11. Principle of Justice I: Gender, (Age, Ethnicity) and Life Sciences Research

Abstract: The principle of Justice states that researchers have a duty to ensure a fair distribution of risks and benefits across society. But, are all social groups treated equally in life sciences research? This question is explored through a gender lens (though the issues raised may well apply to other minoritised populations). In clinical trials, for example, women were long excluded due to risks of impacts on potentially pregnant participants as well as due to the impacts of menstrual cycles on data. This means many medications were released without being tested on women. Similar issues exist for other minoritised populations.

There is also evidence of other factors impacting on the extent to which women benefit from life sciences research. These include a lack of focus on women's health issues (particularly those that don't relate explicitly to fertility and childbirth) in life sciences research and development; a perception that research in women's health is complex and costly (recruitment of subjects, increased insurance costs, etc.); and biases in investors which limit their engagement with Femtech, especially when it involves women leads and is framed in terms of women's rights.

Please note: because of the topics it covers, this chapter describes experiences that can be upsetting and may raise issues which may have personal implications for many people. Please take care of yourself in making your decision as to how to read this chapter.

Endometriosis – the invisible disease

Endometriosis is commonly defined as a chronic inflammatory condition which occurs when cells similar to those found in the inner lining of the uterus (endometrium) are found outside the uterus. Hormonal changes linked to menstruation can lead to the inflammation of these cells, which in turn can give rise to scarring and adhesions. Endometriosis is characterised by diverse symptoms including chronic pelvic pain, heavy bleeding, and lower levels of fertility. Women with endometriosis report frequent or chronic or severe pain, tiredness, more sick days, and a significant physical, psychological and social impact (National Institute for Health and Care Excellence, 2017).

Endometriosis is a disease that has grown in diagnosis significantly in recent years. It is estimated that it affects 10% of people who have female sex characteristics (it can affect anyone with a uterus irrespective of their gender identification). But the disease of endometriosis was not actually identified until the 1920s and, as late as the 1980s, a diagnosis for endometriosis was still relatively rare. Despite growing awareness of the disease, diagnosis is still not straightforward, with average time from onset of symptoms to diagnosis in the UK being 8 years. The UK's National Institute for Health and Care Excellence reports:

> Women often find health professionals normalise their symptoms and have limited knowledge of endometriosis. These can contribute to a delay in diagnosis and increase the risk of misdiagnosis… The reported average delay of 8 years to a diagnosis of endometriosis means that many women with endometriosis have been told their pain, bleeding, painful sex, fatigue and other symptoms ae normal. This can lead to isolation, stress, depression and exhaustion through coping with symptoms without information and support (2017).

In a review of evidence to develop diagnostic and treatment guidelines for endometriosis the UK's National Institute for Health and Care Excellence found only three studies that met the standards for inclusion in a review which could be used to contribute to diagnostic guidelines. The committee identified that these studies appear to give an inadequate overview of reality in that some symptoms that they expected, based on experience, to be found as symptoms of endometriosis (such as digestive symptoms) were not identified. They noted that this may be a function of the small amount of evidence, of misdiagnosis of digestive symptoms, or of the range of questions asked in these studies.

Quesitons

1. The care concept of 'caring for' (responsibility) suggests we need to locate our actions in a social network with empathy for others. Who are the people that are involved in this network?
2. The care concept of 'caring with' identifies the need to act in solidarity with those who are comparatively powerless in society. Who has power in this situation and who has less power? (Another way of framing the same question is to ask whose voice/perspective is typically heard in such situations, and whose voice/perspective is typically silenced?)
3. The World Economic Forum (2024) says that the root causes of gender health gap include (i) scientific research which treats male body as the 'default', (ii) datasets that either don't include sufficient women or which are not gender differentiated, (iii) barriers to healthcare for women resulting in diagnostic delays and difficulties in accessing treatment, and (iv) underinvestment in developing treatments for conditions that

disproportionately impact on women. Identify which one of these four aspects of the situation you would like to focus on in your analysis.

4. In relation to the issue you have decided to focus on, identify who are the actors that most need care or give care in this situation (pick 3 or 4). For each, identify how this situation would be seen from their perspective.
5. For each of these, identify what emotions they would probably feel about this situation. What are the thought action tendencies associated with each of these emotions (refer back to chapter 3 if needed)?
6. What competences do you expect biophysical scientists bring to this situation (think about technical competences such as specific biological knowledge, knowledge of research techniques etc., as well as organisational competences, ethical competences and public advocacy roles)?
7. Who should be involved in arriving at a solution that supports those who give and need care? What might such a solution be? What roles could biophysical scientists and engineers play in such a solution?
8. The care concept of 'receiving care' identifies the need to monitor how the care that is given is received. What monitoring would be put in place in the context of your proposed solution?

Introduction

Bioethics has, since the 1960s been said to be based on four principles: autonomy, beneficence, non-maleficence, and justice. In chapter 9 we identified that, for many projects that involves humans, it appears as if ethics committees pay most attention to the principle of autonomy, and consent is treated as the king of bioethical principles, while other principles are commonly ignored (Ballantyne, 2019: 358). In chapter 10 we identified that, in practice, animal ethics is often treated as a utilitarian assessment of only maleficence and beneficence. It seems as if our final bioethical principal – justice – is at risk of being forgotten. This is all the more worrying since it was justice that was the bioethical principle that was explicitly identified by Ethics of Care researchers as being important. As we saw in chapter 5, and as Joan Tronto has put it: "caring needs and the ways in which they are met need to be consistent with democratic commitment to justice, equality and freedom for all" (2013: 23).

The principle of justice says that those who are the same should be treated the same. It can be reformulated as saying that, across a society, different people should have the same risks and benefits from life science research and engineering (distributive justice). The principle of justice was identified as important in life sciences because, historically, research was often conducted with groups who were comparatively powerless in society, either because they were in prison, in poverty, or otherwise disempowered. Perhaps the most famous example of such research is the Tuskegee Untreated Syphilis study which ran from the 1930s to the 1970s in which poor, rural and uneducated Black men were used as research participants in a US study which involved them being kept uninformed about treatment for syphilis; the US government eventually issued an apology to the men involved in the 1990s.

A no less troubling case involves those who were used to test a contraceptive pill in the 1950s. At the time, distributing contraceptive devices was illegal in some states of the United States and so researchers decided instead to test their pill on the island of Puerto Rico. The island was densely populated and poor, had many uneducated women who could be attracted into the study by the promise of a free "medicine that would keep them from having children they couldn't afford" (details and quotes from Cleghorn, 2021: 317-319). The women were not, however, told that this was a research study, were not informed of side-effects and did not give informed consent. The developers viewed the women as "a cage of ovulating females to experiment with".

The study highlighted serious side effects, with 17% of participants suffering symptoms including nausea, dizziness, gastrointestinal problems, bleeding, vomiting and headaches. So, while the pill was found to be effective in preventing pregnancy, it was recommended that, in light of the side effects, the pill was not suitable for use. This was dismissed by the developers as reflecting "emotional super-activity of Puerto Rican women", and the medicine became licenced in 1960. By 1963, 272 cases of thrombosis and thirty deaths amongst users of the Pill were reported. It was revealed later that three women in the Puerto Rico trial died suddenly of heart failure and pulmonary embolisms, but their deaths were not properly reported in the trial findings, nor were they investigated.

Reflection Questions

1. Who do you see as being the features of the comparatively powerless groups that were voiceless in the studies to develop the contraceptive Pill?
2. What attitudes towards comparatively powerless groups enabled the (mis-)treatment of these people?

This chapter focuses on gender issues related to justice, but this is not intended to imply that gender is a more important facet of social identity than age, ethnicity, sexuality or “race”. I take gender as being an example, but many of the same issues would equally apply to other social groups. In this chapter I use both the terms ‘sex’ and ‘gender’. The term ‘sex’ refers to a classification – usually binary – based on physical sex characteristics and is typically identified with genetic features. The term ‘gender’ is defined as socially constructed roles, behaviours and expressions of identity in girls, women, boys, men and gender-diverse people. ‘Sex’ and ‘gender’ often align but need not do so. Since health is related both to innate biology and to, people’s behaviours and their environment, both sex and gender can be relevant to health issues. However it is rare for a distinction between sex and gender to be adequately considered in life sciences research, and so in the empirical findings related below it remains hard to distinguish sex and gender.

The extent of the challenge

The burden caused by a disease is frequently measured in ‘disability-adjusted life years’ (DALYs). This measure combines both years lost due to premature mortality (Years of Life Lost - YLL), and a measure of loss of quality of life linked to disease (Years Living with a Disability - YLD). Although women live, on average, longer than men, they also live an estimated 25% more time in ‘poor health’ when compared to men. At a global level, women’s poorer health outcomes when compared to men equates to an estimated 75 million disability adjusted life years, or, on average, seven days per woman per year (WEF, 2024: 5). Of this, 34% is estimated to be related to lower quality of services from medical carers. The rest (49.5 million disability adjusted life years) is estimated to be linked to the way in which sex and gender are treated within the life sciences research that underpins that care.

Although women’s health is often simplified to include only sexual and reproductive health, this reflects only a minority of the disease burden gap. The WEF estimate that the sex and gender health gap is accounted for by four types of diseases:

- Conditions which impact men and women equally account for 43% of the total gap. This includes conditions like ischaemic heart disease or tuberculosis. While these are equally prevalent in men and women, they often have different profiles of misdiagnosis and treatment efficiency.
- Conditions which disproportionately affect women account for 47% of the total gap. Examples include migraine, depression and autoimmune disorders like multiple sclerosis, lupus and rheumatoid arthritis.
- Conditions which affect women differently account for about 4% of the total gap.
- Conditions such as endometriosis or menopause which are sex-specific account for about 5% of the total gap.

To take one example of a non-sex-specific disease, cardiovascular disease affects both men and women. However there is research evidence that women wait longer before seeking treatment for chest pain and spend longer waiting in hospital to see a doctor or a nurse when compared to men who report similar symptoms. When seen by a doctor they are less likely to receive standard diagnostic tests, less likely to be referred to a specialist, and less likely to be hospitalised. Women who receive treatment tend to have worse outcomes than men do (Corliss, 2022).

Invisible women

One of the contributing factors to the sex and gender differences in health outcomes in cardiovascular disease is differences in research related to diseases. Saunders et al., writing in *Nature* in 2024 describe the situation as follows:

> Clinical trials on [cardiovascular disease] CVD are the third-largest group of trials in medicine, accounting for approximately 10% of all clinical trials. However, fewer than a third of participants are women. CVD is the leading cause of death in women…In the context of this burden, women with CVD are repeatedly under-recognized, understudied, underdiagnosed and undertreated (2024: 433)

These gender differences in available data translate both into the behaviour of humans and into digital tools. Greenwood et al. (2018) reported higher mortality rates for women than men following heart attacks, with this difference being accounted for by the gender of the physician; women had worse survival rates when treated by male physicians than when treated by women. These differences were reduced when the male physician worked with female colleagues. In the digital domain, Trendall (2019) reported that in the UK, the National Health Service used a health app called ‘GP at Hand’ which provides pre-screening advice to patients. A female patient aged 59 who smokes and who reported pain in the centre of their chest was told by the app that the most likely causes are panic attack or depression, which can be treated at home. A male patient with an identical profile was told that it may be a panic attack, gastritis or a heart attack; if he suspects a heart attack, he is advised to call an ambulance immediately. One of the app developers, Dr. Keith Grimes, noted that the differences arose from differences in the underlying data: “Our app was working as intended at the time – it was providing information and a triage outcome,” Grimes says. “Clearly there are going to be differences in cases and in symptoms between men and women – they are biologically very different.”

Sing and Swarup (2025) have recently identified that this is not simply an issue with cardiovascular research but is far more widespread. In the 1960s, the use of a drug named Thalidomide gave rise to birth defects when taken by pregnant women. In the 1970s this led the US Food and Drug Administration to ban the inclusion of women of child-bearing age in early stage clinical trials. Since the 1990s recognition of the problems caused by this ban have led to policies to increase participation of women in clinical trials, but the effect has been severely limited. In industry-sponsored trials, women make up fewer than 30% of participants. Even where women are included in clinical trials as participants, this may not make it into the data reported: A 2018 review of 107 NIH funded randomized control trial studies that enrolled both men and women found that 72% did not include sex in their analyses (Geller et al., 2018). The World Economic Forum (2024) found that 50% of the studies they looked at did not include gender disaggregated data but, for those who did, only 26% showed equal results across sex and gender while, 64% showed worse outcomes for women (2024: 10). Zucker and Prendergast (2020), for example, have studied 86 FDA approved commonly used medications, and found that 76 exhibited pharmacokinetic differences in men and women. These differences were associated with a higher rate of adverse differences in women than men for these approved and commonly used medications.

Based on a review of factors which contribute to women's under-representation in cardiovascular trials, Saunders et al., (2024) propose guidelines for clinical trial design to address this gap. These are outlined in the table below.

Clinical trial design and delivery strategies to optimize women's participation in the generation, translation and implementation of sex-specific evidence

Strategy	**Action**
Promote inclusivity and accessibility for women in cardiovascular clinical trials	Revising inclusion criteria, promoting information on research opportunities and conducting sex-specific analyses will mitigate barriers, ensure equitable representation and address the historical exclusion of women from clinical trials
Improve statistical analyses for sex-specific outcomes in clinical trials	Sex-specific analyses should be expected in cardiovascular clinical trials, supported by robust methods and adequate statistical power. Government, health, funding and editorial policies must prioritize addressing the deficit of sex-specific evidence
Improve communication in cardiovascular clinical trial research	Co-designing with women, enabling discussions between family and clinicians, and diversifying communication channels will reduce participation obstacles
Address women's perceptions of risk in cardiovascular clinical trial research	The reluctance of women to participate in cardiovascular clinical trials due to perceived risks can be mitigated by minimizing procedures and providing tailored study information. The willingness of women to participate might be increased by addressing misconceptions and fears about trial-related procedures, thereby promoting inclusive research outcomes
Alleviate burdens of clinical trial research for women	Measures are needed to mitigate social burdens, such as financial constraints and childcare and travel commitments. Financial reimbursement, flexible appointments and minimization of trial-related procedures will increase female recruitment and retention rates
Increase stakeholder engagement in cardiovascular clinical trial research	Incorporating patient and public involvement improves the relevance, acceptability and dissemination of research findings. Female patient and public involvement representatives can best address barriers to women's participation
Align research questions with women's health priorities	Partnering with women to develop women-centred studies that determine and prioritize issues relevant to women will elevate the importance of cardiovascular research among women

Questions

1. Review the strategies and actions proposed by Saunders et al. to increase participation by women in clinical trials. Of these, which do you thank are the most important strategies, and why?
2. Can you think of any additional strategies that should be considered?

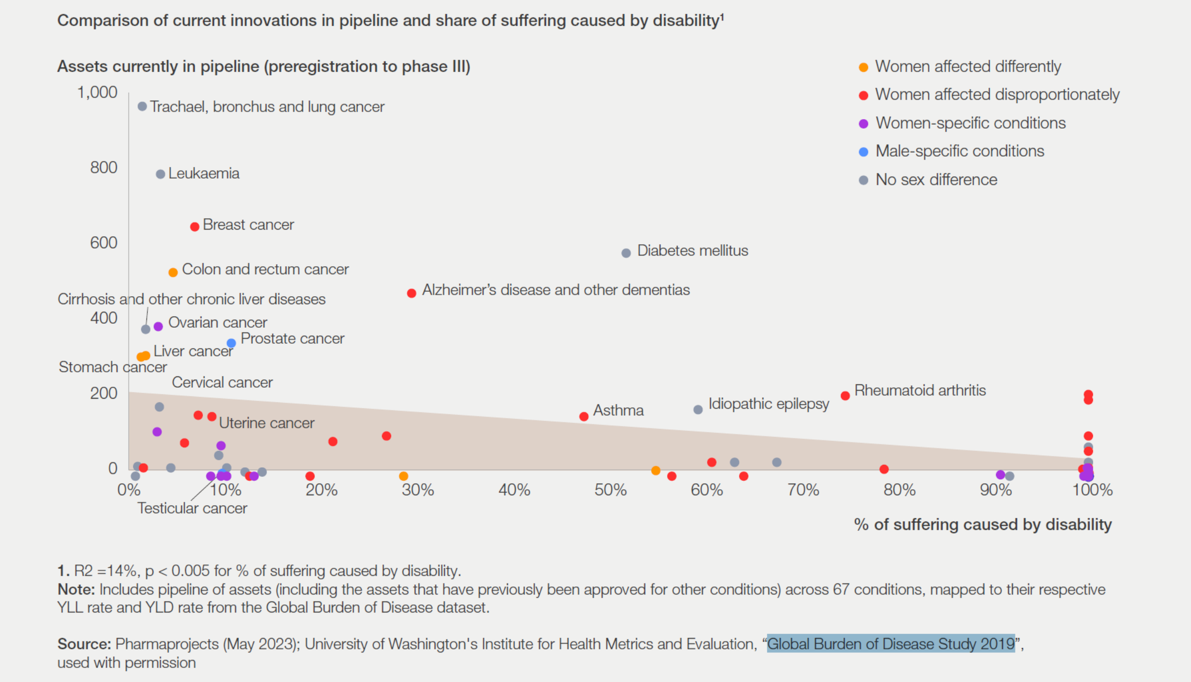
(Please note, Saunders et al.'s strategies are based on a review of evidence and not only on creative thinking – the purpose of these questions is to help you engage and understand these strategies better, and not necessarily to critique them as such).

What health problems aren't problems that are to be solved?

As was noted above, conditions which disproportionately affect women account for 47% of the total gap in health outcomes between sexes and genders. Examples include migraine, depression, mental illness, and autoimmune disorders like multiple sclerosis, lupus and rheumatoid arthritis.

Not all diseases are, however, equally subject to research. *Nature* has visualised data on funding for research on conditions which have a gender disproportionate effect (Smith, 2023). The result can be seen here: https://www.nature.com/immersive/d41586-023-01475-2/index.html. The visualisation shows that, when one looks at diseases which disproportionately affect one sex more than another, many of these diseases that have the biggest impact on people's quality of life disproportionately affect women. However, when one looks at funding targeted at the diseases which disproportionately affect one sex more than another, the diseases that disproportionately affect women do not feature heavily.

A consequence of this lack of funding for research into diseases that disproportionately affect women is that there are fewer therapies under development at present for such diseases. As the graph below shows (from the Word Economic Fortum report of 2024), many of the conditions that disproportionately effect women have relatively few therapies currently under development.


Comparison of current innovations in pipeline and share of suffering caused by disability[1]

1. R2 =14%, $p < 0.005$ for % of suffering caused by disability.
Note: Includes pipeline of assets (including the assets that have previously been approved for other conditions) across 67 conditions, mapped to their respective YLL rate and YLD rate from the Global Burden of Disease dataset.

Source: Pharmaprojects (May 2023); University of Washington's Institute for Health Metrics and Evaluation, "Global Burden of Disease Study 2019", used with permission

They note:

> Currently, global life sciences R&D efforts primarily focus on conditions with a high contribution of years of life lost (YLL) to the overall DALY. This has often disadvantaged women because they have a higher probability of being affected by conditions that affect quality of life (years lived with a disability, YLDs) rather than length of life (YLL), such as rheumatoid arthritis, endometriosis, uterine fibroids or diabetes… gynaecological conditions, such as endometriosis and uterine fibroids, which affect up to 68% of women, have 26 assets in the pipeline. Comparatively, other conditions may affect a lower percentage but have more assets (2024: 22).

They suggest that there are significant untapped investment opportunities in women's health, with the market for endometriosis treatments being estimated at 180 to 250 billion dollars. This compares to a global projected spend on respiratory disorders in 2027 of 90 billion dollars.

However even if there is a large global market for addressing health issues that disproportionately affect women, gender bias in investors may make it hard to achieve these targets. Hill (2024) for example reports that since 2010, on average, female-founded femtech companies in the UK, US and Canada have raised 23% less capital for each deal compared with similar, male-founded companies. It was also reported that femtech companies with men on the board fare better with investors than female-only-headed technology companies: femtech companies exclusively founded by women receive 28% of venture capital funding, compared with 38% of the funding won by femtech companies founded entirely by men with a little over one-third of funding going to companies founded by mixed-gender teams. Female headed femtech companies were also less likely to receive funding if they framed their funding pitch in terms of equity issues by using words such as dignity", "discrimination", "empower", "equality", "feminism", "gender gap", "inclusive" and "social change". Researchers hypothesised that investors saw women using these terms as more interested in social impact than in profit. Male-headed femtech companies using these terms did not suffer funding losses, which researchers hypothesise is because the use of such language by men is seen as proof of their marketing capacity and economic competence.

Gender and international differences in asthma experiences

Liv is 18 years of age and lives in western Europe. As a child she suffered frequently from laryngitis and from breathing problems. She also suffered with eczema. Her breathing problems were treated with soluble prednisone (a glucocorticoid) and, when they were severe, with a nebuliser (inhaled corticosteroid [ICS]) treatment as a hospital outpatient. As a child she was not diagnosed with asthma, despite regularly identifying the respiratory problems on doctor visits. Not having any clear indication as to the cause of her respiratory problem was a significant cause of stress for her family. About the age of 12, following a respiratory tract infection, she developed a persistent cough. At this point she was diagnosed with asthma. She was prescribed a salbutamol inhaler (a short-acting β_2 adrenergic receptor agonist [SABA]) which she took according to need. This gave some relief, but was of limited benefit.

At the age of 16, her breathing problems became again more pronounced. She found that her breathing problems reduced her ability to engage in sport; running became more difficult and often led to pronounced wheezing which could last for days. Swimming also became difficult as she found she could not inhale sufficiently when in the crawl position and so she was only able to swim backstroke (i.e., with her face out of the water). At this time she had wheezing over periods of days and the salbutamol inhaler did not give her as much relief as before, despite using it frequently. This caused significant anxiety, and frustration. She found that the inhaler was lasting for weeks instead of months. She ran out of her inhaler while on a foreign vacation and had to be given an emergency supply without prescription by a pharmacist due to a severe wheezing attack (this also led to an outpatient hospital visit and treatment). Her treatment was subsequently changed by her doctor to a medicine called Symbicort (budesonide, an inhaled corticosteroid [ICS]). This gave her increased relief, although the delay in finding an effective treatment caused anxiety and anger in her family. She found that she was able to recommence running, and to swim in a crawl position once more.

Asthma is a chronic disease that causes tightness in the chest, airway obstruction and wheezing. In Europe, almost 10 million people under 45 years old have asthma (Selroos et al. 2015). The Global Burden of Disease Study estimated that asthma caused the loss of 21.6

million healthy years of life (disability-adjusted life years [DALY]) and 461,069 deaths in 2019. Approximately 90% of the asthma burden of disease is borne by people living in low and middle income countries (LMICs). Some countries report very high (up to 90%) rates of uncontrolled asthma. Differences in disease burden across countries may result from cultural or environmental factors (air pollution, smoking rates etc.) but may also be linked to differences in treatment linked to underdeveloped health care systems which are designed to address the needs of a comparatively affluent minority, cultural differences in how treatments are understood and adopted, and a lack of research on the effectiveness and implementation feasibility of treatments in these populations (see Mortimer et al., 2022).

As children, boys are reported to have a higher prevalence of asthma than girls and are twice as likely as girls to be hospitalised for asthma treatment. Fuseuni and Newcomb (2017) report that this pattern reverses during adolescence, and, by adulthood, women have a higher prevalence of asthma than men, and are three times more likely than men to be hospitalized for asthma related events. Asthma symptoms are frequently linked to menstrual cycle, with 30-40% of women with asthma reporting pre or peri-menstrual worsening of symptoms. This increased prevalence in women is maintained until menopause, when a decrease in asthma prevalence in women is noted. Fuseni and Newcomb report that “While pre-menstrual asthma impacts many women with asthma, the molecular mechanisms driving the cyclic increase in symptoms are poorly understood” (2017: 19). Similarly, the relationship between asthma symptoms and contraceptive use is poorly understood. While there are a number of studies on this topic, they give rise to discordant findings (some finding increased asthma symptoms with contraceptive use, others reduced and some no change). These discordant findings may be related to small sample size, short study duration and to many different forms of contraceptives in use in those involved in these studies. Fuseni and Newcomb suggests a need for longer, more controlled, and larger studies.

Despite the increased prevalence of asthma in women which suggests that factors associated with biological sex may play a role in the disease, existing international recommendations for the management of asthma do not provide any sex-related indications for treatment. This would be justified if there were in fact no relevant differences between people of different biological sex. This hypothesis of no difference has not, however, been adequately tested. But, there are some initial indications from research about sex-related differences which suggests that common treatments like inhaled corticoid steroids have less positive effects on asthma symptoms in women than in men (Rogliani et al., 2022). In addition to biological sex differences, contextual and environmental factors may also play a role in asthma. We might therefore expect that gender differences (defined as socially constructed roles, behaviours and expressions of identity in girls, women, boys, men and gender-diverse people) may also be relevant. However there is even less data on the experiences of gender diverse people than there is on sex differences (Jenkins et al., 2022).

Case study analysis questions

1. The care concept of 'caring for' (responsibility) suggests we need to locate our actions in a social network with empathy for others. Who are the people that are involved in this network?
2. The care concept of 'caring with' identifies the need to act in solidarity with those who are comparatively powerless in society. Who has power in this situation and who has less power? (Another way of framing the same question is to ask whose voice/perspective is typically heard in such situations, and whose voice/perspective is typically silenced?)
3. The World Economic Forum (2024) says that the root causes of gender health gap include (i) scientific research which treats male body as the 'default', (ii) datasets that either don't include sufficient women or which are not gender differentiated, (iii) barriers to healthcare for women resulting in diagnostic delays and difficulties in accessing treatment, and (iv) under investment in developing treatments for conditions that disproportionately impact on women. The same four factors (lack of scientific research, lack of data, barriers to healthcare and underinvestment in research specific to these

contexts) may also be assumed to impact on differences in health outcomes across wealthier and lower income countries. Identify which one of these four aspects of the situation you would like to focus on in your analysis, and whether you would like to focus on questions of gender, international differences or on both (you have 4*3=12 different scenarios you could focus on – you can pick one).

4. In relation to the issue you have decided to focus on, identify who are the actors that most need care or give care in this situation (pick 3 or 4). For each, identify how this situation would be seen from their perspective.
5. For each of these, identify what emotions they would probably feel about this situation. What are the thought action tendencies associated with each of these emotions (refer back to chapter 3 if needed)?
6. What competences do you expect biophysical scientists bring to this situation (think about technical competences such as specific biological knowledge, knowledge of research techniques etc., as well as organisational competences, ethical competences and public advocacy roles)?
7. Who should be involved in arriving at a solution that supports those who give and need care? What might such a solution be? What roles could biophysical scientists and engineers play in such a solution?
8. The care concept of ‘receiving care’ identifies the need to monitor how the care that is given is received. What monitoring would be put in place in the context of your proposed solution?

The sources I used in preparing this case are:

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Conclusion

Our focus in this chapter is on the issue of justice, that is, are the risks and benefits of life sciences research and technological development shared equally across different groups. This issue is often framed in terms of groups which are perceived as having less social power or less ‘voice’. In this chapter we explored that question through the lenses of sex and gender.

As we noted in previous chapters, ethics reviews for life sciences research is often, in practice, reduced to questions of consent and autonomy. Issues of justice are less often considered at ethics review committees. Significant gender issues do arise in relation to life sciences research however:

- Questions as to what diseases gets studied and what technologies get developed are justice issues. It is evident that conditions like endometriosis, menopause and migraine cause very significant disability and loss of quality of life. Yes these are little researched and few technologies are under development for these conditions.
- Questions as to what data gets collected and reported are justice issues. The persistent failure to recruit adequate numbers of women into studies, or to report gender or sex disaggregated data means that differences in effects of technologies or medications are not known, and the evidence suggests that the invisibility of women in data has a disproportionately negative effect on them.
- Questions as to the wider culture in which life sciences research takes place – a culture in which women are less likely to be in leadership positions and are dependent on funding and investment decisions made by men who seem to operate in the context of sexist assumptions – is a justice issue.

From an ethics of care perspective, it is important to remember that these issues will not be addressed by individual heroes working alone, but rather by collectively building social systems that care for those who give care and need care.

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