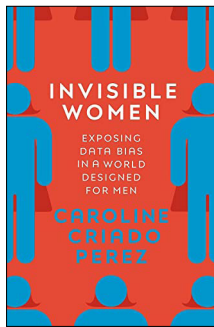




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Invisible women: Exposing data bias in a world designed for men



**AUTHOR:**

Caroline Criado Perez

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**REVIEWERS:**

Nezerith Cengiz<sup>1</sup>   
Siti M. Kabanda<sup>1</sup>

**AFFILIATION:**

<sup>1</sup>Centre for Medical Ethics and Law, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa

**CORRESPONDING EMAIL:**

ncengiz@sun.ac.za

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# Biased and sex-aggregated data: The forgotten half of the population

Big data, data science and artificial intelligence (AI) in research hold enormous potential to improve health and the quality of life for all. However, when harnessing benefit from new digital technologies, a major concern is to minimise harm. Inherent bias in historical data presents a major threat to the veracity of data and the impact thereof on algorithms, machine learning and, ultimately, AI.

In this respect, *Invisible Women: Exposing Data Bias in a World Designed for Men* by Caroline Criado Perez makes a timely contribution by exploring the gender data representation gap in health care, education, economic development, and public policy. Criado Perez is a feminist author, journalist and social activist who has successfully campaigned for empowerment and representation of women in a multitude of different contexts, including the media presence of female experts and social media, in particular.

The preface clarifies an important concept – namely the distinction that must be drawn between sex and gender in biological and social sciences. Criado Perez refers to sex as the “biological characteristics that determine whether an individual is male or female” (XX or XY). By ‘gender’ she refers to the social framing of the biological distinction or the way in which women are treated based on perceptions of them being female. In her book, the term “gender data gap” is used throughout because Criado Perez says “sex is not the reason women are excluded from data. Gender is.”

Although many women are aware of the gender inequality and bias they face on a daily basis, there are many spheres of a woman’s life that are negatively affected by exclusionary practices which may be less obvious. These range from car design (seatbelts, headrests and airbags), travel data, politics, sanitation and employment conditions, to clinical trials and health care that are all geared towards serving men, first and foremost. In some of these aspects, the bias goes beyond discrimination and places women’s lives at risk, such as where road safety and health are concerned.

*Invisible Women* is structured into six parts with each focusing on various aspects of the many daily struggles that women face simply because the data fail to account for them and exclude them from overall planning and decision-making. The author justifies her arguments with extensive research, statistics, and case studies, and provides vast endnotes for further reading. Each intriguing chapter of this book appears to arrive at the same inevitable conclusion: the gender data gap is “both a cause and a consequence of the type of unthinking that conceives of humanity as almost exclusively male”. Disregarding gender data bias fosters the placement of women as subordinate in our society, where what gets measured, weighed, and made statistically visible is prejudicially determined by the stereotypes that portray distinct social roles and the related spheres of activity for men and women. Generating high-quality data relies on eliminating gender bias at all phases. This in turn requires cognisance of data biases in order to take preventative measures and to make better decisions using data.

Criado Perez essentially provides all the gender data gaps that have occurred through her compilation of studies conducted, statistics reported, and data collected centuries ago that have been used to inform resource allocation, decision-making and policy development. The biggest societal issue seems to be that there is a collective lack of understanding amongst both men and women on the potential for bias in data that are collected. Discriminatory practices raised in the book are not intentional – but because things have been done a certain way for so long that people fail to identify the bias therein. *Invisible Women* unpacks unconscious gender bias and the unconscious way in which things have always been done, which cannot simply be removed mathematically or made ‘unbiased’ on a data level.

Chapters 10 and 11 will be of particular interest to basic scientists, researchers and health professionals. Here the bias inherent in medical research starts with preclinical research, specifically in animal studies in which female animals are not included in investigations on diseases that affect female humans predominantly. Criado Perez quotes Yoon et al.’s<sup>1</sup> review of high-impact surgical journals which found that up to 22% of articles did not specify the sex of the animal studied and, when reported, 80% of studies used only male animals.

It is astonishing that women are not equally included in clinical research and that most male-biased research findings and conclusions are generalised to represent the whole population. Non-representative data negatively affect the quality and validity of results and inferences. Criado Perez reveals that the same applies to drug trials investigating drug responses: results from male participants have been unconsciously considered valid for female individuals because of the assumption that sex did not affect outcomes, yet men and women are known to manifest different symptoms and reactions to various treatments. The chapters ‘The Drugs Don’t Work’ and ‘Yentl Syndrome’ emphasise that these issues can prove fatal for women who are misdiagnosed or medically mistreated unless their clinical indicators or illnesses conform to those of men. Criado Perez highlights that 80% of prescription drugs withdrawn from the US market at the beginning of the 21st century were shown to cause higher adverse drug reactions in women.

Criado Perez shows that the exclusion of women could only have occurred in a culture that conceives men as the default human and women as a niche aberration. Although true, it is also important to consider the role that different cultural, religious, and geographical contexts play.

In the chapter ‘A Cost-less Resource to Exploit’, the author writes: “...the unpaid work that women do isn’t simply a matter of ‘choice’. It is built into the system we have created...”. This statement is potentially correct when

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considering patriarchal cultural societies in which women are subjugated and seen as subordinates or second-class citizens with no autonomy to make judgements or decisions. However, some of the 'unpaid work' done by women is done by choice to maintain a healthy family structure. Not all women see 'unpaid work' as burdensome.

Contexts like developing countries in Africa have not been explored in as much depth as settings in the Global North, leading to some claims made on flawed inferences from uncontextualised aggregated data. Readers of *Invisible Women* would have benefitted from inclusion of more cases or examples from Africa to better balance different perspectives. It would also have been valuable to present more optimism about women rather than repeatedly depicting them as victims.

The afterword of the book summarises its key message well:

*The solution to the sex and gender data gap is clear: we have to close the female representation gap. When women are involved in decision-making... women do not get forgotten... This is to the benefit of women everywhere... and it is often to the benefit of humanity as a whole.*

This book is a valuable resource for both men and women in the current century and may stimulate ideas to close the gender representation gap. Unbiased and sex-disaggregated data collection are essential to guide problem-solving and improve decision-making that impacts populations at large. Most importantly, evidence-based medicine depends strongly on accurate, objective, high-quality data. Gender and ethnic biases seriously undermine this approach and erode trust in science and the health profession. In the era of data and AI-driven technology, eliminating bias is an ethical imperative. This book is essential reading for students, researchers and professionals, especially those working in data science as well as those in the biological and health sciences.

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