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TABLE OF CONTENTS

1. INTRODUCTION	3
2. AIM	8
3. DEFINITIONS	8
<i>3.1 Inclusion</i>	8
<i>3.2 Gender Equality</i>	8
<i>3.3 Diversity</i>	8
4. CHALLENGES	9
5. CASES	10
<i>Case 1: Gender Balance in the FEMaLe project</i>	11
<i>Case 2: Conference</i>	13
<i>Case 5: Policy Development</i>	18
6. RECOMMENDATIONS	20
7. CONCLUSION	27
8. REFERENCES	27
9. APPENDIX	34
<i>Appendix 1: Gender breakdown in the FEMaLe project</i>	34

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Finding Endometriosis using Machine Learning: FEMaLe

1. INTRODUCTION

Addressing the Gender Gap in Health

Gender inequality harms the health of millions of people worldwide (Sen & Östlin, 2007). The term refers to unequal opportunities for groups of people, regardless of sex, to access and control social, economic, and political resources, including legal protection, e.g., health services, education, and voting rights (PDAC, 2019). When it comes to men's and women's opportunities for health, equality, and inclusion, it seems that a gender gap exists. Gender and inclusion are an important discussion for all sexes³, genders⁴, and identities, but in this white paper, we will primarily focus on those who identify themselves as female or those assigned female at birth.

Studies show gender inequality, where women are typically employed and segregated in lower paid (Penner et al, 2022), insecure (Menéndez-Espina et al, 2020), and informal occupations, which tend to be more associated with caring occupations (OECD, 2016; Samulowitz et al, 2018). In 2020, Caroline Criado Perez published the book *Invisible women*, which highlights the way our society is organised and how women have often been neglected in the process. Hidden gender discrimination is present everywhere, from politics and medical research, to technology, workplaces and in the media (Criado-Perez, 2020). Especially for medical research, studies show that women are less likely than men to have their pain treated, their symptoms taken seriously or to be given a diagnosis (Ruggeri, 2018). The same is true for girls, who report poorer mental health, less access to education (European Institute for Gender Equality, 2021), and have more physical limitations (Abbasi, 2014; Baird et al, 2019). This gender inequality is contrary to the perspective of gender inclusion, which recognises that everyone deserves to be treated with respect regardless of their gender identity and expression and ensures that systems and processes treat all genders equally (PDAC, 2019). Thus, there is great potential to act and prioritise differently by taking action to improve gender equality and ensure women's rights to health.

³ 'Sex refers to the different biological and physiological characteristics of females, males and intersex persons, such as chromosomes, hormones and reproductive organs' (https://www.who.int/health-topics/gender#tab=tab_1).

⁴ 'Gender refers to a person's deeply felt, internal and individual experience of gender, which may or may not correspond to the person's physiology or designated sex at birth' (https://www.who.int/health-topics/gender#tab=tab_1).

The fight for gender equality is, after all, a well-known phenomenon. The 1970s marked the beginning of a series of women's movements, which led to the establishment of the UN Decade for Women (1975-85). Since then, the WHO Commission on Social Determinants of Health recognised in 2005 that *gender*, among other social determinants, is a determinant of health risk (CSDH, 2008). It was further recognised that restrictive gender norms perpetuate a hierarchical system in which dominant forms of masculinity are favoured over dominant forms of femininity (Sen & Östlin, 2007). Nevertheless, there is still a long way to go in terms of gender and inclusion.

In recent years, the fight for gender equality has continued to take centre stage, especially through social media trends, such as campaigns against sexual harassment in the workplace (#MeToo), violence against women (#NiUnaMenos), gender pay gaps (#EqualPay) and the global movement transgender rights (#WhereLoveIsIllegal) (Equal pay today, 2022; Goñi, 2016; O'Neil et al, 2018; Where Love Is Illegal, 2018).

Gender inequality may be caused by a historical understanding of conditions that affect individuals assigned female at birth, which is perpetuated in the worldwide inequality we see. This also influences the fact that women-specific diseases are clearly under-prioritised in the allocations of research funding (Galea & Parekh, 2023; As-Sanie et al, 2019; Jones, 2018; Regitz-Zagrosek, 2012). The U.S. National Institutes of Health has found that in three-quarters of cases where a disease primarily affects one sex, funding favours men (Mirin, 2021). This systematic gender bias may be caused by an androcentric understanding of female specific diseases (Loudon, 1999; Young et al, 2020), which has led to a lack of knowledge about the female body, with serious personal and societal consequences in terms of under-treatment of women, under-diagnosis of female diseases and lack of support for female lives (Kidd, 2017; Langton, 2010).

Need for Increased Focus on Menstrual Health

While women make up 51% of the population and, on average, live longer than men, they spend a significantly greater proportion of their lives in ill health, with lower mental wellbeing, and experience more disability when compared to men (Department of Health and Social Care, 2022). Furthermore, when discussing women's health, it is impossible not to address *menstruation* and *menstrual health*. The issue of menstrual health has recently been firmly placed on the global agenda by WHO in the fields of health, education, human rights, and gender equality.

It acknowledges women's experiences of shame and embarrassment and the barriers they may face in managing menstruation (WHO, 2022). In society, menstruation is associated with taboo and stigma and is subjected to a certain etiquette, meaning that menstruation-related practices, symptoms, and pain are hidden from the public and from men (Seear, 2009). Simultaneously, there is a social normalisation of pain related to menstruation (Przybylo & Fahs, 2018), which overall suggests that cultural determinants may lead women to hide their menstruation and falsely lead women to perceive pain as normal. This is particularly a problem for the group of individuals where the pain is caused by an underlying condition, such as endometriosis.

Endometriosis

Endometriosis is a debilitating and inflammatory chronic disease associated with pelvic pain and infertility, characterised by lesions of endometrial-like tissue outside the uterus (Zondervan et al, 2020). Worldwide, endometriosis affects 10% of all individuals assigned female at birth (Fedele, 2021), making its prevalence similar to diabetes (MOGA, 2022). Despite this, endometriosis is still highly underprioritized, -financed, and affected by a lack of awareness from health care providers, families, and friends (Mirin, 2021; Seear, 2009; Young et al, 2014).

The societal normalisation of pain and the stigmatisation of endometriosis, contribute to a diagnostic delay of 4-11 years between the first symptoms until the eventual time of diagnosis (Agarwal et al, 2019). In the meantime, endometriosis has significant physical (Hållstam et al, 2018), social (Fedele, 2021) and psychological (Gallagher et al, 2018; Rowlands et al, 2016) consequences for the those affected. Additionally, the impacts are observed at a societal level, where symptoms of endometriosis are associated with significant absence from education as well as a productivity loss in workplaces averaging 11 hours per week (Graaff et al, 2013).

The impacts on education are further evident in an English survey, which found that 42% of participants are often or very often absent from school due to their symptoms, and 12% often or very often miss exams (APPG, 2020). Endometriosis also has a major economic impact on society, and it is estimated that health care costs (surgery, monitoring tests, hospitalization, and physician visits) for endometriosis are approximately € 3,113 per affected person (Simoens et al, 2012).

When added to the cost of lost productivity, the total annual cost per person with endometriosis equals € 9,579 (Simoens et al, 2012), which is comparable to the costs associated with other chronic conditions, such as type 2 diabetes, Crohn's disease, and rheumatoid arthritis (Zondervan et al, 2020). This suggests a *complex* problem that is not only individually, biologically grounded at the individual level, but also has a social aetiology rooted in societal discourses that affect the relational, structural, and cultural levels, based on a socio-ecological understanding.

To address this, WHO has recommended that menstrual health, including endometriosis, be recognised, framed, and addressed as a health- and human rights issue rather than a hygiene problem. This emphasises that (1) menstruation is recognised as a health problem with physical, psychological and social dimensions, (2) individuals who menstruate have access to information and education, (3) menstruation is viewed as something positive and healthy rather than something to be ashamed of, and (4) these activities are included in the relevant sectoral work plans and budgets, with outcomes being measured (WHO, 2022).

Women's Health on the Political Agenda

To recognise women's health and menstrual health as a societal issue, as described in the recommendations from WHO, several governments, including those in Australia, Canada, England, France, Ireland, and Scotland have already implemented 'National Action Plans' for women's health and endometriosis (Department of Health, 2018; Department of Health and Social Care, 2022; FranceInfo, 2022; Parliament of Canada, 2022). These broad political objectives aim to improve women's health, with awareness and education about endometriosis being a key priority.

The National Action Plans include prevention and health promotion interventions that address multiple levels of society, including healthcare, workplace, and educational institutions. The broad social and structural measures are designed to help tackle taboos about women's health, improve the quality of medical treatment, and prioritise research in this area. A common characteristic across the four countries is the perception of women's diseases as hidden problems in society.

Another common characteristic is that governments primarily focus on awareness-raising strategies, which can, however, be considered a weakness, since awareness-raising strategies alone may not be sufficient. This suggests that 'gender' and 'inclusion' needs to be addressed and tackled in ways that the current approaches do not necessarily succeed with.

Articles from *The Guardian* also criticised the Australian National Action Plan for being hampered by a lack of quality scientific evidence and for not using a gender inclusive language (Abbott, 2022; Davey, 2020). This suggests that there is room for improvement and that the issue needs to be addressed from a broader health perspective, as individuals are affected by the cultural, structural, and social structures that surround them.

The Canadian Endometriosis Network has attempted to address the lack of inclusion of all genders by developing recommendations for gendered language. The inclusive language is intended to include minorities with endometriosis, since many transgenders, non-binary, or gender-diverse people experience being denied health services, not receiving an endometriosis diagnosis and are facing discrimination by society (Leggott, 2020).

Also, social media are found to play a meaningful role in achieving the goals from the National Action Plans, by serving as a platform to communicate messages in a cohesive and branded way that reach a wider population (Le Busque & Mellish, 2023).

Other Horizon 2020 projects, among others [the FEMaLe project](#), target women's health and illness:

- SPEAR (ID:824555) addresses the underrepresentation of female scientists at the highest academic level and has developed a learning platform to support the implementation of gender equality plans (European Commission, 2019).
- REIncluGen (ID: 101093987) aims to rethink gender and inclusion of migrant women and girls through participatory action research. The project focuses on gender equality, (sexual) violence, representation, socio-cultural participation, and labour market integration through education, networking, legal counselling, and psychological therapy (European Commission, 2023).

All of this shows that the women's movement still has a long way to go to achieve gender equality. Changes in gender equality require not only changes in awareness and behaviour, but also changes in the fundamental power dynamics that determine gender norms and relationships.

In this white paper, we aim to bring together experiences to better understand *gender* and *inclusion* from an international perspective, which can help develop an updated set of recommendations to improve women's health.

2. AIM

The aim of this white paper is to gain a deeper understanding of *gender* and *inclusion* from an international perspective and provide an overview of how these factors may influence women's health and illness, with a particular focus on **endometriosis**. Based on these findings, the white paper aims to provide recommendations to guide future actions.

3. DEFINITIONS

3.1 Inclusion

The term *inclusion* in this white paper refers to creating an environment that recognises and values differences, where everyone feels respected, supported, and empowered to participate in the same activities and enjoy the same experiences (Cambridge Dictionary, 2023). Inclusion involves embracing differences and actively working to create a sense of belonging for all individuals, including those who would otherwise be excluded or marginalised. It also ensures that everyone has equal access and resources to participate fully in society (Collins Dictionary, 2023).

3.2 Gender Equality

Our understanding and practice of the term *gender equality* refers to the equal rights, opportunities, and treatment of all individuals regardless of gender, sex, age, sexual orientation, gender identity, ethnicity, religion, ability, or other characteristics (VIG Government, 2023). It involves the belief that all genders should have access to the same resources, rights, and privileges in all aspects of life, including education, employment, healthcare, politics, and law.

3.3 Diversity

The term *diversity* refers to the presence of a variety of human differences within a particular group, organisation, or society. These differences can include people from a range of different social and ethnic backgrounds and of different genders, sexual orientation, race, age, socio-economic status, religion, and abilities (Oxford English Dictionary, 2023). The concept of diversity recognises that individuals have unique backgrounds, experiences, and perspectives, and valuing these differences can lead to a richer and more inclusive environment.

4. CHALLENGES

In recent decades, the world has witnessed several positive developments in gender equality, diversity, and inclusion. While these initiatives have provided a solid foundation for potential gender equality, diversity, and inclusion for women's health and illness, challenges can arise when it comes to putting these principles into practice.

One of the first challenges is the **lack of awareness and education** about gender and inclusion. There is a lack of education about menstruation and menstrual health, especially among young people (European Institute for Gender Equality, 2021). Without a proper understanding of gender and inclusive approaches, individuals may unintentionally make decisions that discriminate against towards certain genders or groups.

This can also lead to misinformation and myths, leaving individuals who menstruate unaware of their menstrual health needs, including warning signs of menstrual disorders (UNICEF, 2019). Increased awareness and education about menstruation and menstrual health can thus help break down the stigma surrounding menstruation and promote inclusivity and equality.

A second, and potentially largest, challenge is the **lack of funding** for research addressing women's health and illness. Women's reproductive health attracts far less research funding compared to almost all other medical research (MNT, 2022). This is also true for endometriosis, where in 2020, the US funded a total of \$26 million for endometriosis research (Endofound, 2020), while in the same year, the National Institute of Health reported research spending on diabetes of \$1,156 million (NIH, 2023), despite the two conditions having similar prevalence. Underfunding and lack of research in endometriosis limit our understanding of the disease and hinder innovation in diagnostic and treatment options (As-Sanie et al, 2019).

Additionally, when comparing the funding amount with the burden of the disease, diseases that affect female are underfunded. A recent article in *Nature* examined funding data from The National Institute of Health (NIH) and found that diseases like migraine, headache, endometriosis, and anxiety disorders, which disproportionately affect women, all attract much less funding in proportion to the burden they impose. In contrast, diseases such as HIV/AIDS and substance misuse, which disproportionately affect men, receive much higher funding (Kerri, 2023). This is a challenge and shows a structural gendered inequality in funding.

The third challenge is the **lack of representation in the media**. Diseases that primarily affect individuals assigned female at birth are less likely to be mentioned in media. This poses a challenge since there is a close association between representation in media and social change. Media influences social attitudes toward health behaviours and plays a central role in the formation of the public sphere (Alvarez-Mon et al, 2021; Mannila, 2017).

Further, women are still underrepresented in many areas in the media, and gender stereotypes remain persistent, based on how women are portrayed (Mannila, 2017). Therefore, media practices need to be improved to ensure a more diverse, inclusive, and gender equal media industry.

The fourth challenge is the **lack of involvement** in promoting gender, inclusion, and diversity, as it perpetuates systemic inequalities, creates a harmful environment for marginalised people, and negatively impacts society by missing out on the benefits of a diverse and inclusive environment. Involving citizens in research provides them a valuable tool to play a more active role in sustainable development (Smallman, 2018). It also contributes to more nuanced research and offers more useful perspectives.

To promote a more inclusive, diverse, and gender equal society, there is a need to change the narrative surrounding diseases that primarily affects individuals assigned females at birth. This involves creating **opportunities** to influence people and organisations internationally and encouraging them to change the harmful or dominant norms, attitudes, and patterns of inequality that hinder women and other marginalised groups from reaching their full potential.

Achieving these **potentials** require robust support and leadership from key stakeholders, including the public, governments, businesses, and other relevant institutions to not only recognise and respect these challenges but to actively engage and have a willingness to effect changes that promote gender equality.

5. CASES

The following section will present five examples of how the FEMaLe project is working with *gender* and *inclusion*. The purpose of these examples is to clarify how to effectively promote a more inclusive culture both at an organisational and at societal level. However, the examples also highlight areas where there is room for improvement still.

Case 1: Gender balance in the FEMaLe project

Gender balance in the workplace has become an increasingly important issue in recent years. A report by the World Economic Forum shows that the gender balance in 2022 was 62.9%, which is the lowest score since the index was first compiled (World Economic Forum, 2022). While progress has been made in many countries to reduce the gender gap (PwC, 2023; WGEA, 2023), women continue to be underrepresented in certain fields, particularly in leadership positions (McKinsey & Company, 2022). Although the number of women in leadership roles have been increasing since 2016, they still remain severely under-represented, holding less than a third of leadership positions globally (World Economic Forum, 2022).

Studies have shown that gender diversity in the workplace leads to a range of benefits, including improved decision-making, greater innovation, and increased profitability (Catalyst, 2020). Conversely, gender imbalance in the workplace is associated with increased sexual harassment and gender pay gaps (Folke & Rickne, 2022; PwC, 2023). Therefore, there is great potential to achieve gender equality in the workplace, ensuring that individuals have equal access and benefit from rewards, resources, and opportunities regardless of gender (WGEA, 2023). In light of this, it is relevant to analyse the gender distribution within the FEMaLe project, as well as among the project's partners.

The project members of FEMaLe are distributed among its 17 partners, which represent a wide range of disciplines. A gender distribution analysis shows that within the project, 43% are women and 57% are men, as illustrated in Figure 1. Further details of the gender distribution can be found in *Appendix 1*, where the breakdown shows that out of the 33 researchers working in the project, 42% are women, and among the workforce in disciplines other than researchers, 44% are women out of a total of 41 individuals.

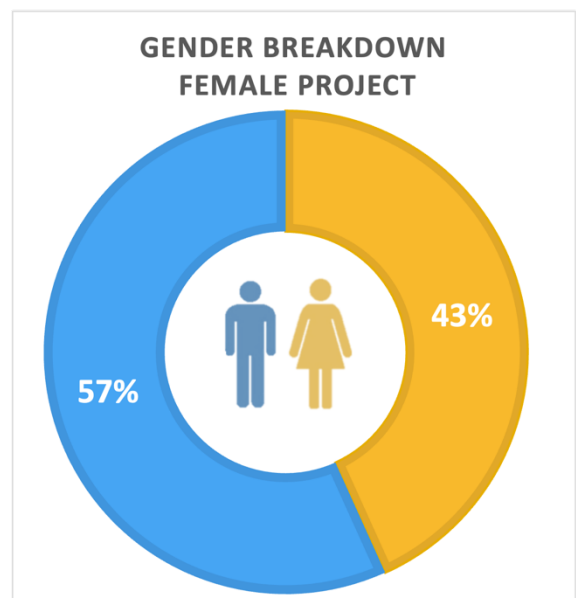


Figure 1: Gender breakdown FEMaLe project

Thus, the project's gender distribution is close to being equal, but Technical Universities and SMEs with an engineering profile in particular contribute to creating the imbalance.

To gain a deeper understanding of the gender balance of the project, we have also examined the gender distribution among the project partners. This provides greater insight into the organisations involved in the project. The gender breakdown of the partners can be seen in Figure 2, which shows an average equal distribution of genders, with a slight predominance of women (mean: 48.3% males; 51.7% females).

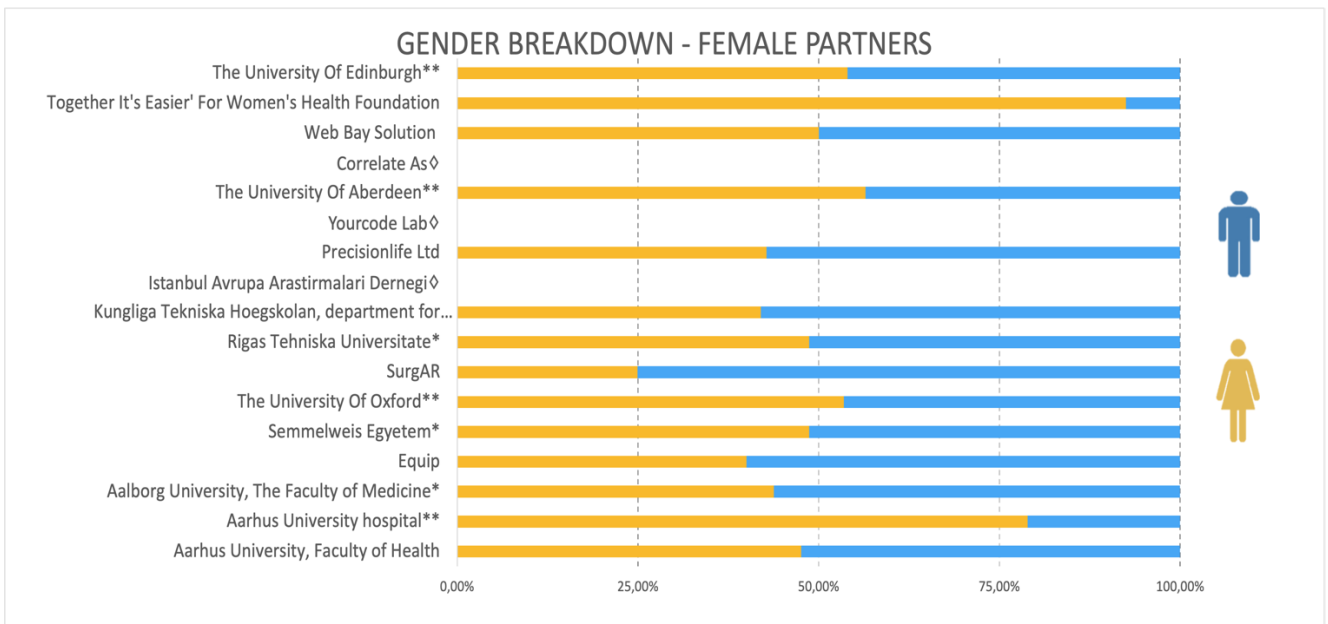


Figure 2: Gender breakdown – FEMaLe partners 2023

* Data from 2022. ** Data from 2021.

◇ Unable to obtain data from partner.

Especially, the project's hospital partner (Aarhus University Hospital) has a high proportion of women employed. This is presumably due to the number of female nurses, who account for 96.4% if the staff (Region Midt, 2021). However, when it comes to senior doctors at the same hospital, only 43% are female, with the remaining 57% being male (Region Midt, 2021).

Similar imbalances exist in Universities, where there are fewer women in the highest positions. For instance, at Aalborg University, female professors account for only 16.2% (Faber et al, 2017) and at Oxford University, female professors account for 20.8% (University of Oxford, 2022).

This suggests that, despite an overall equal distribution of gender on average, there is a clear imbalance in the representation of gender in the highest positions, as supported by the literature.

Case 2: *Diversity in the making Conference*

Diversity in the workplace was also discussed at a conference held in March 2023 at Aarhus University, which focused on diversity, gender equality and inclusion in research communities (Aarhus University, 2023a). The conference aimed to explore how Universities can foster a more inclusive culture. This is relevant as societies today face several major challenges: Climate change, economic instability, social inequality, and threats to democracy (Aarhus University, 2023a). Each of these challenges affects us in a different way and reflects the diversity of our world. The central message of the conference was that we can only succeed if we are able to use diversity as a strength. Universities have an obligation to contribute with solutions to these challenges through research, education, and innovation. Only by incorporating diverse perspectives from people with different genders, sexual orientations, racial and ethnic identities, age groups, beliefs, faiths, and cultural and social backgrounds, can we strengthen our impact on society (Aarhus University, 2023a).

For this reason, three keynote speakers from the private sector, the cultural sector and academia shared insights, experiences, and ambitions. Some of the actions discussed for Universities to work towards an inclusive culture, were the introduction of gender quotas in the workplace to reduce the number of men in the highest and often best paid positions.

One keynote speaker had introduced a diversity training program for all staff members, to raise the awareness about diversity and to build a more positive workplace for everyone. At the Faculties of Health, researchers had developed a dilemma game consisting of a series of action cards describing challenging scenarios, based on actual situations. Some of the issues addressed were #Metoo, don't steal my work, maternity leave, and gender quotas. The aim was to challenge the culture of silence and address the working environment problems, which was illuminated by a major KVINFO survey (Aarhus University, 2023b). These initiatives are one out of many to help make Universities a better and more inclusive work environment.

While there was an agreement that there is still a long way to go to achieve a gender diverse and inclusive University, it was emphasized that having a strong purpose and strong values are the first steps. If we are to produce knowledge about society, we need to involve all parts of society to achieve the best possible outcome. Achieving a diverse, equal, and inclusive culture in Universities will require sustained and concerted effort. Conferences like this one serve as a source of inspiration for the next steps in this important mission.

Case 3: Citizen Science workshop for the Academy for Talented Youth (ATU) students

In collaboration with the research project [Giving Young People a Voice](#), the FEMaLe project organised three workshops in March 2023, with a total of 52 high school students from Denmark participating. The workshops were part of a seminar about 'Citizen Science', which invites young people to participate as co-creators in research projects. This concept will be further described in *D2.4 White paper on RRI (Responsible Research and Innovation)-oriented and Open Science health and care systems*.

The recent mandate that sex education will be mandatory in Danish high schools from autumn 2023 presented an ideal opportunity to conduct workshops on menstrual health and discuss the topic with high school students; it also paved the way for young people to influence the content of the sex education themselves. The purpose of the workshops was to share knowledge from both research projects (Giving Young People a Voice and FEMaLe) and insights about menstrual health among young high school students, with the goal of empowering and engaging the students in the process.

To better understand the students' experiences and perspectives on menstruation, we initially asked them to describe menstruation using the first three words that came to mind. All the provided words were subsequently analysed and categorised into 11 themes, as illustrated in Figure 3:

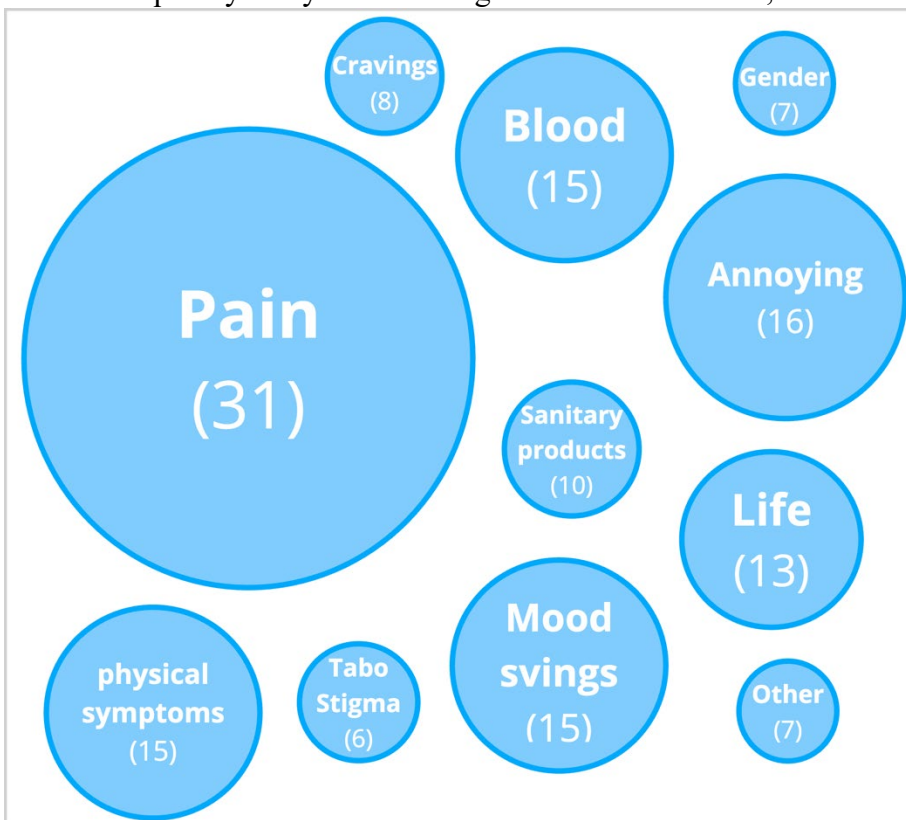


Figure 3:
Young people's description of menstruation in only three words. The number in parentheses represents the frequency of the mention of the theme.

The most common theme was *pain*, highlighted by 31 out of 52 participants (60%). Menstruation was mentioned as being *annoying* (16, 31%), causing *mood swings* (15, 29%), associated with *blood* (15, 29%), *physical symptoms* (15, 29%), and *sanitary products* (10, 19%). A minority of participants described menstruation as a positive experience, as it could lead to the possibility of giving life to a child or fostering a sense of community among women.

Afterwards, the participants were asked to discuss and identify the challenges they experienced in relation to menstruation, either personally or knowing someone who menstruates. During these discussions, participants highlighted challenges related to lack of information, inadequate sex education and lack of knowledge, particularly among men. Participants also mentioned a lack of knowledge about what was considered *normal* or abnormal during menstruation.

Furthermore, participants discussed a general lack of recognition for menstruation and that it was often a taboo or shameful to have a period and to talk about it with others. They also mentioned the inconvenience of menstruation and the high cost of hygiene products. Regarding pads, participants expressed concerns about climate impact and waste from tampons and sanitary pads, and that they needed environmentally friendly options that are socially accepted. Another challenge raised by the students was the feeling of not being understood by society as menstruating queer individuals.

To address some of the challenges, the 52 young people were asked to suggest solutions that could improve menstrual health, increase knowledge about menstruation and reduce the existing taboo. In particular, the young people argued that several challenges could be addressed through education, both by teaching and including all genders and sexes, by using up-to-date and relevant teaching material, and by targeting the education better according to the students' ages, preferably starting at an early age. They recommended that teachers receive additional training or that external teachers deliver the education. Other solutions discussed included developing a dialogue game to facilitate discussions among young people, increasing media attention on menstruation, and considering the implementation of menstrual leave, as recently done in Spain.

The above findings indicate the importance of continuing to involve young people in the process of identifying the challenges and contribute to the research process to find sustainable solutions that address menstruation, gender, and inclusion.

Case 4: Guidance for the Period Equality Movement

FEMaLe adviser Dr. Maria Tomlinson and Acushla Young, menstrual health advocacy specialist, have collaborated to create a guidance to communicate effectively with young people about menstruation by using social media. The guidance is for organisations, communities, and individuals who are championing the *Period Equality Movement* and the aim is to ensure that social media is creating meaningful impact through engaging, educating, and empowering young people.

The guidance draws on Dr. Maria Tomlinson's findings from her Leverhulme funded research project: 'Menstruation and the Media: Reducing Stigma and Tackling Social Inequalities'⁵. In total, 77 teenagers (aged 16-19) across Yorkshire were interviewed about the online Period Equality Movement to see how it has influenced their views of periods and how the movement can better engage, educate, and empower them.

Using her expertise in menstrual health advocacy, Acushla examined these findings to see how they could benefit the Period Equality Movement. From this work, a simple six-point guide was created to ensure that social media is optimally utilised when communicating with young people about menstruation as well as the period poverty, shame, and stigma they can experience. The principles are as follows:

- 1) Redefine Your Activism!**
- 2) Be Youth Led!**
- 3) Be Inclusive and Intersectional!**
- 4) Engage Boys and Men!**
- 5) Collaborate Effectively!**
- 6) Educate Honestly!**

Further, the guide includes a section on how young people would like to learn about periods through social media. They expressed a preference for realistic and accurate education that goes beyond the biological aspects of menstruation. They suggested that online menstrual content should avoid traditional femininity and appreciated humorous content as long it did not perpetuate stigma against girls and others who menstruate.

⁵ Further findings from this research are forthcoming in the monograph: *The Menstrual Movement in the Media: Reducing Stigma and Tackling Social Inequalities* (Palgrave, 2024)

The guidance is considered extremely useful for including and communicating with young people about menstruation, as it is based on their own experiences and perspectives. It is also useful to disseminate to other contexts, cultures, and target groups to raise awareness and knowledge about menstruation.

USING SOCIAL MEDIA TO COMMUNICATE EFFECTIVELY WITH YOUNG PEOPLE ABOUT MENSTRUATION

Guidance for the Period Equality Movement



The guide, entitled *Using social media to communicate effectively with young people about menstruation*, is freely available at: <https://www.mariatomlinson.co.uk/advocacy>

Case 5: Policy development – Expert endometriosis hearing in the Danish Ministry of the Interior and Health's Health Committee

The FEMaLe project has been working on influencing the political agenda by leveraging research findings, innovations, and social media co-created campaigns to bring much-needed attention to women's health, particularly endometriosis. These efforts to close the gap between patients and policymakers, enabling them to gain a much deeper understanding about how debilitating it is to live with endometriosis and which effective actions to take on the political level.

On 02 March 2023, the FEMaLe Coordinator together with a Danish journalist and patient advocate kick-started the Endometriosis Awareness Month in a fantastic way, as they had 15 minutes in total before the Danish Ministry of the Interior and Health's Health Committee, focusing on health, sickness, and prevention of endometriosis. They received many positive comments and questions from the Danish Members of Parliament (MP).



On 24 March, the same Danish journalist and patient advocate aired on Go' Morgen Danmark, one of Denmark's largest television channels, accompanied by the Director of the Endometriosis Clinic at Copenhagen University Hospital, who is also a FEMaLe Adviser. The live TV interview offered an opportunity to shed some light on endometriosis as an underexposed, -prioritized, and -funded disease. During the interview, they advocated for increased research and innovation resources to enhance the quality of life for women and promote more inclusive workplaces.



Next, the Danish Ministry of the Interior and Health's Health Committee invited two FEMaLers to an invitational expert hearing on endometriosis on 25 May 2023 at the Danish Parliament. The aim was to inform Danish MP about the prevalence, causes, and treatment options for endometriosis and to suggest policy development (National Action Plan), as seen in Australia, France, and the UK.

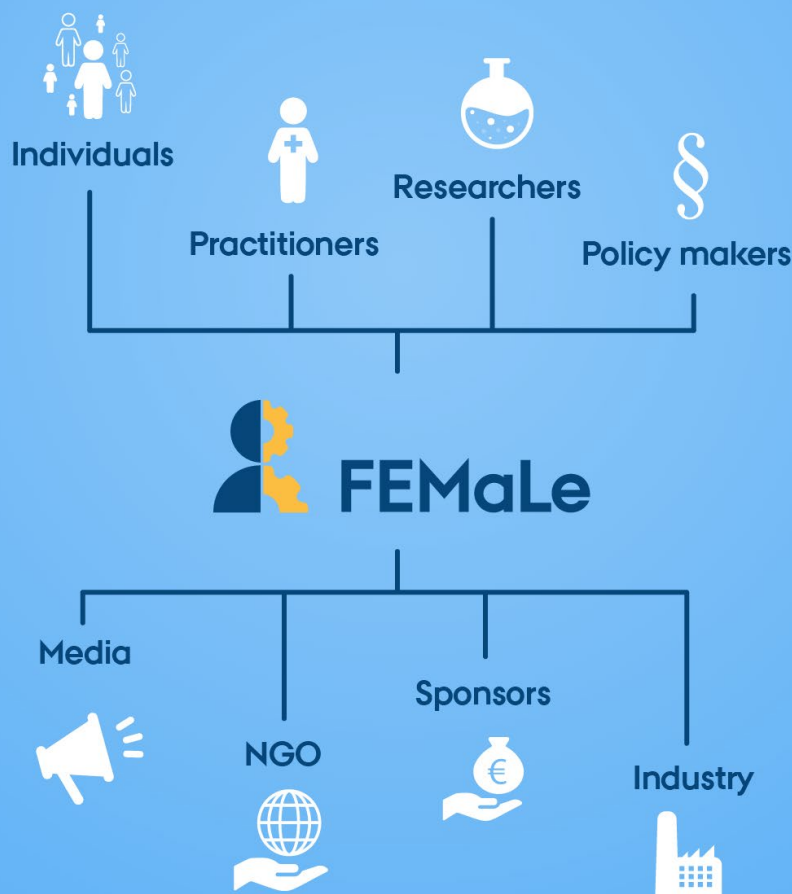


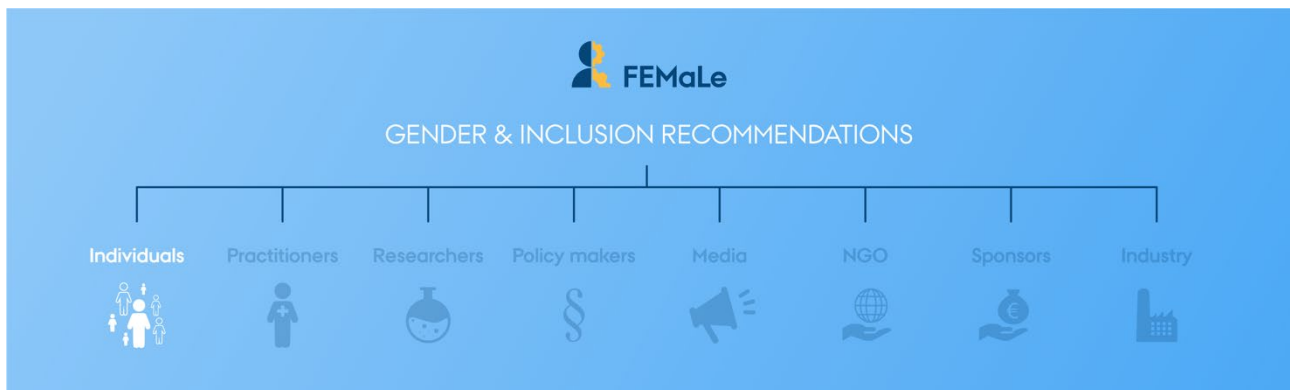
Now, we hope that by taking part in direct dialogues with the Danish MPs, FEMaLe can initiate the first significant steps forward for endometriosis in Denmark and translate research into policy.

6. RECOMMENDATIONS

This white paper has focused on the issue of gender inequality in women’s health and highlighted the importance of *gender* and *inclusion*. It has emphasised the need for increased awareness about women’s health to ensure that women feel recognised and understood by society. It has stressed the inadequate prioritisation of research funding for diseases that primarily affects individuals assigned female at birth, leading to a lack of knowledge and support for women’s health issues.

In the white paper, we have also highlighted a few FEMaLe project examples to address gender and inclusion. Drawing on diverse experiences and multi-actor expertise, we provide recommendations to guide future stakeholder-specific actions:

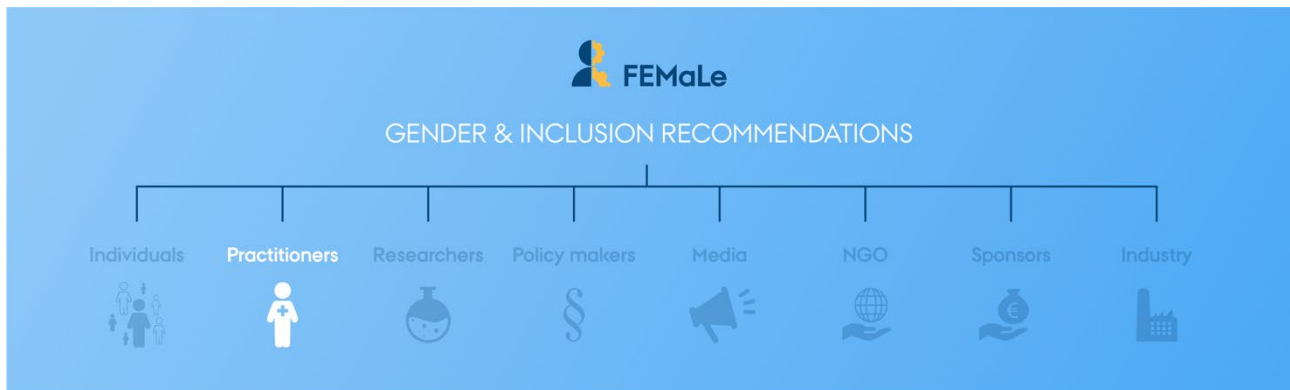




Individuals:

From an individual perspective, we recommend empowering everyone to advocate for their experiences and rights. This includes patients with endometriosis, individuals in marginalized groups, or anyone who feels excluded. This empowerment can be established by offering access to a range of resources such as:

- *Offering tools in multiple languages*, to ensure broader accessibility and reach, so more people can benefit from them.
 - *Lucy App* has been translated into multiple languages, allowing users to learn about endometriosis and receive guidance on whether they should seek medical attention.
- *Empowering individuals through (SoMe) campaigns*
 - FEMaLe launched an *Endometriosis Glossary* campaign in spring 2023, aiming to provide all terms associated with endometriosis and women's health. The goal is to empower people to openly discuss endometriosis.
 - We recommend utilizing *infographics* for communication purposes to reach a much wider audience, as they are easier to understand and more likely to be remembered.
- *Communicating differences*, including disparities in funding, recognition, and other aspects, to highlight the existing gender and inclusion inequalities to individuals.

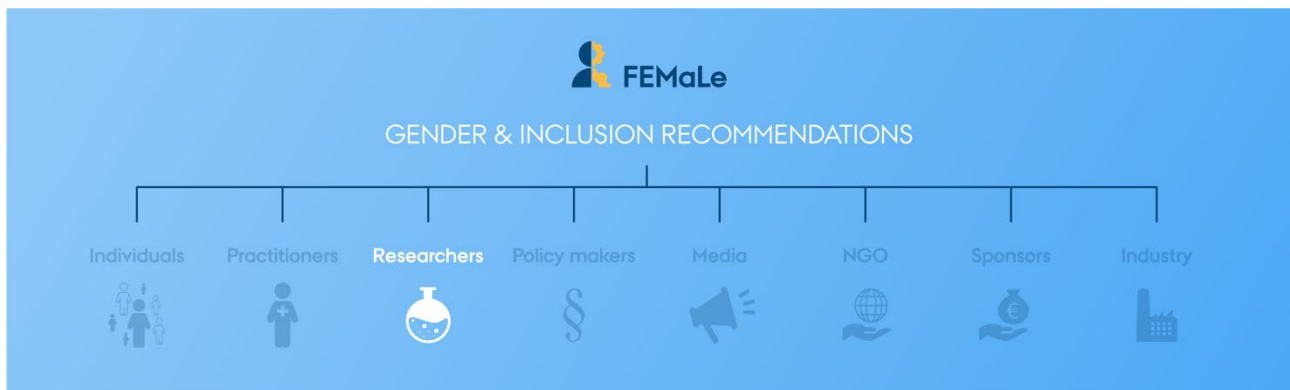


Practitioners:

We recommend providing *Education and Training* for practitioners to enhance diagnosis of conditions like endometriosis.

Education and training are a broad phenomenon and should cover various topics, including:

- *Complexity and uncertainty* in diagnosing and treating endometriosis.
- *Interdisciplinary treatment* approaches that involve collaboration with different healthcare professionals.
- *Continuous professional development (CPD) programs* to ensure practitioners stay updated with the latest advancements.
- *Produce position statements* to guide practitioners in their clinical practice.



Researchers:

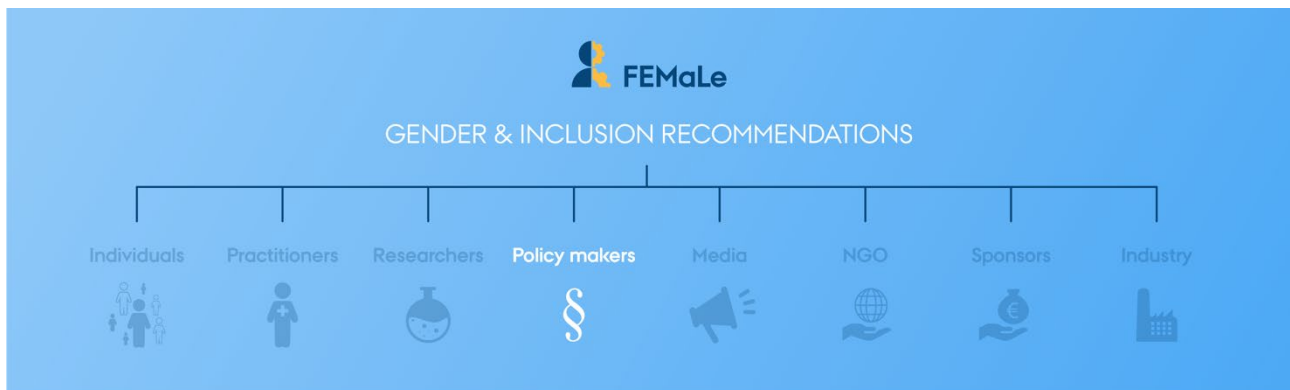
From a researcher's perspective, we recommend that researchers are better equipped to work inclusively and ensure their data sets encompass a gender equal and diverse group.

We recommend that researchers should consider the following:

- *Increase the use of participatory research.*
- *Uses a holistic approach* that considers the broader context and multiple factors related to the research topic.
- *Providing research findings and materials in multiple languages* to enhance accessibility and reach.
- *Increases collaboration across different stakeholders.*

We also suggest that the organization or research group makes greater use of the following recommendations:

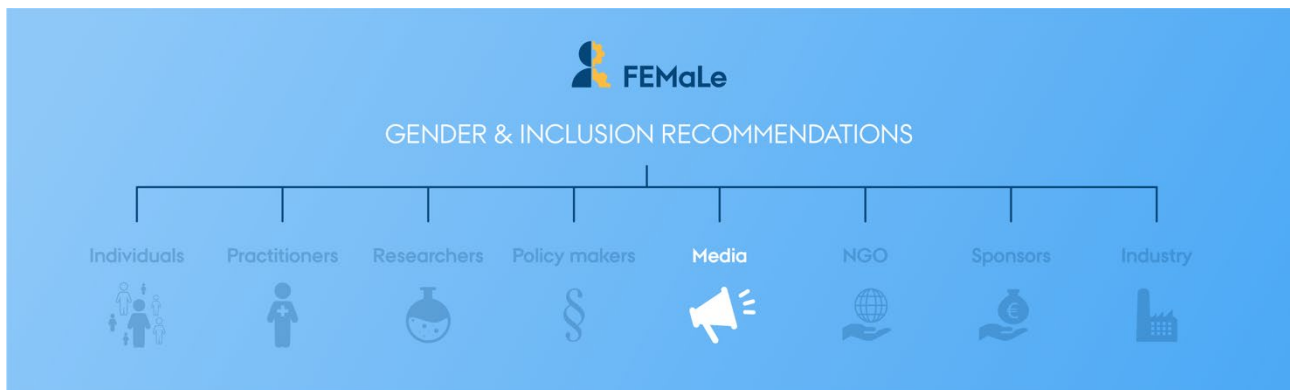
- Providing *diversity training* to improve the work environment and promote inclusivity, and
- *Enhancing the visibility of female researchers* within the organisation to encourage representation and recognition.



Policy makers:

We recommend that policy makers actively engage in these discussions and take appropriate actions. While some countries have implemented *National Action Plans* for women's health and endometriosis, the report highlights the need for a more comprehensive approach beyond awareness raising strategies. Policy makers should consider the following actions:

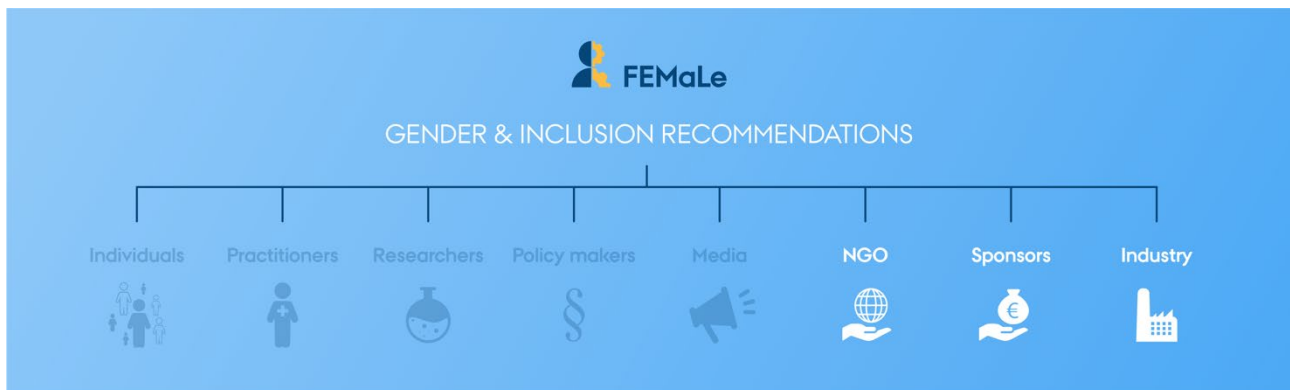
- *Allocate dedicated funding to address women's health issues,*
- *Develop quotas* to promote gender equality and inclusion in healthcare and research,
- *Organise (expert) hearings* to gather insights and perspectives from relevant stakeholder,
- *Engage High-level panels* focused on women's health and gender equality,
- *Support data sharing easiness* among researchers and healthcare professionals,
- *Promote work-life balance* enabling individuals to manage their health and career responsibility effectively,
- *Get feedback from divers groups* to ensure policies are inclusive and representative.



Media:

Media plays a crucial role in disseminating knowledge to the general population, making it essential to prioritize gender equality and inclusion in their coverage. We strongly recommend that media outlets focus on the following:

- *Focus on gender balance* in their reporting by ensuring equal representation of diverse voices,
- *Rewrite scientific articles* into publications that are accessible and understandable for general public,
- *Use sensitive language* that respects individuals and avoids perpetuating stereotypes or stigmatizing language,
- *Provide training on unconscious bias* to journalists and media professionals,
- *Share facts and statistics about gender imbalance*, and
- *Promote diverse voices in media* by featuring individuals from different backgrounds and experiences in their content.



NGO:

We recommend NGOs to foster *empowerment through (SoMe) campaigns* and to *produce articles for LGBTQ+ knowledge portal*.

We suggest sharing *guides* and *guidelines* on how to develop a *diversity, equity, and inclusion plan*.

Sponsors:

We recommend sponsors to *share facts and statistics about gender gaps* and to develop a *diversity, equity, and inclusion plan*.

Industry:

We recommend the industry to focus on *developing FemTech solutions*.

It is crucial for the industry to create *strategic, diversity, equity, and inclusion plans*.

This will help to *support equal opportunities and fair recruitment* for all.

The industry must, as well as the Media and sponsors, *share facts and numbers about gender gaps*.

7. CONCLUSION

This report highlights the urgent need to address gender inequality, enhance gender inclusion, and prioritise women's health. By implementing comprehensive strategies that encompass education, research funding, healthcare improvements, and societal changes, we can work towards achieving better health outcomes and equality for all genders.

In line with this, the *BMJ Editorial* on 'Ending the neglect of women's health in research' (Galea & Parekh, 2023) concludes that a greater focus on women's health is an imperative that will translate into improved health for all; the paper also proposes recommendations on how to do it better:

- Governments and funding agencies must increase funding for research focused on women's health across multiple conditions to a level commensurate with the burden of disease.
- Change requires sustained funding for research into improving the health of women and gender diverse people.
- Equitable investment in research is critical to inform safe and effective healthcare.
- Increase transparency of data and reporting.
- Train researchers in sex specific research design and analysis.
- Journals also have a role in prioritising studies relevant to women as well as sex specific analyses.
- Studies to understand how best to increase researchers' engagement in women's health are urgently required to ensure meaningful and sustained change.
- Female researchers are more likely to complete sex or gender-based analyses, and diverse research teams recruit more diverse clinical trial participants.

We hope that this report contributes to raising awareness and inspiring action towards positive transformations in women's health.

It is high time to prioritize gender equality and inclusion in healthcare and society.

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9. APPENDIX

Appendix 1: Gender breakdown in the FEMaLe project

Beneficiaries	No. female researchers	No. male researchers	No. females in workforce other than researchers	No. males in workforce other than researchers	Total no. females in workforce	Total no. males in workforce
1: Aarhus Universitet	2	2	2	1	4	3
2: Aarhus Universitetshospital	2	2	0	0	2	2
3: European Society for Quality and Patient Safety in General Practice/Family Medicine	0	0	0	2	0	2
4: Semmelweis Egyetem	1	2	2	0	3	2
5: The University of Oxford	2	1	0	0	2	1
6: SurgAR	0	0	4	5	4	5
7: Rigas Tehniska Universitate	1	4	0	0	1	4
8: Kungliga Tekniska Hoegskolan	0	3	0	0	0	3
9: Istanbul Avrupa Arastirmalari Dernegi	0	0	2	2	2	2
10: Precisionlife Ltd	2	2	1	1	3	3
11: Yourcode Lab	0	0	0	4	0	4
12: The University Of Aberdeen	1	1	0	4	1	5
13: Correlate AS	0	0	2	2	2	2
14: Web Bay	0	0	3	2	3	2
15: Together it's easier For Women's Health Foundation	0	0	2	0	2	0
16: The University of Edinburgh	1	1	0	0	1	1
17: Aalborg Universitet	2	1	0	0	2	1
Total	14	19	18	23	<u>32</u>	<u>42</u>