusion of testing in health budgets and support the formation of gender responsive health services that prioritize diagnostic services. We are here to help improve access to testing, and improve the female representation in leadership positions."
>
> *Her Excellency Reem Al Mansoori, member of the Council and ambassador of the Women Political Leaders in Qatar*

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.[118] 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; moreover, they found the biggest falls in maternal mortality where gender quotas had been in place the longest.[119] Beyond reducing maternal mortality, research has shown that parliamentary gender quotas have positive impacts on infant health outcomes, and women's education and empowerment.[120]

In the COVID-19 response, female political leaders around the world have stepped up the challenge. In January 2020 only 12 out of 193 countries (6.2%) had a female head of government.[121] Nevertheless, one study in July 2020 found female-led countries had fewer COVID-19 deaths per capita, a shorter number of days with confirmed deaths, a lower peak in daily deaths per capita, and a lower excess mortality. The study concluded that female leaders had acted quickly, implementing measures of lockdown early on as recommended by national health experts.[122] A second study concluded that deaths from COVID-19 were six times lower in female-led countries due to early, decisive action.[123] Other commentaries have noted that more inclusive communication skills of female leaders have helped build collective action, public trust and compliance with public health pandemic response measures.

Conclusion

In 2019, before COVID-19 had become a feature of all our lives, FIND and WGH embarked on a joint programme of work to gather the evidence from diverse low- and middle-income countries on barriers to testing faced by women and the role that could be played by women in the health sector, communities and political leadership to overcome those barriers. We were driven by the knowledge that access to testing would be a gamechanger for millions of women, enabling them for the first time to manage their own health and lives.

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 universal health coverage 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.

Some of the barriers to testing faced by women are gendered barriers women in some contexts face to accessing healthcare in general, including lack of autonomy to seek health care, lack of mobility and unsafe transport and affordability for the poorest women. Other barriers, however, are specific to testing, including the question of how to persuade women to come for screening when they might not have symptoms that trouble them. The evidence in this report also confirms that the delivery of diagnostic testing can be customized to reach even the most marginalized women, for example, in the form of self-testing. Once barriers to access are known and understood, solutions are possible.

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

FIND and WGH, having documented the testing gap for women in low- and middle-income countries, will continue to advocate for the gender transformative changes that can be made in health systems to put women's health in their own hands through diagnostic testing.

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.

Call to action from WGH Nigeria:

- Coordination of National Screening Programs
- Health education programs targeted at women
- Enhance human resources for women's health
- Improve access to funding
- Priority should be given to most vulnerable women and aim to achieve Universal Primary Education for women
- Mobilize political will and commitment to encourage involvement of women in decision and policy making.
- Strong advocacy to drive political commitment to increase support in women's health initiatives

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.

3 key messages from WGH Zambia:

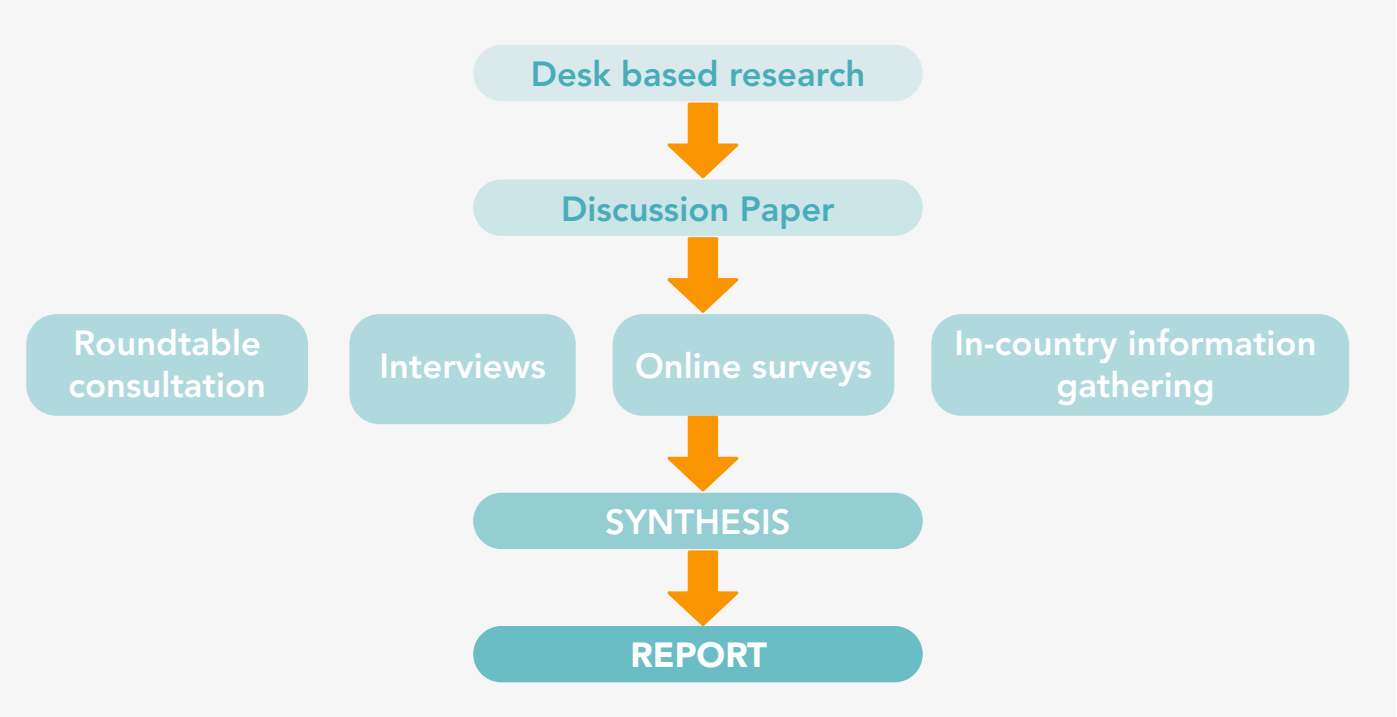
1. Quality is only enhanced through testing and empowering women to drive the diagnostic agenda can bring gains for government and populations

2. By giving women the opportunity to bring inexpensive and less complex tests to communities, we can enhance access for many and everybody wins

3. To achieve universal health coverage, no women should be left behind in access to testing.

Annex I: Methodology

The diagram below outlines the methodology for the report:



Desk based research (literature review)

The key search words were "access to testing," "access to diagnostics," "barriers to diagnostic testing," "access to diagnostic testing for women," "barriers to diagnostic testing for women," "female community health workers testing," "stigma <insert disease>," "diagnostic testing in humanitarian settings". Databases used: PubMed and Google Scholar, ArticlesPlus.

This desk-based research informed the discussion paper, which presented six key themes to be explored by the project:

1) Women face barriers to accessing testing

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

3) Women in humanitarian settings are particularly hard to reach

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

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

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

Roundtable

Drawing on the themes raised in the discussion paper, qualitative data for this report was also gathered during a virtual roundtable meeting held on July 14 2020.

Participants:

- WHO Regional Office for Africa
- International Council of Nurses
- UHC2030
- University of Yaounde, Cameroon
- The Partnership for Maternal, Newborn & Child Health Organization (PMNCH)
- United Nations Population Fund (UNFPA)
- National AIDS Council, Seychelles
- International Pharmaceutical Federation (FIP)
- NCD Alliance
- CORE Group
- WHO Gender Equity Hub, Global Health Workforce Network
- Eastern Mediterranean NCD Alliance
- Liverpool School of Tropical Medicine
- Uniting to Combat Neglected Tropical Diseases
- FIND South Africa
- FIND India
- WGH Somalia
- International Confederation of Midwives
- International Rescue Committee (IRC)
- Amref Health Africa
- Women Parliamentarians Forum, Inter-Parliamentary Union (IPU)

Interviews

Open-ended interviews were conducted among roundtable participants. Snowballing was used to identify further interviewees including from NGOs (PSI), donors (Government of Netherlands) and Commissioners from the Lancet Commission on Diagnostics.

Online survey

Using a Google survey template, we collected information from health organizations in using the questionnaire below. Responses were received from individuals involved on testing in Brazil, Ecuador, and Peru, as well as organizations working across Sub-Saharan Africa.

In country information gathering

WGH Chapter members used their local knowledge and networks to prepare short country snapshots to inform the report. We wish to thank WGH Nigeria, India, Cameroon and Zambia for their efforts. In addition, FIND staff in Vietnam, Kenya, Ethiopia, South Africa and India also provided important inputs.

Annex II: What tests will women need in 2030?

This table shows the tests for key diseases required to help close the testing gap for women by 2030.

Key message: the vast majority of tests currently available can only be performed with clinical laboratories.

Indicates tests that can be performed with no to minimal laboratory infrastructure

What tests will women need in 2030? *based on unpublished analysis by Dr Mikashmi Kohli using data from the Global Burden of Disease study 2017		
Predicted highest mortality diseases for women that require testing	*Diagnostics*	
	Type	*Tests*
Ischemic heart disease	IVD	Cholesterol levels, triglycerides, sugar levels, lipoproteins
	Imaging	Echo, ECG, Cardiac CT scan, Cardiac MRI, Coronary angiography, Chest X-ray, Coronary guidewire sensor technology, Cardiac PET scan, Coronary calcium scan, Cardiac MRI
	Clinical	Stress test
Diabetes mellitus	IVD	**Glucose levels,** HbA1c
Alzheimer disease and other dementias	IVD	Complete blood count, B12 levels, TSH levels
	Imaging	Brain MRI, Brain CT, PET scan
	Clinical Test	Mental status tests, neuropsychological tests
Lower respiratory infections	IVD	Biochemical bacterial typing, blood culture, mucus test, complete blood count, erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), sputum test, pleural test, urine test for Legionella, urine test for pneumococcus, bronchoscopy, NAAT
	Imaging	Chest CT scan, chest X-ray
	Clinical test	Pulse oximetry, Blood gas
Chronic kidney disease	IVD	Kidney function test, Urine test, microscopy (tissue)
	Imaging	ultrasound
HIV/AIDS	IVD	**HIV self-testing, HIV-1/2 RDT,** HIV-1/2 ELISA, HIV RNA quantitative and qualitative, HIV DNA quantitative, CD4 counts
Hypertensive heart disease	IVD	Cholesterol levels, triglycerides, sugar levels, lipoproteins, B type natriuretic peptide (BNP)
	Imaging	Echo, ECG, Coronary angiogram, Cardiac CT (computed tomography) scan, Chest x-rays, Cardiac MRI (magnetic resonance imaging), cardiac positron emission tomography (PET) scanning, coronary calcium scan, coronary guidewire sensor technology, Doppler ultrasound, Holter monitor, Nuclear heart scan, Cardiac catheterization
	Clinical test	Blood pressure monitoring, Stress tests
Breast cancer	IVD	Complete blood count, genetic testing, immunohistochemistry
	Imaging	Mammography, PET Scan, CT, MRI, Bone scan

Chronic obstructive pulmonary disease	Imaging	Chest X-ray, CT scan
	Clinical test	Lung function tests, arterial blood gas measures, oximetry
Diarrheal diseases	IVD	Complete and differential blood counts, Bacterial culture-stool/blood, Faecal leucocytes, Biochemical bacterial typing in stool/blood, Stool microscopy, Stool culture, Stool parasite microscopy, NAT for Shigella
Colon and rectum cancer	IVD	CBC, Tumour markers, Liver enzymes (for checking if it spread to liver, Histopathology)
	Imaging	CT, MRI, Colonoscopy, Proctoscopy, Ultrasound, PET scan, Chest X-ray
Cervical cancer	Clinical test	**Speculum, Acetic acid test**
	IVD	Pap test (microscopy), Histopathology, Immunohistochemistry, NAAT
	Imaging	X-ray, CT scan, PET-scan, MRI, Bone scan
Tuberculosis	IVD	**TST,** AFB microscopy, light and fluorescent, CBNAAT, Culture for MTB, Urine LF LAM, Drug susceptibility testing-for drug resistance, histopathology/ cytology for EPTB, body fluid biochemical analysis for EPTB
	Imaging	chest x-ray, CT scans, PET scans (for EPTB)
Tracheal, bronchus, and lung cancer	IVD	Sputum cytology, Immunohistochemistry
	Imaging	MRI, PET scan, chest x-rays, bone scan, CT scan
Malaria	IVD	Malaria light microscopy, Malaria LED-FM, Serology, **Malaria RDT**
Cardiomyopathy and myocarditis	Clinical test	**blood pressure, stress test (treadmill)**
	IVD	CBC, typhoid function, kidney function, liver function, iron levels, B-type natriuretic peptide, troponin T, creatine kinase (CK), CK-MB, myoglobin, antibody tests, molecular biology (genetic myocardiopathy), anatomopathology
	Imaging	X-ray, Ultrasound, Electrocardiogram, Cardiac catheterization, MRI, CT scan
Liver cancer	IVD	complete blood counts, liver function tests, hepatitis B and C tests, alpha-fetoprotein blood test, biopsy for histopathology
	Imaging	X-rays, PET scans, CT scan, Bone scan, Ultrasound, Magnetic Resonance elastography

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About us

Women in Global Health:

WGH, founded in 2015 and registered as a not for profit, is a global movement with more than 35,000 supporters across more than 90 countries and national chapters in around 25 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 120 national and global NGOs working for gender responsive UHC.

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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. FIND, in its strategy review for 2021-2023 has brought a greater focus to the gendered aspects of testing, the role of women in models for delivery of testing in communities, the potential for self-testing to reduce stigma and other barriers to care.

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