

Women in Data®
Policy paper:

DATA-DRIVEN ACTION TO CLOSE THE GENDER HEALTH GAP

INTRODUCTION

Women in Data[®] and **Capgemini Invent** have formed a partnership to join the movement and to be a force for positive change in the data science and analytics industry. We champion this platform for female and gender diverse data professions and encourage the sharing of technical knowledge and experiences as well as the illumination of women in the industry. The partnership will act as an engine of innovation and change, combining **Capgemini Invent's** transformative expertise with the insight of **Women in Data's**[®] network of over 25000 data professionals.

The partnership was launched with a leadership roundtable focusing on healthcare data and its impact on women's health. This was in recognition of the persistently poor healthcare outcomes women face and the urgent need to tackle ingrained gender inequalities in healthcare systems.

The event brought together senior experts from a range of private and public sector organisations, including NHS England, Cancer Research UK and the Department of Health and Social Care. The mission of the event was to draw on the expertise of those in attendance to better understand the role that data plays - and could play - in improving women's health outcomes.

The discussion focused in detail on how the healthcare sector can think and act in a more informed, inclusive and productive manner. To unpack the issues in as much detail as possible, discussion was structured around key processes in the data lifecycle:

Data collection

Data processing

Data analysis

Data consumption

This short paper captures the key outcomes of the discussion in order to inform health care policymakers and practitioners able to affect change. In particular it focuses on the role data could play in addressing the issues - and the challenges that need to be overcome in doing so; as well as the recommendations that arose during the leadership roundtable. Importantly, the discussion and this paper are intended as staging posts on a much longer journey. The intention is to provide direction for further research, exploration and discussion on how data's potential to improve women's health can be unlocked by the appropriate actors in the space.

PART 1

UNDERSTANDING THE GENDER HEALTH GAP

The leadership roundtable began with an introduction by Dame Clare Gerada, President of the Royal College of General Practitioners. Dame Clare starkly outlined the persistence of gender inequality in the health service, pointing towards the need to “give women the choice and means to get safe, accessible healthcare.”

Dame Clare’s comments brought to life the fact that in many areas of healthcare women experience poorer outcomes.

It is a major issue that has been outlined over many years through a range of studies, not just in the UK but globally. These include:

- A 2016 paper by researchers at University College London that found that [women with dementia receive poorer medical treatment than men with the condition](#). They found that women make fewer visits to the GP, receive less health monitoring, and take potentially more harmful medication.¹
- [A study that found that in US emergency departments, women who are in acute pain are less likely to be given opioid painkillers than men](#). Women also had to wait longer to receive painkillers when they were prescribed.²
- University of Rhode Island researcher Karen L Calderone’s findings that [women are half as likely to receive painkillers after surgery](#).³
- The [Royal College of Obstetricians and Gynaecologists \(RCOG\) ‘Better for Women’ report](#), which focused on improving the health and wellbeing of girls and women in the UK. Examining women’s access to healthcare through their entire life, the report said that several themes emerged that were common to each stage of women’s lives:
 - women cannot always find accurate information;
 - the NHS remains largely an intervention service, not a prevention service, and opportunities are often missed to empower girls and women; and
 - many women’s healthcare services are fragmented and difficult to access.

The gender health gap has also been acknowledged by the UK Government, with a [press release issued in March 2021](#) outlining some of main issues of gender inequality in health, stating that:

- Less is known about conditions that only affect women, including common gynaecological conditions that can have severe impacts on health and wellbeing. For example, on average it takes 7 to 8 years for women to receive a diagnosis of [endometriosis](#), with 40% of women needing 10 or more GP appointments before being referred to a specialist.
- There is evidence that the impact of female-specific health conditions such as heavy menstrual bleeding, endometriosis, pregnancy-related issues and the menopause is overlooked.
- Studies suggest that gender biases in clinical trials are contributing to worse health outcomes for women. A University of Leeds study found that women with a total blockage of coronary artery were 59% more likely to be misdiagnosed than men, and that UK women had more than double the rate of death in the 30 days following a heart attack.

Commenting on these findings, the Government said that there was strong evidence about the need for greater focus on women’s health. It also highlighted that although in the UK female life expectancy is higher than for men, women on average spend less of their life in good health compared to men. In addition, it noted that female life expectancy has been improving more slowly than male life expectancy since the 1980s.

All of the evidence shows that the gender health gap is real, it is all encompassing, and it has an impact on women internationally.

¹ Claudia Cooper, Rebecca Lodwick, Kate Walters, Rosalind Raine, Jill Manthorpe, Steve Iliffe, Irene Petersen, *Inequalities in receipt of mental and physical healthcare in people with dementia in the UK Age and Ageing, Volume 46, Issue 3, May 2017, Pages 393–400*

² Chen EH, Shofer FS, Dean AJ, Hollander JE, Baxt WG, Robey JL, Sease KL, Mills AM. *Gender disparity in analgesic treatment of emergency department patients with acute abdominal pain. Acad Emerg Med. 2008 May;15(5):414-8. doi: 10.1111/j.1553-2712.2008.00100.x. PMID: 18439195.*

³ 1989 presentation to National Conference for Women in Psychology

PART 2

DATA-DRIVEN OPPORTUNITIES

Data is increasingly being recognised as one of the world's most valuable resources, driving economies and holding the potential to effect major social change. Nowhere is this more so than in the ability of data to drive innovation in healthcare systems, with a recent [Capgemini analysis of key trends in healthcare](#)⁴ showcasing how data and digital technology are driving innovations towards more people-centred healthcare systems.

The UK Government has recognised the value of data with the recent publication of [Data Saves Lives: reshaping health and social care with data](#)⁵, a strategy to make the NHS and social care more data-driven. The strategy sets out a series of commitments, including:

- Investing in secure data environments to power life-saving research and treatments.
- Using technology to allow staff to spend more quality time with patients.
- Giving people better access to their own data through shared care records and the NHS App.

However, while the power data holds to drive innovation is incontestable, there are concerns that need to be addressed to ensure that the ways in which it is utilised do not reinforce gender inequalities that are already prevalent in healthcare systems.

In particular, it is clear that there are major issues to address in ensuring that gender bias does not inhibit the potential for data-driven ways of addressing the data health gap.

Most significantly, in her book, 'Invisible Women: Exposing Data Bias in a World Designed for Men', the author Caroline Criado Perez set out a range of statistics that show how women are treated unevenly. She has argued that the [data shows that healthcare is "systematically discriminating against women, leaving them chronically misunderstood, mistreated and misdiagnosed"](#). Criado Perez argues that women are routinely underrepresented in clinical trials and that medical research proposed by women, for women, is not allotted the same funding as medical research proposed by men, for men.

Data has the power to drive innovation in healthcare systems. But it could also exacerbate the gender health gap. Further discussion on the relevant and appropriate use of data could help to deliver benefits in this space.

⁴ [capgemini.com/insights/expert-perspectives/2022-key-trends-in-healthcare](https://www.capgemini.com/insights/expert-perspectives/2022-key-trends-in-healthcare)

⁵ [gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data](https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data)

PART 3

SETTING THE DIRECTION FOR CHANGE

Women in Data® and Capgemini Invent came together in mutual recognition of the issues outlined in this paper, determined to find ways of ensuring data is used to improve women's healthcare outcomes. Aligning a passion for change with technical expertise, the leadership roundtable that the two organisations convened was the first step on a journey towards having a real, lasting impact on the way that data is collected and applied in the healthcare system.

The event drew on the combined insight and expertise of the senior leaders in attendance to define the issues that most urgently need to be addressed.

First, the group agreed that **fundamental change is needed to ways in which data is collected**. The group discussed how the datasets that are used in all parts of the healthcare system too often tend to be unrepresentative of women's experiences and distinctive health issues. As such, far too much of the current practice is biased towards men women, with the implication that women's healthcare needs can go unidentified or mistreated.

In light of this, a potential recommendation identified during the discussion was to review data collection methodologies in the context of healthcare and life science to ensure that datasets are truly representative. This could include taking action to lower the barriers women often face in being part of data collection exercises - for example, making it easier for women to take part in clinical trials. It could also mean encouraging greater levels of data altruism, creating the conditions within which data subjects are willing to permit data-holders to use their data for general good.

Second, there was a clear determination to **ensure that data processing practices take better account of women's health needs**. In particular, there was a strong feeling that data analysis goals need to be aligned with the need to improve women's health outcomes. For example, this could mean that Key Performance Indicators (KPIs) about health outcomes need to be readdressed - possibly leading to better disaggregation of healthcare data to ensure that women's experiences do not remain hidden. Such fundamental change would require a clear commitment from the most senior decision makers, suggesting that growing female representation among healthcare leaders would also need to be prioritised.

Third, action is needed to **embed better recognition of women's health needs in data analysis**. As with data processing, women's health needs often go unrecognised as so much data analysis is carried out from an overwhelmingly male perspective. This lack of women's perspective invariably means that data is not being analysed in ways that will effectively shed light on women's healthcare needs.

The number of women data scientists is low and falling in the UK - something that Women in Data® is already working hard to counter. Further effort is needed to tackle this imbalance at every level of the healthcare system, from ensuring more women and girls are recruited to relevant education programmes, to putting measures in place that support women to flourish in data science careers. With healthcare in particular, attention needs to be given to the integration between data scientists and medical professionals.



Finally, the experts that **Women in Data®** and **Capgemini Invent** gathered in the room felt that **data consumption needs to be readdressed to have a positive impact on women's health outcomes**. This included recognition of the variety of groups that need access to correct and connected health data to make a difference, including patients, healthcare workers and public institutions. This will require the encouragement of a collaborative culture built on trust, as well as support in building data-understanding. For example, one option is to develop specific training programmes on data and its uses for medical professionals.

The breadth of issues covered in the discussion reflected the all-encompassing nature of the challenge. Gender inequities exist across the entire data lifecycle, from the ways in which data is collected, how it is processed and analysed through to the actions and innovations it informs. Action to address this needs to be equally multi-faceted, with interventions at every level. This means making changes to ensure that the right data is collected in the right format, that it is shared and used effectively, and that feedback loops are developed that avoid gender bias.

There is a need for all parts of the healthcare system to rethink how data studies are designed from first principles, accounting for possible gender biases and factoring in measures to counter them, ensuring that outcomes are truly representative of women's experiences and perspectives.



PART 4

MAKING CHANGE HAPPEN

As the evidence cited on this paper shows, gender inequalities in healthcare systems are having a devastating impact on women's health outcomes. While data offers the promise of positive innovation, there is a risk that existing inequities could be exacerbated rather than broken.

That's why it is so important that no more time is wasted - urgent action is needed to ensure that women's health is no longer allowed to suffer. **The Women in Data® / Capgemini Invent** leadership roundtable was an important first step. Thanks to the passion and commitment of the people that took part we have sight of a clear path towards real change, but there is still a long way to travel.

The goal is now to develop a fully detailed set of recommendations by drawing on an even wider set of expertise and insight and carrying out further research, towards the goal of launching landmark recommendations at next March's **Women in Data®** Annual Conference.

We cannot do this alone though, so over the coming months we want to marshal every force possible in progressing conversation around the challenges and potential recommendations outlined in this paper. We are calling on the active involvement of all aspects of the healthcare system: from clinicians and academics, to policy makers and representatives of the life sciences industry. Only a coalition of this nature can help to ensure data is a powerful force to improve the health inequalities that women face everyday.

The dream is to give women the choice, facilities & means to get safe, accessible healthcare.

*Professor Dame Clare Gerada,
President of the Royal College of General Practitioners*

It has been a privilege to facilitate such an intense discussion during this first women health and data event and provide a platform for a committed group of experts to look at women health through the data lenses. This powerful and committed group could really make a difference in better defining and amplifying the role of data with the ultimate aim of improving women health outcomes.

*Elisa Sai,
Senior Director - Analytics and AI at Capgemini Invent*

As data leaders, we are in a privileged position to effect change and we wish to exploit this to improve the lives of women the world over. **Women in Data®** and our community are equipped, informed and engaged to drive real impact on the way Data is leveraged to benefit women. With the greatest minds in Data and Healthcare at the table, the opportunities are endless!

*Roisin McCarthy,
Founder of Women in Data®*

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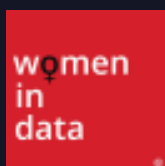
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