

POVERTY-RELATED AND NEGLECTED DISEASES THROUGH A GENDER LENS

This is a snapshot of a study available at this link.

**WORLDWIDE,
2.8 BILLION
PEOPLE ARE
AFFECTED BY PRNDs**

Worldwide, around 2.8 billion people are affected by poverty-related and neglected diseases (PRNDs), which includes the three major diseases HIV & AIDS, tuberculosis (TB), malaria, and neglected tropical diseases (NTDs). **COVID-19 has caused devastating setbacks in global health gains, with funding and implementation efforts to tackle PRNDs stalling.**

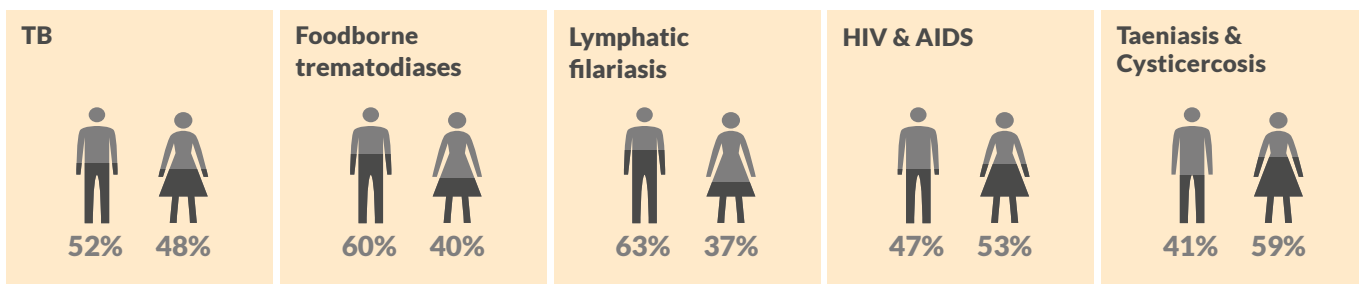
**THE COVID-19
CRISIS ADVERSELY
IMPACTED WOMEN AND
PEOPLE WHO FACE
DISCRIMINATION**

Women and girls have been particularly affected by the COVID-19 pandemic and the resulting economic downturn as they generally earn less, have less job security, are major caregivers, and are adversely impacted by a lack of access to healthcare. Similarly, people who face discrimination, stigmatisation, intolerance, or violence because of their actual or perceived sex, gender identity and expression or sexual orientation are particularly at risk.

**A STRONG
GENDER LENS
IS CRUCIAL
TO ACHIEVING POSITIVE
HEALTH IMPACTS**

Keeping a strong gender focus is key to staving off what is for now an almost silent but imminent and multifactorial global health crisis. Applying a gender lens to tackling PRNDs in this context is all the more crucial to achieving positive health impacts. This is a summary of a study highlighting a number of gender-related aspects of PRNDs, analysing the implications on research and innovation (R&I) and **stressing the benefits of gender-sensitive and gender-responsive approaches in fighting PRNDs.**

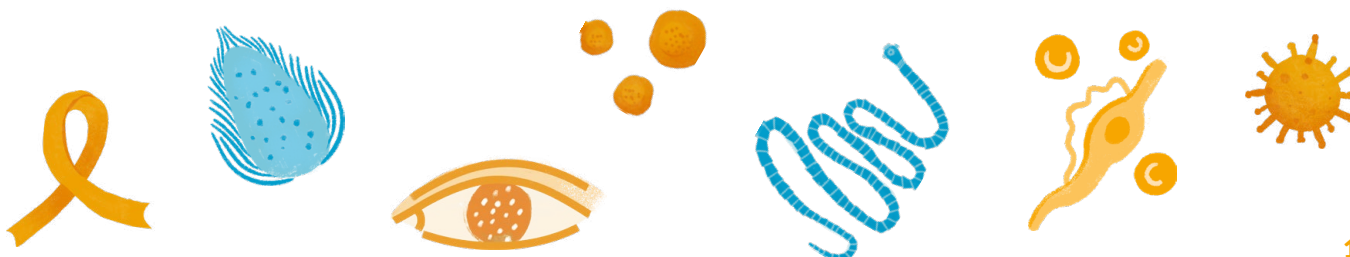
Global prevalence of selected PRNDs



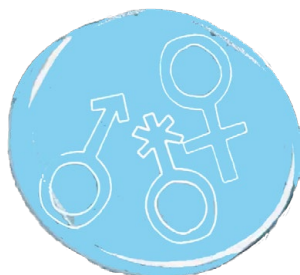
**PREVALENCE
OF DISEASE
IN MALES & FEMALES
IS INFLUENCED BY BOTH
SEX (BIOLOGICAL) AND
GENDER (SOCIETAL)**

Some PRNDs are more prevalent in males, others in females, and sometimes the disease burden is equal. **Prevalence is influenced by factors such as biological susceptibility, but also certain societal roles.** For example, women and girls are at a higher risk of contracting echinococcosis because they are more likely to be taking care of animals and preparing food, both of which enhance the likelihood of transmission of this zoonotic tapeworm.

The prevalence of disease, especially in women, may be underreported, especially for diseases affecting "hidden" body parts (which may engage in sexual activity, and can induce a social taboo), with women delaying or even avoiding to seek treatment altogether. The perception of a disease as a 'male disease', such as in the case of TB, because of its higher prevalence in males has shown to negatively influence women's health seeking behaviour, and can potentially lead to them being misdiagnosed.



BLIND SPOTS AND BIASES EXIST AT EVERY STEP OF THE R&I CYCLE



Following COVID-19, R&I needs for diagnostics, treatments, and vaccines received unprecedented global attention, as did the consequence of failing to include diverse populations in the development of new tools.

For other infectious diseases, such as **PRNDs, some of which have a high prevalence in females, the gendered dimensions of diseases and their significant impacts on health outcomes are often overlooked in R&I.**

'Blind spots', knowledge gaps, and biases exist at every stage of the R&I cycle. For example, research studies rarely report on the sex of the cells used in-vitro, and where the sex is reported, female cells account for only 5% of cells used. Females are underrepresented in preclinical animal studies, and clinical trials in humans tend to be skewed towards men.

IN PRACTICE

Disaggregate data by sex and gender

at each step and at each level of the R&I process and integrate both female and male sex in all phases of research and product development. Capture differences at biological and social levels through a holistic approach in order to improve treatment efficacy, efficiency, and safety.

Overview of selected NTDs, their cause, symptoms and intersection with gender and sex

Disease	Cause	Symptoms	NTD intersection with gender and sex	
			With risk infection	With impact of disease
LF	Parasitic worms transmitted by mosquitos.	Damage to the lymphatic system, resulting in swelling of arms, legs, or genitals.	Preventive treatments are not safe for pregnant women. Men and boys are at greater risk in many countries.	Disfigurement and disability can impact employability and marriageability of men and women differently. Hydrocele in males. Men may not seek treatment due to perception of masculinity.
Trachoma	Bacteria spread by people and houseflies; exacerbated by poor hygiene.	Eyelid turns inward; can lead to visual impairment or irreversible blindness.	Child-care and caregiving increase women's risk. Preventive treatment safe for pregnant women, but often not offered.	Women are four times as likely to need eye surgery. Women account for 86% of trichiasis cases.
OV	Filarial worm, transmitted by black fly bites.	Visual impairment, i.e. permanent blindness; intense itching and skin disfigurement.	2/3 of water-based domestic activities are completed by women, increasing risk. Preventive treatments not safe for pregnant women.	Disfigurement and disability can impact employability and marriageability of both men and women in different ways.
STH	Egg ingestion from contaminated soil, poor hygiene, or skin penetration by larvae in soil.	Aggravate malnutrition, amplify rates of anemia, and lead to cognitive impairment.	Men or women working in agriculture. Gendered cultural norms, such as open defecation. Out of school children may not access deworming campaigns.	Severe hookworm-related anemia in pregnant women. Low birth weight babies and/or premature birth. Infertility (caused by hookworm) for females.
SCH	Parasitic larva in water.	Leads to chronic ill health (e.g. damage of the bladder and urinary tract).	2/3 of water-based domestic activities are completed by women. Disease is exacerbated during pregnancy. Men and boy's work can increase risk.	Female Genital SCH causes reproductive organ damage, infertility, and increased risk of HIV. Can increase females' risk of anemia.

WOMEN MAY FACE A DOUBLE BURDEN WITH DISEASES AFFECTING NOT ONLY THEIR HEALTH BUT ALSO THEIR "ROLES" IN SOCIETY



When looking at how PRNDs affect different populations, **rather than looking only at prevalence, it is vitally important to also consider the differing impact that PRNDs may have.**

Studies suggest that **PRNDs impact men and women differently**, not only because of their sex but also, importantly, because of their gender and socially prescribed roles and expectations. For example, some diseases can result in women and girls not being able to fulfill prescribed care-taking roles or men being less able to fulfill prescribed income-earning roles.



For PRNDs that have disfigurement or infertility as a consequence, women may also face a double burden as their role in society often depends on marriageability and the ability to bear children. For people who are pregnant, some diseases bear the risk of vertical transmission, with often complicated implications for both the physical and mental health of the individual. Chagas disease, even though it has a higher overall global prevalence in females, actually has a higher mortality rate in males, which in turn, however, places women under additional physical, psychological, and financial stress. **These dynamics, existing gender norms, and power relations consequently impact the health-seeking behaviour of women and men.**

IN PRACTICE

Systematically integrate a gender perspective

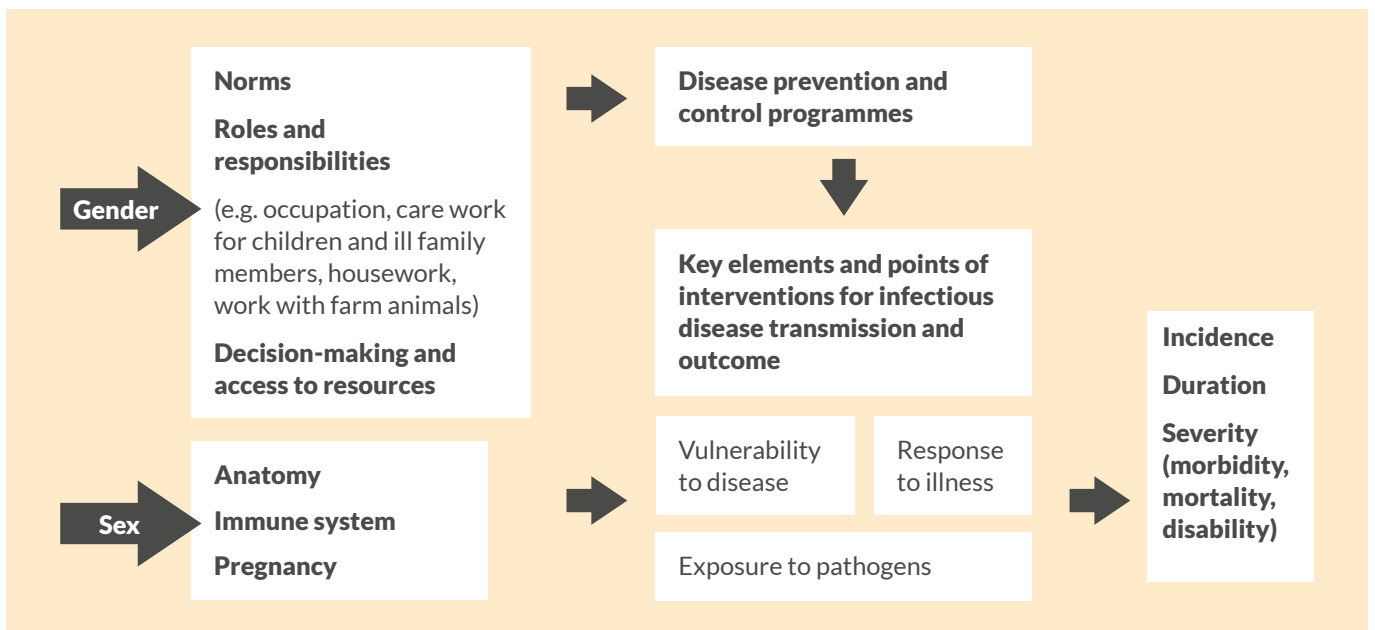
rooted in a contextual analysis of the gender-specific impact (and not only prevalence) of diseases and conditions. Mandate gender mainstreaming and intersectional gender analysis in the R&I process e.g. by establishing impact indicators specifically on gender.

IN PRACTICE

Consider all people beyond the binary focus on males and females

Data on how PRNDs affect LGBTQ+ individuals is limited as the collection of valid, reliable, and accurate data on different gender identities and sexual orientations may not only be very difficult but also dangerous in some contexts.

Framework for sex and gender and emerging infectious diseases





**NEXT TO
SEX AND GENDER,
OTHER FACTORS SUCH AS
AGE OR PREGNANCY
NEED TO BE CONSIDERED**

The intersection of sex, gender, and age is another important factor to consider as people’s biology and socio-cultural needs change throughout their life. **Diseases affect people of different sexes and genders differently at certain stages of their lives.** For instance, in 2021, 63% of all new HIV infections in sub-Saharan Africa were among young women, highlighting the need to consider the intersection of gender and age in HIV elimination efforts.

Pregnant and breastfeeding women have historically been excluded from clinical trials due to ethical and safety considerations. This may in turn lead to no treatment or treatment for which little data on efficacious dosing, safety, or effectiveness is available. **At the moment, the European Medicines Agency (EMA) defines pregnant and breastfeeding people as a ‘vulnerable’ population, which has major consequences for the possibility of including them in clinical trials.** As a result, pregnant and breastfeeding people may not be offered treatment because clinicians withhold the drug out of a lack of information or erroneous safety concerns. Similarly, pregnant and breastfeeding women are regularly excluded from Mass Drug Administration (MDA) programmes.



Examples of disease-specific impacts on pregnant women

Malaria	has a high prevalence among pregnant women and can pose a risk for both mother and foetus because the immune reaction in females can weaken during pregnancy, increasing the risk of contracting malaria. In addition, malaria may cause anaemia in pregnant women.
Chagas disease	bears the risk of vertical transmission of the disease to the foetus, and certain drugs are contraindicated in at least the first trimester of pregnancy.
Hookworm	may cause anaemia in pregnant women.
Leishmaniasis	decreases the fertility rates of women and impacts the perception of women in society.
LF	may increase susceptibility in infants and children to the infection, despite treatment of the mother.
Sleeping sickness	bears the risk of vertical transmission of the disease to the foetus, and decreases the fertility rates of women, impacting the perception of women in society.

IN PRACTICE

Address the lack of pregnancy safety trials.

Revise pharmacovigilance standards, and redefine existing concepts to include pregnant and breastfeeding people in the research process in a safe and ethically sound way. New strategies need to be devised to consistently and safely include them in MDA campaigns wherever possible.

Key decisions made by research teams but also implementers in the R&I cycle can be crucial - or detrimental - to sex- and gender-sensitive research. **Women in leadership and decision-making positions within research teams are more likely to consider and report sex-differentiated outcomes,** yet they are underrepresented in leadership positions. There is generally a need for more diversity across R&I teams in order to ensure that science delivers for everyone.



IN PRACTICE

Foster greater representation of women in science,

to facilitate better integration of sex- and gender considerations at all levels. Equal pay should be guaranteed, and greater support made available, including the provision of parental leave or child-care support, to foster a non-discriminatory workplace.



Failing to take into account the differing impact of PRNDs on women and men and overlooking social, and cultural factors when it comes to PRND R&I runs the risk that the end product may not be safe, or accessible for certain affected individuals, nor cost-effective for health care systems. This is why **a gender lens needs to be consistently applied throughout the entire R&I cycle - from discovery, pre-clinical, and clinical stages, all the way to regulatory approval, and post-approval studies.** Regulatory authorities have an essential role to play here by mandating the inclusion of women, and intersex people, where safe to do so. After all, research that incorporates sex and gender dimensions from the start has the potential to develop knowledge and tools that work better - for everyone.

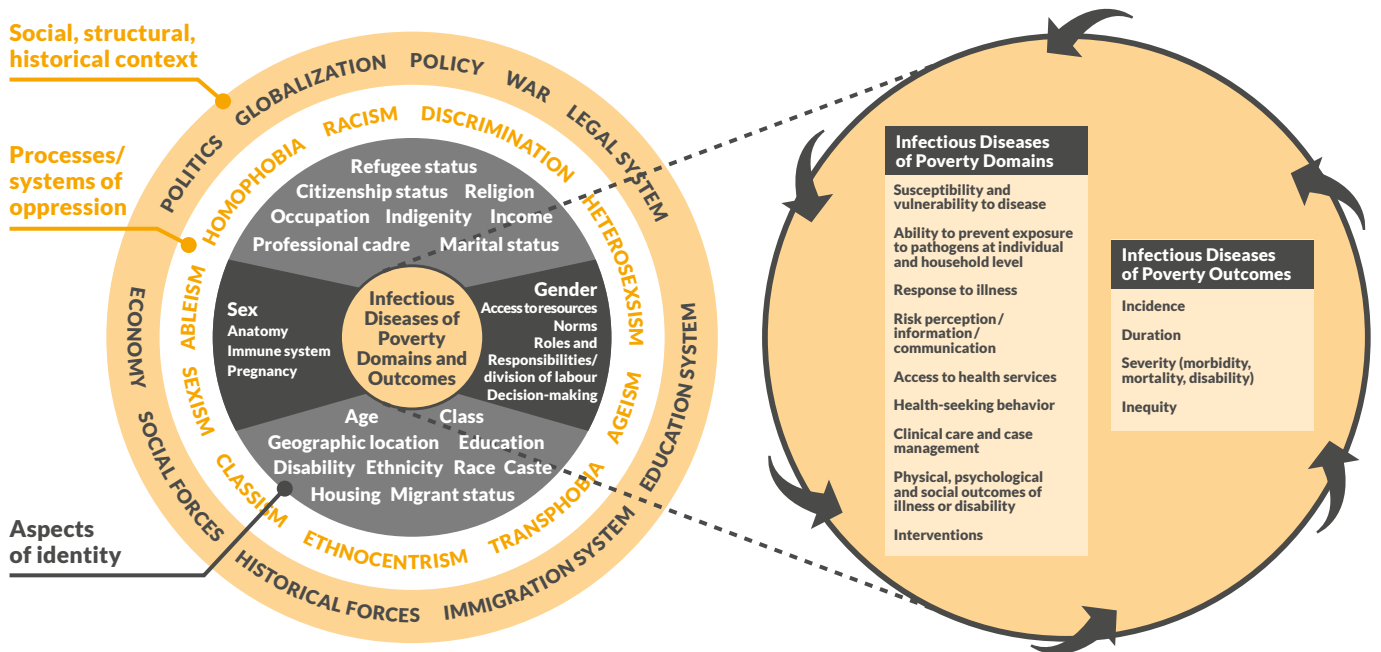


IN PRACTICE

Adopt a gender-sensitive approach in medical regulation.

Use regulatory enforcement, penalties, incentives, and other tools to foster the inclusion of sex and gender data in drug evaluation. Set up sex- and gender-disaggregated global performance indicators.

Intersectional gender analysis framework for research on infectious diseases of poverty



Source: TDR (2020)^{16:37}, design adapted for this study



THE NECESSARY CHANGE WILL ONLY HAPPEN WITH APPROPRIATE INCENTIVES AND DEDICATED FUNDING



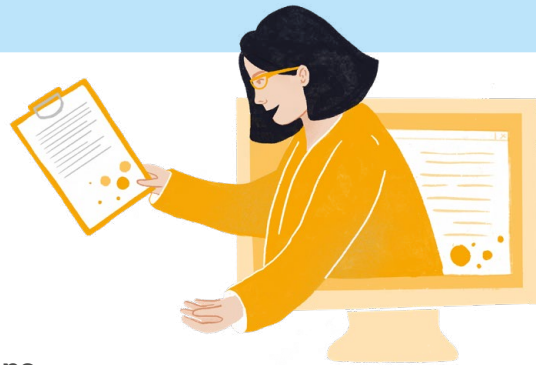
The implementation of all of the above recommendations will require that funding is made available to **fill knowledge, research, product, and regulatory gaps, and to increase gender capacities** within responsible authorities, organisations, research teams, etc. Standards and requirements for project funding proposals need to be re-defined, including through **setting relevant indicators that can support the mainstreaming of sex- and gender-considerations** in PRND R&I, rule out 'gender blindness' of the funded research, and serve as an incentive for relevant stakeholders and organisations to make necessary changes.

But there is also a **need for additional, dedicated funding** and calls for proposals that specifically address some of the existing knowledge gaps, invest in further developing and implementing gender transformative approaches, and recognise women and girls, LGBTIQ+ people, transient, or minority populations as priority populations.

IN PRACTICE

Allocate (additional) dedicated funding and set new standards.

Make public R&I funding conditional on the systematic inclusion of the gender dimension, allocate (additional) dedicated funding for sex and gender-related R&I projects and set new standards.



Research & Innovation needs through a gender lens

