At the intersection: bringing an ecofeminist perspective to empirical (bio)ethics and equity in international research

by

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Abstract

This thesis presents, discusses and critically evaluates the contribution of a selection of research outputs since 1990. Collectively, these publications make a novel contribution to the literature in intersectional feminist bioethics, with demonstrable impact over time.

Five commissioned book reviews and one sole-authored peer-reviewed journal article (translated and anthologised as a key movement text for an international audience after 18 years) established my ecofeminist theoretical foundation.

This was developed through the field of applied ethics, and is discussed in relation to one co-authored report, two co-edited peer-reviewed books, and a total of nine co-authored book chapters, and four further peer-reviewed journal articles (one sole-authored).

My funded academic work has centred on, 1. the challenges for fair benefit sharing in international research in the context of the 1992 UN Convention on Biological Diversity, and 2. building equitable north/south research relationships which connect these sustainability demands with more traditional research ethics principles. It pays particular attention to identifying gender issues in exploitative research, and mechanisms to prevent 'ethics dumping' between High-Income Country researchers and Low- and Middle-Income Country research populations.

My work has drawn on the methodology of empirical ethics to develop a novel method of curated comparative analysis of case studies in applied ethics, with application in fields including gender analysis.

The thesis reflexively analyses the role of my ecofeminist theoretical foundations in the development of this method and related outputs, within the context of international policy-making and research ethics. Finally, it looks to further develop inclusive methodologies to co-create research outputs with populations who are vulnerable to exploitation in research.

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Glossary of Terms and Abbreviations

ABS	Access and Benefit Sharing
BUAV	British Union for the Abolition of Vivisection
CBD	Convention on Biological Diversity
CPE	Centre for Professional Ethics
EDCTP	European & Developing Countries Clinical Trials Partnership
GCC	Global Code of Conduct for Research in Resource-poor Settings
GenBenefit	Genomics and Benefit Sharing with Developing Countries – From Biodiversity to Human Genomics
HIC	High-Income Country
ICBG	International Cooperative Biodiversity Group
IP	Indigenous People
IRB	Institutional Review Board
LMIC	Low- or Middle-Income Country
MoU	Memorandum of Understanding
NGO	Non-Governmental Organisation
PIP Framework	Pandemic Influenza Preparedness Framework
REC	Research Ethics Committee
San-Khoba	Prior Informed Consent and Benefit Sharing in the *Hoodia* Case
SMTA	Standard Material Transfer Agreement
THP	Traditional Health Practitioner
TK	Traditional Knowledge
TRUST	To catalyse a global collaborative effort to improve adherence to high ethical standards around the world
UCLan	University of Central Lancashire
UN	United Nations
WHO	World Health Organization

WIPO	World Intellectual Property Organization
Women's Environmental Network	WEN

'Woman' or 'women' (girl / girls) should be taken to refer to and include all people who identify themselves as women (girls).

Acknowledgements

This thesis is about my work in the world, and I would like first to acknowledge four women who have generously trusted me with opportunities to do it: Dr Margaret Jones, Bernadette Vallely, Professor Doris Schroeder and Professor Dame Caroline Watkins.

This thesis spans several decades of research activity. I would like to thank all of those involved in the various projects and adventures it references, especially all my WEN sisters, everyone who participated in the research it presents, and my co-authors who so generously supported this endeavour.

In the more immediate moment, this thesis has been written during the global pandemic of 2020-21, and I would especially like to thank my colleagues Professor Gill Thomson, Dr Kathryn Jarvis, Jane Fitzgerald and Helen Oates for their virtual workplace presence both during and beyond the unprecedented lockdowns.

Dr Kate Chatfield and Dr Philippa Olive have been perfect PhD supervisors, and I would also like to thank Dr Jess Macbeth for RDT support that really made a difference.

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Trinity Sunday

over

sistermotherdaughterlover earth

stars shine

roots grip

silver birch

beside

the rippling water.

Martin Lucas

(1962 – 2014)

Julie Cook[1]: Published Works Portfolio Contents

Short citations used throughout the thesis as indicated in bold

Edited Books (peer reviewed) (2)

Schroeder, D., & **Cook Lucas, J**. (Eds.). (2013). *Benefit sharing in theory and practice: From biodiversity to human genetics.* Springer. **(Schroeder & Cook Lucas, 2013a)**

Schroeder, D., **Cook, J**., Hirsch, F., Fenet, S., & Muthuswamy, V. (Eds.). (2018). *Ethics dumping: Case studies from North-South research collaborations*. SpringerOpen: http://www.springer.com/in/book/9783319647302 **(Schroeder, Cook, Hirsch et al., 2018a)**

Book Chapters (peer reviewed) (9: one a translation of an included article)

Feinholz Klip, D., Garcia Barrios, L., & **Cook Lucas, J**. (2009). The limitations of good intent: Problems of representation and informed consent in the Maya ICBG project in Chiapas, Mexico. In R. Wynberg, D. Schroeder & R. Chennells (Eds.)*, Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case* (pp. 315-331). Springer. **(Feinholz Klip, Garcia Barrios & Cook Lucas, 2009)**

Schroeder, D., & **Cook Lucas, J**. (2013). Benefit sharing: From biodiversity to human genetics – an introduction. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 1-7). Springer. **(Schroeder & Cook Lucas, 2013b)**

Cook Lucas, J., Schroeder, D., Chennells, R., Chaturvedi, S., & Feinholz, D. (2013). Sharing traditional knowledge: Who benefits? Cases from India, Nigeria, Mexico and South Africa. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 65-93). Springer. **(Cook Lucas, Schroeder, Chennells et al., 2013)**

Cook Lucas, J., Schroeder, D., Arnason, G., Andanda, P., Kimani, J., Fournier, V., & Krishnamurthy, M. (2013). Donating human samples: Who benefits? Cases from Iceland, Kenya and Indonesia. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice:*

[1] Between 2000 – 2015 I published as Julie Cook Lucas

From biodiversity to human genetics (pp. 95-127). Springer. **(Cook Lucas, Schroeder, Arnason et al., 2013)**

Cook Lucas, J. & Castillo, F. (2013). Fair for women? A gender analysis of benefit sharing. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 129-151). Springer. **(Cook Lucas & Castillo, 2013)**

Schroeder, D. & **Cook Lucas, J**. (2013). Towards best practice for benefit sharing involving access to human biological resources: Conclusions and recommendations. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 217-229). Springer. **(Schroeder & Cook Lucas, 2013c)**

Cook, J. (2016). (Translated by Noteris, E.). La colonisation de l'écoféminisme par la philosophie. In E. Hache (Ed.), *Reclaim - Recueil de textes écoféministes* (pp. 285-318). Cambourakis. **(Cook, 2016)**

Cook, J., Chatfield, K., & Schroeder, D. (2018). Promoting equity and preventing exploitation in international research: The aims, work and output of the TRUST project. In Z. Koporc (Ed.), *Ethics and integrity in health and life sciences research* (pp. 11-31). Emerald. **(Cook, Chatfield & Schroeder, 2018)**

Schroeder, D., **Cook, J**., Hirsch, F., Fenet, S., & Muthuswamy, V. (2018). Ethics dumping: Introduction. In D. Schroeder, **J. Cook**., F. Hirsch, S. Fenet, & V. Muthuswamy (Eds.), *Ethics dumping: Case studies from North-South research collaborations* (pp. 1-8). SpringerOpen: at http://www.springer.com/in/book/9783319647302 **(Schroeder, Cook, Hirsch et al., 2018b)**

Journal Articles (peer reviewed) (5)

Cook, J. (1998). The philosophical colonization of ecofeminism. *Environmental Ethics*, *20*(3), 227-246. doi.org/10.5840/enviroethics199820316 **(Cook, 1998)**

Alvarez-Castillo, F., **Cook Lucas, J**., & Cordillera Castillo, R. (2009). Gender and vulnerable populations in benefit sharing: an exploration of conceptual and contextual points. *Cambridge Quarterly of Health Care Ethics, 18*(2), 130-137. doi:10.1017/S096318010909022 **(Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009)**

Alvarez Castillo, F., & **Cook Lucas, J**. (2009). Fairness and gender in benefit sharing: Learning from the Kani, San, Nigerian, Kenyan and Icelandic cases for moving forward. *UP Manila Journal*, Special Issue, 140-173. **(Alvarez Castillo & Cook Lucas, 2009)**

Cook, J. (2020). Avoiding gender exploitation and ethics dumping in research with women. *Cambridge Quarterly of Healthcare Ethics, 29*(3), 470-479. doi:10.1017/S0963180120000213 **(Cook, 2020)**

Chatfield, K., Schroeder, D., Guantai, A., Bhatt, K., Bukusi, E., Adhiambo Odhiambo, J., **Cook, J**., & Kimani, J. (2021). Preventing ethics dumping: The challenges for Kenyan research ethics committees. *Research Ethics, 17*(1), 23-44. Published online May 24 2020. doi.org/10.1177/1747016120925064 **(Chatfield, Schroeder, Guantai et al., 2021)**

Funded Project Report (1)

Andanda, P., & **Cook Lucas, J**. (2007). *Majengo HIV/AIDS research case*. www.uclan.ac.uk/genbenefit **(Andanda & Cook Lucas, 2007)**

Commissioned Book Reviews (5)

Cook, J. (1990). Review: Adams, C. J. (1990). The sexual politics of meat. *The Vegan*, 6(3), 24. **(Cook, 1990)**

Cook, J. (1994). Review: Mellor, M. (1992). Breaking the boundaries: Towards a feminist green socialism. *Environmental Values, 3*(3), 278-279. **(Cook, 1994)**

Cook, J. (2000). Review: Cuomo, C. J. (1998). Feminism and ecological communities: an ethic of flourishing. *Environmental Values, 9*(3), 398-399. **(Cook, 2000)**

Cook Lucas, J. (2009). Review: Kheel, M. (2007). Nature ethics: An ecofeminist perspective. *Environmental Values*, 18(2), 247-249. **(Cook Lucas, 2009)**

Cook Lucas, J. (2010). Review: Salleh, A. (Ed.). (2009). Eco-sufficiency and global justice: Women write political ecology. *Environmental Values*, *19*(1), 136-139. **(Cook Lucas, 2010)**

SECTION 1

INTRODUCTION

This thesis critically evaluates the developments and contributions of a selection of my research outputs since 1990. Collectively, my publications make a novel contribution to the literature in applied and feminist bioethics, with demonstrable impact over time.

The included publications illustrate the development of my work over several decades, as I moved between women's health provision, NGO activism, and academia.

Section 2 covers a period from 1990 – 2010, during the early part of which I was a high-profile activist with the Women's Environmental Network, where I became increasingly interested in ecofeminism. Five commissioned book reviews and a sole-authored peer-reviewed journal article, which was translated and anthologised as a book chapter as a key movement text for an international audience 18 years later, establish my ecofeminist theoretical foundation.

Since 2005, this position has developed through the field of applied ethics, in the Centre for Professional Ethics at UCLan. My grant-funded academic work has centred on:

1. The challenges for fair benefit sharing in international research in the context of the 1992 UN *Convention on Biological Diversity*. This is discussed in Section 3, through one co-authored report, a stand-alone co-authored book chapter, a co-edited book containing five further co-authored chapters, and two co-authored peer-reviewed journal articles (2007-13).

2. Building equitable global North/South research relationships which connect these sustainability demands with more traditional research ethics principles. This is discussed in Section 4, through a high-profile co-edited book including a co-authored introductory chapter, an additional commissioned co-authored book chapter, and a peer-reviewed journal article co-authored using an innovative methodology (2018-21).

My work pays particular attention to identifying gender issues in exploitative international research. This is introduced as a cross-cutting theme in my published work in Section 3. Section 4 addresses mechanisms to prevent 'ethics dumping' between High-Income Country researchers and Low- and Middle-Income Country research populations.

Section 5 evaluates the synthesis of these elements through a gender analysis of ethics dumping. The evaluation refers to a sole-authored peer-reviewed journal article, which addresses ways to prevent ethics dumping in research with all-women participants (2020).

Section 6 concludes the thesis with a reflexive account of the development of my ecofeminist orientation, and the impact of this intersectional approach on the published work presented in the portfolio. It considers the relationship between my position and feminist bioethics, identifying this as a distinctively *eco*feminist approach to bioethics.

My work has drawn on empirical ethics to develop a novel method of **curated comparative analysis of case studies in applied ethics**. This approach has featured prominently in my work and the output of the Centre for Professional Ethics, and has potential for wider application in other fields, including gender analysis.

Overall, in this thesis I reflexively analyse the role of my ecofeminist theoretical foundations in the development of this method and the related outputs, within the context of international policymaking and research ethics. Finally, I look to further develop inclusive intersectional methodologies to co-create research outputs with populations who are vulnerable to exploitation in research.

The list of publications included in my portfolio can be found preceding this Introduction.

Throughout the thesis, these publications are cited in **blue bold text** to aid identification.

SECTION 2

ECOFEMINISM: SITUATING MY POSITION

> A basic definition of ecofeminism is that androcentric ideologies are responsible for environmental degradation as well as the oppression of women and that, under specific circumstances, it is possible to posit an alliance between nature and women. (Pandey, 2013, p. 346).

2.1. Becoming an Ecofeminist

I first encountered the term ecofeminism in 1990, in the anthology *Healing the Wounds; the Promise of Ecofeminism* (Plant, 1989). I felt I had found the missing piece between feminism, animal liberation (Collard, 1988; Gaard, 2002), green anti-nuclear politics, and women's health activism. Not because it was a unified theory; like Richard Twine, "I am not suggesting that ecofeminism is a total critical-social theory or even that such a thing is possible" (2001, p. 7), but because it recognised what we would now call the intersections (Twine, 2010a):[1]

It is important to situate my perspective within the UK context. I am a White working-class British cisgender woman from London's East End, steeped in a secular family background of trade unionism (e.g., the 1986-7 Wapping dispute), with mixed English/Celtic/European/Jewish heritage. The first of my family to attend university, I was aware of multiple structural and cultural factors impacting my life. My feeling was (and remains) that understanding this is the purpose of feminist theory if it is to be of use to the wider movement:

> Drawing on the insights of ecology, feminism, and socialism, ecofeminism's basic premise is that the ideology which authorizes oppressions such as those based on race, class, gender, sexuality, physical abilities, and species is the same ideology which sanctions the oppression of nature. (Gaard, 1993b, p. 1).

For me, ecofeminism enables analysis of *how* this theory that "the oppression of women and the oppression of nature are intertwined manifestations of the same oppressive cultural framework" (**Cook, 1998, pp. 228-9**; Section 2.3), can be of political use.

I became consciously involved in ecofeminist work. For example, I reviewed Carol Adams' (1990) book The *Sexual Politics of Meat* for *The Vegan* to draw attention to the inter-related

[1] "The term intersectionality, generally attributed to Kimberlé Crenshaw, began as a metaphorical and conceptual tool used to highlight the inability of a single-axis framework to capture the lived experiences of black women ... Feminist and ecofeminist intersectionality attempts to attend to the variety of ways in which women live and the range of circumstances which influence their often vastly differing experiences." (Kings, 2017, pp. 63-4).

oppressions of women and animals (**Cook, 1990**). Later, I would carry environmental concerns from the Women's Environmental Network (WEN)[2] into anti-vivisection work, in a 1994 national BUAV[3] campaign to include (non)animal-testing in the criteria for the proposed European eco-label for consumer products.

Through the early 1990s, during the heightened awareness around the 1992 Rio Earth Summit (Sontheimer, 1991; Harcourt, 1994), I was a high-profile activist with national London-based WEN. I led a campaign on the women's health and environmental impacts of sanitary protection products (Costello et al., 1989; Cook, 1991a, 1991b, 1993, not in portfolio), which successfully pressured tampon manufacturers to introduce toxic shock syndrome warnings on packs in 1992, and won a British Environment and Media award in 1993 (Appendix A: *Sanitary Protection Women's Health and the Environment* (WEN, 1991, 1993)). I also worked to raise awareness of the impact of international population reduction targets on women's reproductive choices (Burns, 1992; Appendix B: *Population - An Ecofeminist Perspective* (WEN, 1992)). In 1993 I co-organised two lecture series in London including international ecofeminist speakers (Appendix C: Ecofeminism Lecture Series, 1993), and began teaching women's studies at Birkbeck College, University of London, co-founding the first certificated course on ecofeminism in the UK (Appendix D: Ecofeminism Course, Birkbeck College, 1994-5). This led to invitations to give university guest lectures and seminars, piquing my appetite for more theoretical articulations of ecofeminism.

2.2. Tensions around Ecofeminism

Ecofeminism emerged globally in the 1970s and 1980s through the socio-political phenomenon of women's environmental activism (Mies & Shiva, 1993), rather than from any individual's ideas (Salleh, 1991, p. 206; Gaard & Gruen, 1993; Gates, 1996; Lauwers, 2016). It has motivated resistance against woman-nature oppressions, and influenced direct and indirect activism around peace and anti-nuclear campaigns, toxic waste sites, destruction of the physical environment from water, to forests, to wilderness, to wildlife, and consumer boycotts of products and 'lifestyles'. There are many accounts of this history, including case studies, from a range of perspectives (e.g., Spretnak, 1982; Caldicott & Leland, 1983; Dankelman & Davidson, 1989; Plant, 1989; Diamond & Orenstein, 1990; Adams, 1993; Merchant, 1995; Mellor, 1997; Warren, 1997a; Sturgeon, 1997; Salleh, 1997, 2009a; Pandey, 2013; Moore, 2016).

[2] Founded in 1988, WEN aims to educate inform and empower women who care about the environment www.wen.org.uk/ . For WEN's place in the international ecofeminist movement see e.g., Braidotti et al., (1994), pp. 89-90, 161; Salleh, (1997), p. 27; Moore, 2011; Moore, 2016, pp. 42, 55, 58, 94).

[3] British Union for the Abolition of Vivisection, where I was Assistant Campaigns Director, 1993-4.

I was impressed by the clarity and advocacy of the work of the late ecofeminist philosophers Val Plumwood (1986; 1991; 1992; 1993) and Karen Warren (1987; 1990). However, it soon became apparent that there were strong intersections between this theoretical approach, and a feminist discourse resistant to ecofeminism, based on its alleged essentialism (Carlassare, 1994). Essentialism is an ancient philosophical idea. It relates to the attribution of immutable 'essences', and is leveraged to enforce culturally constructed categories (human, animal, race, gender) as 'natural' in a way that limits (denies) possibilities for change (Grosz, 1994, p. 84).

Fear of positing a universal women's essence, identified with characteristics viewed as being specifically feminine, was a dominant concern in Anglo-American feminist theory during the 1980s and 1990s (Fuss, 1990; Field, 2000; Gaard, 2011). Some feminists positioned themselves against women allying themselves with 'nature' as a strategy to effect change:

> As a distinct stream or tendency within the women's movement, I think [ecofeminism] should die a quiet death ... No effort should be put into "improving", "refining" or "exploring" it. (Prentice, 1988, pp. 9-10).

Many such criticisms emanated from US scholars (Biehl, 1991), who claimed that "ecofeminine" variants of ecofeminism were propagating "dangerous views from a genuinely feminist perspective" (Davion, 1994, p. 17) by appealing to this universal essence. Warren (1994b, p. 3) described those alleged to hold these complicit positions as "nonphilosophers", but they were mostly activists outwith academia (others were simply from non-philosophical disciplines), and from a wider range of cultural backgrounds, often beyond North America. Despite calls for inclusion of "the voices of women and other oppressed persons" to build ecofeminist ethics (Warren, 1990, p. 145), both Vandana Shiva, an Indian nuclear physicist and philosopher of science who drew on indigenous perspectives (1989), and US spiritual activists (e.g., Starhawk, 1990) were named as holding non-feminist or antifeminist positions and leveraging "dangerous concepts" (Buege, 1994, p. 60).

This did not reflect my experience of what motivated ecofeminism in the UK. I had spoken with high-profile individuals from Europe, Australia and the US, so I was confident in my understanding of ecofeminism's potential as a radical version of feminism (Salleh, 1984; Plumwood, 1986; 1992).[4] Today, I would say that ecofeminism includes nature as an exploited intersectional category in its understanding of global structural inequalities.

[4] "A key tenet of radical feminism has always been the rejection of biological essentialism … Their movement was united with other social justice movements: for Black power, for the environment, for peace and anti-militarism." (Mackay, 2021). McAfee & Howard (2018), reference radical feminism's respect for intersectionality. I disassociate myself from the use of radical or 'gender-critical' feminism by transphobic TERFS (Stanford University, 2019).

I first challenged the idea that this made ecofeminism "dangerous" (to feminism) in a review of British writer Mary Mellor's *Breaking the Boundaries: Towards a Feminist Green Socialism* (1992), where I critiqued her presentation of ecofeminism for:

> failure to recognise that where ecofeminism is theoretically weak, it is so precisely because it is primarily an activist, social and political movement. Ecofeminism is split into types renamed ecofeminist/ecofeminine, a common academic/journalistic tactic which avoids engagement with the theoretically difficult issues ecofeminism raises. (**Cook, 1994**).

2.3. Theory Versus Activism?

"The philosophical colonization of ecofeminism" (Cook, 1998)

Women environmental activists frequently experience physical threat or harm (Moore, 2008; Ervin, 2018; Chinyavanhu, 2021), both within their communities (McHenry, 2017), and from external hate-narratives. Archive projects comment on how this discourse has functioned:

> By advertently stigmatising many of these women in an attempt to homogenise the group under one definitive stereotype, their unique identities as protestors, mothers, social rights activists and feminists was undermined. (The Gale Review, 2019).

Academic arguments that ecofeminist activists *share(d)* such essentialist universalizing ideologies about themselves still seem poorly grounded (Moore; 2004, 2016), and in my view frequently fail to understand activism. For example, there are many reasons why activists express themselves differently from external commentators, including a lack of knowledge of, interest in, or time for theory, the fact they had written a placard slogan and not a journal article, or straightforward exclusion from the debate (Salleh, 2009c, p. 12). This is amplified once we start to consider cultures outwith North America, both in Low- and Middle-Income Countries (LMICs)[5] and indigenous communities worldwide (Shiva, 1989; Gaebl, 2018; Jabeen, 2000; Sections 3, 4, 5).

"The philosophical colonization of ecofeminism" (**Cook, 1998**) was an article in *Environmental Ethics* which engaged with Warren's anthology *Ecological Feminism* (1994a), along two lines of argument. Firstly, I rejected the anthology's overt recasting of specific ecofeminist positions as essentialist and/or non-feminist without sufficient textual evidence, while no explanation was provided of *why* we should privilege a philosophical approach to ecofeminism:

[5] My work now uses World Bank classifications of High- (HIC) or Low- and Middle-Income (LMIC) Countries https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups While not uncontroversial, this verifiable system avoids complicity with assumptions regarding e.g., 'developing countries'.

> My concern here is not that distinctions are being drawn between different ecofeminisms as such, but that much more invidiously, some ecofeminist philosophers are unjustifiably privileging philosophical ecofeminism over other approaches to ecofeminism. Conceptual analysis is quite clearly being used here not just to *describe* different kinds of ecofeminism, but to *prescribe* what ecofeminism ought to be … We are, therefore, owed some explanation of the authority that lies behind these prescriptive claims. (**Cook, 1998, p. 229**).

Secondly, I interrogated the function of:

> Philosophical discussions which "explicitly take the perspectives of women as integral to [their] analysis", appeal to theories of epistemic privilege, or set out to develop other means of giving primacy to the voices of the oppressed, *while simultaneously dismissing women's voices from developing ecofeminist ethics without adequate justification* ... we do need to ask whether philosophy is an *articulation* of ecofeminist concerns or is trying to *dictate* what those concerns should be ... Ecofeminist philosophy cannot assume the right to call itself ecofeminist if it dissociates itself from the wider ecofeminist movement; nor can it assume the right to construct that movement in its own image. (**Cook, 1998, pp. 245-6**).

I received supportive contacts from the non-US academic ecofeminist community (e.g., Australian ecofeminists Salleh (supportive); Plumwood (engaged)), but Warren stated in her next book, *Ecofeminist Philosophy; A Western Perspective on what it is and why it matters*:

> I think Cook misunderstands both what makes ecofeminist philosophy philosophy and what ecofeminist philosophers offer as the "authority" behind the positions they defend ... The "authority" of a philosophical position that is advanced or advocated is based on the plausibility of the arguments presented by a historically located presenter. (2000, p. 69, note 1).

This effectively closed down any debate regarding *why* some "historically located" presenters, who I understood were mainly, like Warren (2000, p. xiii), predominantly White, US academics, were more 'plausible' than others when describing an international movement.

2.4. Withdrawal From the Field

British feminist scholars noted the increasingly troubling relationship between academic (theory) and other feminisms (Stanley & Wise, 2000). This affirmed my concern that the academic ecofeminist philosophical discourse had become largely self-referential (e.g., Warren, 2002), with no space for wider perspectives, let alone genuinely critical voices, which were

mainly emerging from an activist (and non-US[6]) context. I addressed this in a review of Chris Cuomo's book (1998), *Feminism and ecological communities*:

> her approach to ecological feminist activism is a direct attempt to invent an activist movement from an academic base by "explicitly mapping out potential activist agendas and strategies" … I am surprised she has nothing positive to say about the wealth of activism around the ecofeminist movement (broadly defined) over the last 20 years. (**Cook, 2000**).

Twine noted that:

> as Cook (1998) argues, [ecofeminism] has embarked on a process of identifying and exposing possible cases of essentialist ecofeminism but in a non-rigorous way. This ... seriously risks a theory/practice separation wherein activism is de-emphasised or is separated off from the theoretical advances of ecofeminist theory, such as reflexivity to essentialism. (2001, p. 5).

The apparent impossibility of such reflexivity *within* ecofeminism led to my personal "crisis of relevance". Ariel Salleh captured this phenomenon as "affecting contemporary academic disciplines" (2009c, p. 3), addressing the concern that transnational feminism had been depoliticised by the dominance of North American writing and academic constraints (2009b, p. xi). Recent discussions note how historically "this tendency is to make ecofeminists choose" between theory and practice (Estévez-Saá & Lorenzo-Modia, 2018, p. 126). Whilst continuing grassroots ecofeminist and women's health interventions, I moved into academic work in applied ethics in 2005 (Sections 3, 4, 5).

2.5. Reclaiming Ecofeminism:

La colonisation de l'écoféminisme par la philosophie. Recueil de textes écoféministes (trans). (Cook, 2016)

In 2016, **Cook** (**1998**) was translated and anthologised (**Cook, 2016, trans. Noteris**) as part of a book project. *Reclaim* aimed to bring ecofeminism to the French-speaking world following the Paris Climate Agreement (UN, 2015), with its commitment to gender equality and empowerment of women**.** I was delighted to be introduced as a "rare activist voice", alongside now classic ecofeminist texts (Appendix E: Impact):

> Julie Cook, in one of the rare critical texts of the institutionalization of ecofeminism and its effects, points out what is being played out here, namely the reconfiguration of ecofeminism to make it acceptable in the academy, relying on its division into two distinct entities from which comes the now unshakable idea that there are two

[6] There was however strong activism/analysis in the US outwith the academy around environmental racism and the emergence of the fundamentally intersectional environmental justice movement at this time (Ryder, 2017).

> ecofeminisms - one academically compatible and the other unbreakable, giving rise to tortuous texts starting with an often violent criticism of ecofeminism, to propose a version ultimately quite close to what they had so violently rejected. (Hache, 2016b, trans. JC, p. 27).

It was refreshing to see that my position was regarded as an identifiable critical perspective. I had continued to develop it in commissioned book reviews for the journal *Environmental Values*, e.g., Kheel (2008) in **Cook** (**2009**); Salleh (2009a) in **Cook Lucas** (**2010**). *Reclaim* seemed to invite me to actively reconsider my ecofeminist foundations.

2.6. Taking Ecofeminism Seriously: My Enduring Ecofeminist Orientation

I identify (**Cook Lucas, 2010**) as a materialist ecofeminist, drawing on the work of e.g., Carolyn Merchant (1980; Thompson, 2006; Gaard, 2011, p. 28; Lauwers, 2016), and the understandings of social theorists/activists such as Ariel Salleh to rethink humanity-nature relations, applying an "embodied materialist epistemology" (2009b, p. ix; 2009c, p. 5). My position is a critical politics, bringing women's (lived, gendered, cultural, therefore bodily) experiences (Plumwood, 1993, p. 35) to ecological activism and theory, but "is neither an essentialising standpoint nor an identity politics" (Salleh, 1997, p. 108; Heyes, 2020). I agree that:

> Feminists should note that physiological 'inscription' of the body is just as real as the discursive sort. (Salleh, 1997, p. 37).

The re-emergence of interest in ecofeminism has directly referred to Rosi Braidotti's "neo-materialism", which rejects the linguistic paradigm embedded in post-structuralism, "stressing instead the concrete yet complex materiality of bodies immersed in social relations of power." (2012, p. 21; Torrijos, 2013, p. 25).

There is currently a more open approach within the literature to ecofeminism's range, and its potential to theoretically interrogate and politically address the implications of 'the woman-nature connection' (e.g., Carr, 2011; Phillips, 2016; Foster, 2021). Contemporary ecofeminist work engages with socialism, women's studies and post-colonial theory, incorporating issues of global justice into environmentalism/ecology and the roles played by women in the global South (Gaebl, 2018).

I would argue that a North/South 'axis of analysis' (Sections 3 and 4) is far from new to ecofeminist theory (Shiva, 1989; Mies & Shiva, 1993; Plumwood, 2008) or activism (Appendix A; B; Moore, 2011) or empirical research (e.g., Cox, 1993). However, I have been intrigued by how contemporary approaches to ecofeminism (re)present these materialist connections:

> the women–land connection ... in the post/colonial South Asian societies discussed here is not merely symbolic. However, I also claim this connection cannot be rejected as essentialist because women's lived experiences in the given societies prove that women and land are actually treated in a similar way. (Jabeen, 2020, p. 1096).

Cook (**1998; 2016**) established my enduring position regarding ecofeminism. Its steadily growing citation record and 'public' profile (Appendix E), suggest the article and the related book reviews are useful. I am content with this, as I would not say anything fundamentally different now.

The remainder of this thesis offers a reflexive consideration of how my published work in this portfolio has approached applied bioethics, from this ecofeminist foundation.

SECTION 3

ADDRESSING THE POST-1992 IMPLEMENTATION CHALLENGES FOR FAIR BENEFIT SHARING IN INTERNATIONAL RESEARCH

3.1. Background

Since 2005 I have been a researcher in UCLan's Centre for Professional Ethics (CPE), which addresses questions of justice in international research, and global research ethics; of key importance is that projects have an impact in the real world.

The ten portfolio publications I present in this Section were funded through two policy-orientated research grants regarding the implementation challenges for fair benefit sharing in international research following adoption of the United Nations *Convention on Biological Diversity* (CBD, 1992): San-Khoba!: *Prior Informed Consent and Benefit Sharing in the Hoodia Case* (Wellcome Trust, 2006-8); GenBenefit *(Genomics and Benefit Sharing with Developing Countries – From Biodiversity to Human Genomics)*, (European Commission, 2006-10).

> The established meaning of 'benefit sharing' goes back to the adoption in 1992 of the international *Convention on Biological Diversity* (CBD), which aims to conserve biological diversity and facilitate its sustainable use through fair and equitable benefit sharing with resource providers (CBD, 1992; article 1) ... Developed nations focused on maintaining a high level of global biodiversity ... to secure access to natural resources ... Developing countries lobbied for sovereignty rights to counter exploitation, rights which they secured for plants, animals, micro-organisms and related traditional knowledge within their boundaries. Such natural resources now ... can only be accessed after prior informed consent has been obtained from providers on mutually agreed terms. (**Schroeder & Cook Lucas, 2013b, p. 2**).

This means that to access biodiversity, researchers – predominantly from the global North/HICs – have a responsibility to first identify and then engage in meaningful negotiations with the rights holders – predominantly from the global South/LMICs, and obtain their free and prior informed consent to utilise the natural resources, agreeing arrangements to share any resulting benefits (CBD, 1992, Articles 8j, 15, 16).[7] The national implementation of access and benefit sharing (ABS) legislation, with its accompanying frameworks and processes, has been challenging for policymakers, biodiverse countries, and particularly for traditional knowledge (TK) holders, who are often indigenous or tribal peoples.[8] In 2002 the *Bonn Guidelines* (CBD,

[7] The CBD has 196 Parties; it has been adopted by every country except the Holy See and the USA www.cbd.int/information/parties.shtml

[8] " 'Indigenous and tribal peoples' is a common denominator for more than 370 million people, found in more than 70 countries worldwide. Indigenous and tribal peoples have their own cultures, languages,

2002; 2011) were introduced to help countries implement ABS procedures effectively. A formal international framework was finally agreed in 2010, the *Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the CBD* (CBD, 2010b): "a landmark agreement as it operationalizes equity demands." (**Schroeder & Cook Lucas, 2013c, p. 218**).

My work in CPE was embedded in this process at the international level. For example, both San-Khoba! and GenBenefit attracted the attention and input of Tim Hodges, Co-Chair of the CBD Secretariat's Working Group on Access and Benefit Sharing (Andanda et al., 2013). Both he and Co-Chair Fernando Casas participated in GenBenefit's International Conference on Access and Benefit Sharing for Genetic Resources in New Delhi (2008), lending weight to our recommendations (Appendix F).

My research described in this Section directly contributed to operationalising ABS in the late 2000s, by providing concrete recommendations based on empirical case studies to address the "dearth of good practice examples" (**Schroeder & Cook Lucas, 2013c, p. 224**):

> Only by building on an evidence-based body of knowledge and practice can we move from theoretical understandings of fair benefit sharing and abstract conceptions of justice to better practice which benefits real people. (**Schroeder & Cook Lucas, 2013c, p. 229**).

This focus on identifying complex risks of exploitation in benefit sharing cases was enhanced by my activist ecofeminist orientation towards taking empirical data seriously in ethics (Warren, 1997b). My original interest in the CBD benefit sharing context was related to ecofeminist concerns about biopiracy (Shiva, 1997). It has been shaped by how benefit sharing resonates with both Salleh's materialist ecofeminist conception of "any group that works at the socially constructed margin where culture meets nature" (1997, p. 144), and Warren's characterization of ecofeminist philosophy as:

> centrally concerned with issues that arise out of the intersection of three distinct but overlapping spheres: (1) feminism; (2) science (including the science of ecology), development, technology and "nature"; and (3) local or indigenous perspectives. (2000, p. xv).

customs and institutions, which distinguish them from other parts of the societies in which they find themselves." (ILO, n.d.).

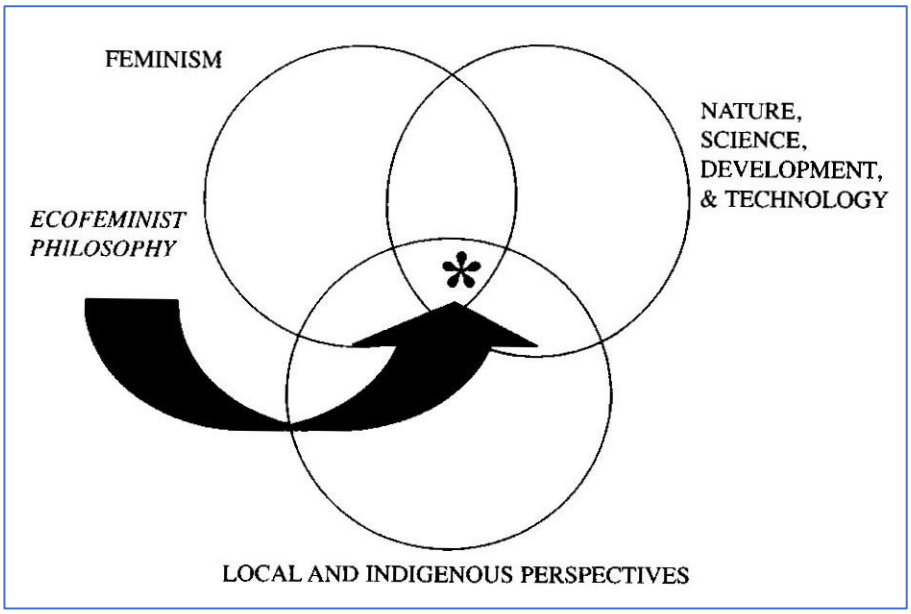


Figure 3.1.

*Warren's vision of "*what to aim for *in one's ecofeminist philosophical understanding of and solutions to a gender or an environmental issue." (2000, pp. 44-45).*

CPE's research agenda therefore presented me with an opportunity to apply my ecofeminist orientation to a contemporary topic, with the direct intention to have an impact.

3.2. Benefit Sharing in International Research

3.2.1. Exploring the field through the San-Khoba! project:

"The limitations of good intent: Problems of representation and informed consent in the Maya ICBG Project in Chiapas, Mexico." (Feinholz Klip, Garcia Barrios & Cook Lucas, 2009)

I began by co-authoring a chapter with two Mexican experts for the book, *Indigenous Peoples, Consent and Benefit Sharing* (Wynberg, Schroeder & Chennells, 2009). The MAYA International Cooperative Biodiversity Group (ICBG) in Chiapas, Mexico (1998-2001), aimed to catalogue preclinical bioactive agents from local plants. The ICBG intended to formally share 0.25% of any profit from pharmaceutical products with the indigenous Mayan people, through a benefit sharing structure that had been pre-planned without any local engagement. I summarised the literature, and undertook a comparative analysis (Appendix G: MAYA-ICBG – San-Hoodia Comparison 2009) with the San-*Hoodia* benefit sharing case from Southern Africa (Chennells, 2007), where researchers had attempted to patent the indigenous San peoples' TK of the *Hoodia*

plant's appetite-suppressant properties without their knowledge, on the basis they "no longer existed" (Wynberg & Chennells, 2009, p. 101).

These two cases were structurally similar. Both played out in a policy vacuum; post-1992 but prior to the adoption of national CBD-compliant legislation (Appendix H: Timeline of CBD cases 1987-2010). This raised questions about adequate processes and structures for negotiating CBD-compliant benefit sharing in international biodiversity research. It raised significant challenges regarding indigenous peoples' representation, inclusion and participation (Vermeylen, 2009a) in forms that are 'credible' to powerful outsiders, whilst remaining authentic and contextually legitimate (Wynberg, Schroeder, Williams et al., 2009; Vermeylen 2009; Vermeylen & Walker, 2011). This lens reflects ecofeminist concerns about the suitability of "ostensibly universal - but really Eurocentric - terms of reference" to conceptualise and conduct these negotiations (Salleh, 2009c, p. 10). It is not always clear who the TK holders are, or should be, creating risks around inclusion and exclusion. In the absence of appropriate engagement and representation strategies, stakeholders' conflicting assumptions regarding 'consent', 'collaboration' and 'benefit sharing' can exacerbate conflicts, which risks the breakdown of the research.

The two cases had very different outcomes. The San, with whom CPE continues long-term research collaborations (Section 4), have ultimately benefitted from hard-won benefit sharing agreements with those who utilise their TK (Schroeder et al., 2020). The MAYA-ICBG was terminated by the funder after 3 years with no output, or benefits.

Substantial influence was wielded by international NGOs and Mexican networks, who advocated for the Mayan people from a position which challenged many 'Northern' notions, including the concept of intellectual property. Some NGOs criticized [the CBD] as:

> the most sweeping biopiracy coup ... [which] legalized "recognition" of national sovereignty over genetic resources (Ribiero, as cited in **Cook Lucas, Schroeder, Chennells et al., 2013, p. 80**).

The MAYA-ICBG literature was dominated by US researchers and funders. My analytical approach based on Mexican researchers' experiences, and openness to critical perspectives (traditional healers and international NGOs) enabled me to contribute to the "remarkably consistent suite of issues" that emerged through San-Khoba!, including "[T]he critical need to build capacity among researchers" (Wynberg, Chennells & Schroeder, 2009, pp. 343-9) (Section 4 presents the development of this research direction). Controversy about the relationships between indigenous cultures, knowledge, identities (and land), and national governance and borders revealed the contextual complexity of the ABS landscape in practice. This understanding shaped my approach as I broadened the comparative analysis to seven international benefit sharing cases in the GenBenefit project (2006-10).

3.2.2. Developing the field through the GenBenefit project: *Benefit sharing in theory and practice: From biodiversity to human genetics*

Book (Schroeder & Cook Lucas, 2013a)
"Introduction" (Chapter 1) (Schroeder & Cook Lucas, 2013b)

Four years of high-profile GenBenefit research generated a substantial part of the work presented in my portfolio (nine publications), and culminated in a co-edited book output, *Benefit sharing in theory and practice: From biodiversity to human genetics* (**Schroeder & Cook Lucas, 2013a**). The "Introduction" explains how the book "starts with discussions about benefit sharing related to biodiversity, but moves on to the as yet unresolved topic of benefit sharing in return for access to human biological resources" (**Schroeder & Cook Lucas, 2013b, p. 2**). I co-edited the book; selected topics, identified themes in the invited contributions and structured their presentation, and co-authored both the "Introduction" and "Towards Best Practice: Conclusions & Recommendations" (Section 3.4).

I was also lead author of the two core empirical ethics chapters 4 (Biodiversity; Section 3.2.3) and 5 (Human Genetics; Section 3.2.4).

Empirical research in ethics is relevant to determining what course of action is right or wrong, respectful or disrespectful etc. It involves the collection and analysis of "ethically relevant empirical data"; "bioethicists may use empirical data to generate 'evidence-based' recommendations about how ethical principles should be realized in specific settings." (DuBois, 2009, pp. 23). Empirical ethicists therefore analyse data that has been collected via their own empirical work, other researchers' studies, or information from civil society, industry and media. In my trajectory from a campaigning perspective to academic research, this has been an appropriate method to develop, as it relies on the same skillset in locating and working with information from diverse sources, and a transferable critical perspective of 'What is relevant here?'.

Case studies are a well-established method in applied ethics, particularly in transdisciplinary contexts, where they bring 'real-life' empirical evidence to situations which demand ethical decision-making (European Commission, 2010). The orientation of my applied empirical ethics approach is described in (Appendix I: Methodological Approach for this Inquiry). This included the extensive use of case studies.

The two empirical ethics chapters analysed seven benefit sharing case studies from four continents, dating from 1984 and falling under two overarching governance frameworks; one recently implemented (CBD), the other well-established regarding human research participants. Both chapters were based on the literature, and primary and secondary data collected into case

study reports by GenBenefit's subject experts,[9] supplemented by additional material, and emerging questions about implementation post-*Nagoya Protocol*.

There was a strong methodological and editorial challenge in analysing and presenting this complexity in a form which would be both accessible and useful as "a helpful resource for policymakers, civil society and academics" (**Schroeder & Cook Lucas, 2013b, p. 6**). This was achieved through the development of what I describe as a **curated comparative analysis of case studies in applied ethics**.

The term curation represents my reflexive responsibility for organising the material to identify trends and themes to develop and present the resulting analysis. An outline summary of the steps in the method is shown in Table 3.1. The first stage of the process addressed each case study individually, identifying the relevant Situation, Context, and Frameworks, in order to select and apply Axes/Lenses of Analysis. These identified specific suites of Exploitation Risks. The results were presented as individual case-based 'Good Practice, Criticisms and Challenges' (**Cook Lucas, Schroeder, Chennells et al., 2013, pp. 73, 77, 81, 89**; **Cook Lucas, Schroeder, Arnason et al., 2013, pp. 104, 115, 121**). In the second stage, I compared individual case findings across the two groups of biodiversity or human samples cases (Appendix J: MAYA-ICBG – San-Hoodia –- Kani – Nigeria Comparison 2013; Appendix K: Iceland – Kenya – Indonesia Comparison 2013). The emergent cross-cutting themes were verified by the co-author subject experts, and summarised to conclude chapters 4 and 5. In the third stage, all results were synthesized to make generalised recommendations, presented in chapter 10, "Towards Best Practice: Conclusions & Recommendations" (Section 3.4).

The curated comparative analysis method relied on my deep familiarity with the material through immersion over time. This helped to retain the individual character of each case within a complex international and theoretical context.

Appendix L (Indicative example of use of curated comparative analysis of collective case studies in applied ethics) provides a detailed example of the method's application.

[9] GenBenefit was funded to produce 5 original case studies; San-*Hoodia*, Kani, Nigeria, Iceland and Kenya. MAYA-ICBG data was drawn from my previous work; Indonesian data from the literature and wider project group.

Table 3.1.

Curated Comparative Analysis of Collective Case Studies in Applied Ethics: Summary Structure of Method.

Curated comparative analysis of collective case studies in applied ethics Summary Structure of Method			
Stage 1: Apply process to each individual case			
Step in process	**Purpose**	**Analytical categories**	**Shaping considerations**
Situation Focus and define the analysis.	Identify specifics: ▪ Topic/issue ▪ Stakeholders ▪ Location ▪ Timeline.	Open	• Assess existing evidence.
Context Dependent on the research question.	Identify the key features.	▪ Setting ▪ Population ▪ Intervention ▪ Outcomes …	E.g., ▪ (Geo)political issues.
Frameworks Decisions made here set the analytical parameters	▪ Identify frameworks that apply directly. ▪ Consider if any others are relevant. ▪ Identify what frameworks have been put in place.	▪ Policy ▪ Legal ▪ Ethical ▪ Human rights ▪ Binding/non-binding/voluntary/ aspirational …	What impact do/could these frameworks have if they are/not applied in the case/to the analysis?
Identifying Lenses/Axes of analysis Based on the data, which are most appropriate?	▪ Identify the patterns. ▪ What / who is missing / overrepresented? ▪ What have **you** noticed (bias / specialism)?	▪ Indigeneity ▪ Gender ▪ Poverty ▪ Historical colonisation ▪ Vulnerability …	This will structure the analysis.
Exploitation risks These should emerge from the analysis.	Identify and assess these in relation to the selected frameworks.	▪ E.g. Corruption undermines legal protections.	What happened / when / who to – could that have been foreseen or mitigated?
Recommendations	▪ Mitigate risks ▪ Model best practice	What could be done differently/better?	

Stage 2: Cross-map findings with other case studies to identify comparative themes			
Step in process	**Points noted *(examples)***	**Counterpoints noted *(examples)***	**Themes *(examples)***
Situation	*Export of samples for R&D.*	*R&D retained in country.*	*Impact of R&D location.*
Context	*Politically unstable setting.*	*Politically stable setting.*	*Setting underpins risks.*
Frameworks	*Local laws and regulations followed.*	*Local laws and regulations unenforced.*	*Frameworks alone may not be sufficient.*
Lens / Axes of analysis	*Poverty*	*Wealthy population*	*Financial status differentiates risks.*
Exploitation risks	*Low levels of literacy in population.*	*Well-educated population.*	*Educational levels relate to validity of consent.*
Stage 3: Synthesis produces recommendations which would be weaker, or missed altogether, based on an individual case study/limited set of case studies.			
Recommendations need to be: ▪ Proportionate, supportive and relevant ▪ Contextual, (to settings / frameworks etc.), and ▪ Implementable by those they are aimed at.			

3.2.3. Biodiversity

"Sharing traditional knowledge: Who benefits? Cases from India, Nigeria, Mexico and South Africa." (Chapter 4)

(Cook Lucas, Schroeder, Chennells et al., 2013)

Here, I built on my previous comparative analysis of the Maya-ICBG/San-*Hoodia* case studies (**Feinholz Klip, Garcia Barrios & Cook Lucas, 2009**) with two TK benefit sharing case studies from India and Nigeria (Chaturvedi, 2007; Wambebe, 2007), using updated timelines and adapted indicators (Appendix J). All four cases concerned research access to indigenous traditional (healing/plant) knowledge for commercialisation.

The case from India commercialised Kani (Tribal) peoples' TK into an Ayurvedic anti-fatigue medicine, Jeevani. Research commenced pre-CBD in 1987 and the product was marketed in 1994, as India ratified the CBD. Analysis further evidenced the impact of: researchers' commitment to benefit sharing; a sympathetic national regime; active inclusion of TK holders and communities in research and development, and underscored the need for transparent and supportive decision-making processes and structures (e.g., a benefit sharing trust to manage income; training to avoid over-harvesting of plants). However, my analysis identified concerns about the initial access to TK, and the late involvement of the wider community.

The Nigerian case (commencing 1992) concerned an individual traditional health practitioner's (THP) medication (Niprisan/Nicosan) for the management of sickle-cell disease. This was licensed to a US company, becoming the first example of reverse transfer of medical technology in Africa. A unique Memorandum of Understanding (MoU) between researchers and the THP has been adopted by the World Intellectual Property Organization (WIPO) and the World Health Organization (WHO) as model practice. However, my case analysis raised issues around the individual THP's assumption of TK rights. The lack of affordability of the drug in Nigeria, including to those who participated in clinical trials, identified concerns about the availability of any benefits to the wider originating communities.

The curated methodology led me to structure the second stage (comparative) analysis of these four TK case studies chronologically. The resulting synthesis was the first to analyse benefit sharing cases along an axis of the introduction of the CBD; they straddled the uneven boundary between unregulated and regulated access to non-human biological resources, as countries took time to introduce national legislation to enact the CBD (Appendix H). The findings therefore offered useful insights into what works, under what conditions, and identified barriers and facilitators to fair benefit sharing processes. This created a bridge to fruitful comparisons with three case studies on the donation of human research samples/data.

3.2.4. Human genetics

"Donating human samples: Who benefits? Cases from Iceland, Kenya and Indonesia." (Chapter 5)
(Cook Lucas, Schroeder, Arnason et al., 2013)

Case study: Majengo HIV/AIDS research case. (Andanda & Cook Lucas, 2007)

Human biological/genetic 'resources' fall outside the scope of the CBD, but within a long-standing biomedical governance regime of largely non-binding ethical instruments/guidelines, e.g.: the *Declaration of Helsinki* (World Medical Association, 2013)[10]; *International Ethical Guidelines for Health-related Research Involving Humans* (CIOMS, 2002; 2016), and the *Universal Declaration on Bioethics and Human Rights* (UNESCO, 2005). Generally, access to the benefits of scientific advancement is seen as a universal and generic right (e.g., UN, 1948, Article 27[1]). There are deeply ingrained ethical sensitivities to undue inducement (coercion) to participate in biomedical research, which intersect with safeguarding for vulnerable participant groups to problematise benefit sharing arrangements for individuals or communities to 'profit' from participating in research (**Schroeder & Cook Lucas, 2013b**; Arnason & Schroeder, 2013).

In lead-authoring chapter 5 (**Cook Lucas, Schroeder, Arnason et al., 2013**), I used the steps of the curated case studies method to explore the risks of research exploitation in three settings: Iceland (deCODE biobank, commencing 1996) (Arnason, 2007); Kenya (sex workers and HIV/AIDS research, commencing 1984) based on (**Andanda & Cook Lucas, 2007**), and Indonesia (H5N1 virus samples, 2005-11). In the first stage of analysis I introduced additional key indicators as they emerged from the data (e.g., highly vulnerable populations; risk of inducement; export of samples). In the second stage (comparative) analysis (Appendix K), the cross-cutting exploitation themes were verified as relating primarily to gaps in the global legal framework governing access and benefit sharing for human samples.

The attempt by the company deCODE genetics to effectively use Iceland as a genetics laboratory, using samples and an opt-out database, in return for free population-wide access to new treatments, was declared unconstitutional in 2003. Analysis of this case raised deep ethical issues about meaningful community participation and consent to such proposals, even in an affluent, high-functioning democracy.

Indonesia withdrew from WHO virus sample-sharing during the H5N1 pandemic in 2006. This exposed how LMIC resources underpin richer nations' pharmaceutical industries and public health strategies, whilst e.g., vaccines are not accessible to the originator countries. Crucially,

[10] The 2008 *Declaration of Helsinki* was current when writing **Cook Lucas, Schroeder, Arnason et al., 2013**.

Indonesia appealed to its sovereignty rights over biological resources under the CBD as its point of reference. This demonstrates the rhetorical power of symbolic/material connections between internationally exploited people (and their biological samples) and 'nature', akin to ecofeminist analyses. This unprecedented action eventually leveraged a significant international Pandemic Influenza Preparedness (PIP) Framework and related SMTAs (Standard Material Transfer Agreements) in 2011, to safeguard global virus sharing and address the distribution of resulting 'benefits', particularly access to vaccines.

However, it was the large cohort of impoverished female Kenyan sex workers' participation in international HIV/AIDS research since 1985 that connected most strongly with my research interests. I co-authored the original GenBenefit case study *Majengo HIV/AIDS Research Case: A Report for GenBenefit* with a Kenyan legal expert (**Andanda & Cook Lucas, 2007**). Interview data with researchers, participants from Majengo in Nairobi, and governance stakeholders enriched my examination of the negotiation and decision-making procedures throughout the Kenyan research programmes. The most significant ethical issues emerged as participants' multiple vulnerabilities, their inclusion in research design, and consent to export of samples,[11] and the limited potential for ethical benefit-sharing within existing frameworks. This exposed tensions regarding structural exploitation risks in even well-managed research.

> *I agreed because when I am sick they help me a lot and when my immunity is down they will also help me.* (Majengo research participant, as cited in **Andanda & Cook Lucas, 2007, p. 10**; **Cook Lucas, Schroeder, Arnason et al., 2013**).

My conclusions for the original Kenyan case study were therefore foundational to the third (synthesizing) stage of the **curated comparative analysis** of all three human samples case studies for this chapter, particularly in relation to recommendations to strengthen compliance with existing biomedical benefit-sharing frameworks (Section 3.4).

Before presenting GenBenefit's final recommendations, I will consider the development of the use of gender analysis in my research around benefit sharing in theory and practice.

3.3. Including Gender as a Category of Analysis in Benefit Sharing Theory and Practice, 2007-13

There was significant originality in opening up the nascent debate around women's role in benefit sharing in the 2000s, in relation to the CBD (1992) and the development of its *Nagoya*

[11] "The volunteer (sex worker) participants themselves have at all stages given individual consent to their participation in the ongoing studies, which use their blood, cervical, vaginal and saliva samples." (**Cook Lucas, Schroeder, Arnason et al., 2013, pp. 107-8**).

Protocol (CBD, 2010b). GenBenefit's gender specialist, Professor Fatima Castillo (University of the Philippines), was one of the few people who had previously published in this area (Alvarez-Castillo & Feinholz, 2006).

My existing philosophical skills in conceptual analysis could be applied regarding, for example, meanings and justifications embedded in benefit sharing-related social practices (e.g., Warren, 2000, pp. 43-71).[12] But taking an applied ethics approach to the topic (Appendix I) required integration of the empirical aspects of GenBenefit's work. I was unfamiliar with using relevant methods such as sociological gender analysis, which was originally developed as a tool to uncover and challenge gender-based dimensions in development projects (UNDP, 2016). Warren emphasises that, "A feminist approach uses gender analysis as the starting point; gender is the *lens* through which the initial description and analysis occur" (2002, p. 2). But one has to do something with a 'description' in order to turn it into an 'analysis', especially when aiming for real-world recommendations. My ecofeminist-orientated applied empirical ethics approach emerged in the three publications discussed in this Section. I think of this methodological development as moving from a gender 'lens' through which one observes and describes things, to the introduction of axes (in my case ecofeminist sightlines) (Sections 4, 5, 6), along which one locates intersections where interventions might have an impact.

3.3.1. "Gender and vulnerable populations in benefit sharing: an exploration of conceptual and contextual points."

(Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009)

This approach was first applied to concepts around benefit sharing for an article in a special journal issue which focussed on vulnerability in research (Schroeder & Arnason, 2009). I applied feminist conceptual analytical tools to critique Schroeder's generic definition of vulnerability (Schroeder & Gefenas, 2009), addressing their appeal to the "problem of 'false categorisations', by specifying the vulnerabilities of individuals and groups in the context of gendered relations" (**Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009, p. 130**). Building on this, the article defined vulnerability as both complex, due to interacting factors, and fluid due to shifting power relations; it demonstrated how for women vulnerability is "layered, multidimensional, and dynamic", involving multiple factors (axes) including gender, poverty and class. Here I built on the Kenyan case study (**Andanda & Cook Lucas, 2007**), and my existing commitments to inclusive ecofeminist analyses, including critiquing Andanda's (2009) work in the same journal issue for

[12] All three publications used Warren's philosophical formulations to ground descriptions of patriarchy and domination: (**Alvarez Castillo & Cook Lucas, 2009**, p. 145; **Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009**, p. 136; **Cook Lucas & Castillo, 2013**, p. 130).

"not addressing the *gendered* nature of the vulnerabilities she identifies" in Majengo. I contributed the significant recognition that "where vulnerable populations are at risk from exploitation in medical research, this should act as a marker to indicate that benefit sharing arrangements must explicitly protect women's rights" (**Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009, p. 131**). I have returned to this idea of vulnerability as a marker in subsequent work (Sections 4, 5).

3.3.2. "Fairness and gender in benefit sharing: Learning from the Kani, San, Nigerian, Kenyan and Icelandic cases for moving forward."

(Alvarez Castillo & Cook Lucas, 2009)

This article identified gender inequality concerns in benefit sharing using data from GenBenefit's five original case studies (Kenya, Nigeria, South Africa, India and Iceland). It focused on benefit sharing decision-making, from consent to access TK, through to allocation of benefits. Using gender analytical tools the analysis was situated "in the larger social matrix of the societies where the cases are located" (**Alvarez Castillo & Cook Lucas, 2009, p. 151**). A range of independent gender equality criteria, which were both sensitive to context and comparable (e.g. % women's political participation) were used to draw case comparisons with each national context. Cross-comparisons were then drawn between the five settings. (Appendix M: Gender Analysis: Selected Indicators 2009, with 2021 comparison):

> We did not find any significant differences in issues of fairness in benefit sharing arising from gender between the human and non-human resources cases. (**Alvarez Castillo & Cook Lucas, 2009, p. 163**).

This analysis related to the five case studies, contextualised by women's general rights, rather than referring specifically to the CBD framework. But our findings that the variations in gendered inequalities between the five nations precisely differentiated the gender concerns identified in each case study provided evidence that gender issues had a strong impact on outcomes regardless of the governance frameworks in place:

> We see that in societies characterized by very low female political participation, high poverty incidence and lack of control of economic assets among women, their direct participation in negotiations and decision-making regarding benefit sharing is minimal. By contrast, in a society like Iceland, although the political gender gap exists ... there was a greater degree of women's direct involvement compared to the other cases. (**Alvarez Castillo & Cook Lucas, 2009, p. 163**).

The successful extension of gender analysis to an empirical ethics approach to benefit sharing laid the ground for my later **curated comparative analysis of case studies in applied ethics** method in 2013, and demonstrated how:

> The questions we ask here are important in that these can lead us to search for data that may not be immediately obvious. The challenge is to identify the sites of vulnerabilities and inequalities which are hidden in socio-political formations in order to be able to formulate responses that address the roots of inequality and vulnerability. (**Alvarez Castillo & Cook Lucas, 2009, p. 144**).

3.3.3. Impact of this work in the pre-*Nagoya Protocol* context

These findings were presented in policy circles. This included a presentation and lively debate at an event at the sixth meeting of the Ad-Hoc Open-ended Working Group on Access and Benefit-sharing to the CBD, November 2009, Montreal, Canada (Appendix N; CBD, 2010c). Our empirical data demonstrated that men had dominated decision-making. We made strong recommendations that to be consistent with the CBD *Preamble* in "Recognizing also the vital role that women play in the conservation and sustainable use of biological diversity and affirming the need for the full participation of women at all levels of policy-making and implementation for biological diversity conservation" (CBD, 1992), guidelines and policies for benefit sharing in human and non-human genetics should *explicitly* require women's meaningful participation in *all* phases of decision-making, and should include examples of the kinds of mechanisms that will enable women to have an effective voice. I was told by one delegate that it was "the best-flowering debate on gender and benefit sharing" they had seen (personal communication).

GenBenefit's gender output therefore formed part of the debate around finalising the content of the 2010 *Nagoya Protocol*, which includes specific references to the identification and enhancement of the capacity needs and priorities of women (CBD, 2010b, Articles 22.3, 22.5j, 25.3j) (**Cook Lucas & Castillo, 2013, p. 137**; Section 3.3.4). The outcomes of the 10th Conference of the Parties to the CBD (CBD, 2010a) incorporated many 'Decisions' on the active inclusion of women and gender issues in national and international biodiversity strategies and targets (CBD, 2012, pp. 14-18), and changed the landscape so that consideration of gender in benefit sharing became mandatory.

3.3.4. Chapter 6: "Fair for women? A gender analysis of benefit sharing." (Cook Lucas & Castillo, 2013)

In 2013, I lead-authored a chapter for the GenBenefit book, "Fair for women? A gender analysis of benefit sharing" (**Cook Lucas & Castillo, 2013**). Here, I built on previous findings in the post-*Nagoya Protocol* context of an international ABS implementation framework. This was another milestone in my development as a researcher, with lead-authorship of 3/8 topic chapters in the

book I was co-editing with the leading subject expert (**Schroeder & Cook Lucas, 2013a**). This gave me a real sense of empowerment and confidence in this work, where I wanted to paint a broader, more integrated picture of the relationship between benefit sharing, sustainability and global women's issues.

This analysis was framed by the CBD Preamble's recognition (1992) of the need for women's full participation in policymaking and implementation around biodiversity, and the *Nagoya Protocol* Preamble's reiteration of this in relation to benefit sharing (CBD, 2010b). Using the curated comparative analysis method, I revisited the Situation elements of the case study data to identify a broader range of updated gender issues (Appendix O: Comparison of Gender Indicators 2009-13). This enabled me to apply additional Frameworks to the analysis of benefit sharing guidelines and the extent to which they incorporated and protected international commitments to women's rights; including biomedical governance guidelines, international women's rights instruments, and guidelines relating to sacred sites, Indigenous Peoples and TK.

The biggest Exploitation Risk continued to be women's marginalization in decision-making. This connects strongly with ecofeminist concerns that 'gendering' global governance policies assumes women's uncritical participation rather than empowerment (Francisco & Antrobus, 2009; **Cook, 2010**). Given the *Nagoya Protocol*'s commitment to address consideration of women, particularly indigenous communities and their TK (CBD, 2010b, Articles 2.3, 22.5j)[13], one of the 'Axes' applied here considered what 'fair representation' or 'full participation' in benefit sharing might look like. This discussion was situated in the global context that the UN 30% threshold for the minimum share of decision-making positions held by women by 1995 was still rarely met, despite having been adopted across many sectors (UNDP, 1995; 2005).

The analysis reflexively acknowledged the need for caution around the imposition of a 'Northern' (feminist) framework, e.g., when setting targets for public participation, particularly in vulnerable or indigenous societies. However, my research found that many IPs' perspectives already incorporated demands for 50% representation rights, while others were more nuanced; our San consultee suggested simply that women should be asked about what would work for them. The chapter recommended that:

> The definition of meaningful participation should be contextualised in *but not bound by*, cultural, social, political and economic practices and relationships. This is because these practices and relationships could be the sources of inequality and women's exclusion, as shown in the case analysis. (**Cook Lucas & Castillo, 2013, pp. 138, 146**).

[13] The *Nagoya Protocol* and its appendices provide examples of such mechanisms.

This informed the strong Recommendations that emerged from GenBenefit (Section 3.4).

3.4. "Towards Best Practice for Benefit Sharing Involving Access to Human Biological Resources: Conclusions and Recommendations." (Chapter 10) (Schroeder & Cook Lucas, 2013c)

The implementation element of 'how' benefit sharing should take place was a major theme in GenBenefit's work, with a clear distinction made between substantive (should) and process (how) elements (**Schroeder & Cook Lucas, 2013c, p. 227**), strongly informed by the case study analyses and gender work.

GenBenefit's Recommendations included that guidelines and policies for benefit sharing should explicitly require women's meaningful participation in all phases of decision-making, allowing for appropriate consultations to include women's views, with equal membership of bodies that negotiate or take decisions.

The Recommendations' central focus however, was on the significant governance role for Research Ethics Committees (REC) in benefit sharing; to mitigate exploitation in biomedical research, and develop the potential for long-term equitable relationships between researchers and participants. This could deliver alternative benefits to participants via community-building and empowerment to generate fairer outcomes, particularly in international research between HIC and LMIC settings. These Recommendations were carried forward beyond benefit sharing, in CPE's subsequent research programme, as reflected in my portfolio publications discussed in Sections 4 and 5.

SECTION 4

ETHICS DUMPING

4.1. TRUST (2015-19)

The term "ethics dumping" originated in the European Union Horizon 2020 programme to characterize research carried out by institutions from HICs in LMICs in a way which would not be accepted in the home settings (European Commission, n.d.; 2015. p. 35).

The TRUST project was funded *to catalyse a global collaborative effort to improve adherence to high ethical standards around the world* (European Commission, 2015-19), expanding CPE's previous work. The four portfolio publications presented in this Section emerged from this project.

TRUST's ultimate goal was the transdisciplinary *Global Code of Conduct for Research in Resource-Poor Settings* (GCC) (TRUST, 2018; Appendix P). This frames the overall work and impact of TRUST, including my contributions to its development (Schroeder et al., 2019). The GCC is currently applied in around 50 countries in Europe, Africa and Asia through a range of adopters, including the European Commission, European & Developing Countries Clinical Trials Partnership (EDCTP), funders, universities, foundations and individual projects. I am one of its 56 authors. However, the GCC is not included in my portfolio or discussed in detail here for reasons of proportionality.

4.2. Ethics Dumping

(Schroeder, Cook, Hirsch et al., 2018a)

From its inception, TRUST's work considered multiple axes of vulnerability to exploitation in research, as expressed in my co-authored "Introduction" to the project book, *Ethics dumping: Case studies from North-South research collaborations*:

> Achieving equity in international research is a pressing concern. Exploitative North-South research collaborations often follow patterns established in colonial times. Whether the objects of exploitation are human research participants, institutions, local communities, animals or the environment, this raises questions about how such exploitation can be avoided. (**Schroeder, Cook, Hirsch et al., 2018b, p. 1**).

Ethics Dumping (**Schroeder, Cook, Hirsch et al., 2018a**) presented 14 case studies, including one of good practice. Each concluded with specific recommendations. Contributions were sourced

from academics, policymakers, NGOs and multi-stakeholder engagement (Section 4.3.1). I had an extensive co-editorial role to select and verify submissions, ensuring inclusion across research disciplines and geographical location.

My curated comparative analysis of case studies in applied ethics method was instrumental in evidencing the circumstances where ethics dumping flourishes. I analysed the 14 selected case studies through adapting the method to this larger more heterogenous sample (Appendix Q: 12 Ethics Dumping Case Studies: Selected indicators for comparison 2018). In the first stage, charting individual case-based Situation, Context, and Frameworks suggested that useful Axes of Analysis to identify Exploitation Risks would be: the dynamics between research setting and source of researchers/funding; interactions between external elements and host researchers, participants and governance regimes; vulnerabilities of potential participants in relation to relevant frameworks; and outcomes.

These emergent cross-cutting themes were verified by the co-editors in the second stage. I then provided tailored iterative support to the diverse range of international contributing authors to explore these themes further in each case study. This ensured the original contributions remained contextually authentic, whilst generating specific case-based recommendations which took the themes into account.

In the third stage, the synthesized results from the curated comparative analysis of the finalised case studies identified six overarching Exploitation Risks. While there is significant overlap, the analysis demonstrated that research participants' pre-existing vulnerability was the strongest pre-disposing factor for ethics dumping, compared to e.g., topic, research design or governance issues. Again this emphasised how vulnerability itself is a marker for exploitation (Sections 3; 5).

I used these Exploitation Risks to structure the 14 case studies in the collection, as described in the "Introduction" (**Schroeder, Cook, Hirsch et al., 2018b**):

- Vulnerable participants (4/14);
- Clinical trials (3/14);
- Benefit sharing (1/14);
- Animal research (1/14);
- New & Emerging Technologies (3/14);
- Ethical Governance & Processes (2/14).

These themes of where we should look for vulnerability to exploitation in ethics dumping were my primary significant original contribution to *Ethics Dumping*, which has become a seminal collection, with 153,000 downloads demonstrating its reach and engagement (Appendix E).

4.3. Towards Creating Equitable Research Relationships

> 'Ethics dumping' occurs mainly in two areas. First, when research participants and/or resources in low- and middle-income countries (LMICs) are exploited intentionally, for instance because research can be undertaken in an LMIC that would be prohibited in a high-income country. Second, exploitation can occur due to insufficient ethics awareness on the part of the researchers, or low research governance capacity in the host nation. (**Schroeder, Cook, Hirsch et al., 2018b, p. 2**).

As indicated in Sections 3.2; 3.2.1; 3.4, TRUST developed its work to address well-intentioned and/or under-resourced researchers and governance systems, in order to have most impact.

4.3.1. "Promoting equity and preventing exploitation in international research: The aims, work and output of the TRUST project"

(Cook, Chatfield & Schroeder, 2019)

I showcased TRUST's methodological approach in the opening chapter of *Ethics and integrity in health and life sciences research* (Koporc, 2019). This work was commissioned by the series editor, Ron Iphofen, the European Commission's mid-term reviewer, in order to raise awareness of ethics dumping issues among a health and life sciences readership. I undertook 90% of the research and writing, with verification by co-authors.

This chapter provided me with an opportunity for further reflexive analysis of four *Ethics Dumping* case studies and to advocate for the effectiveness of TRUST's innovative multi-stakeholder involvement when developing resources to protect vulnerable participants (Fig. 4.1).

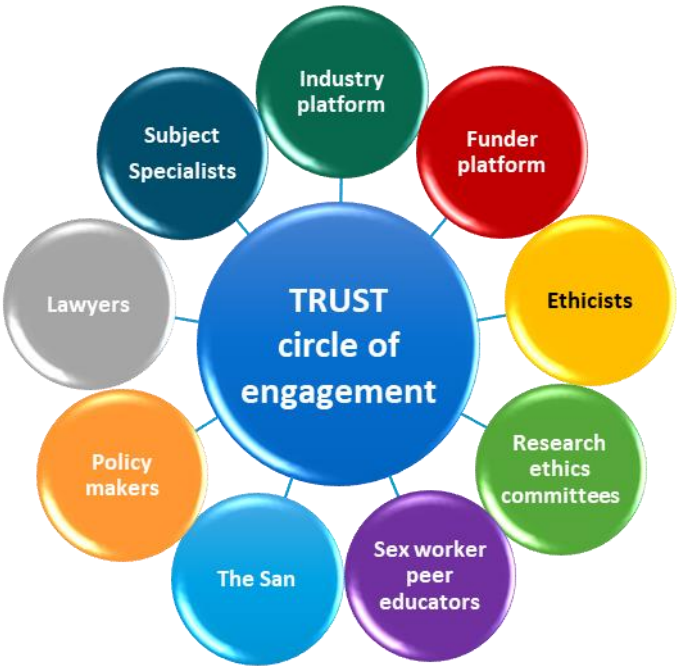


Figure 4.1.

*The TRUST Circle of Engagement. Engagement activities brought together a broad range of stakeholders who worked collectively to achieve the TRUST goals. (**Cook, Chatfield & Schroeder, 2018, p. 19**)*

This engagement strategy enabled identification of good as well as poor practice, on which ultimately to build the GCC (Schroeder et al., 2019; Appendix R: TRUST Timeline of Stakeholder Engagement).

There are enormous strategic benefits from incorporating multi-stakeholder perspectives in the development of governance tools and guidelines. But TRUST also facilitated connections and dialogue between disparate vulnerable research populations (the San; Nairobi sex workers) to share concerns and strengthen input. This enabled additional long-term capacity-building.

Developing mutual understanding between stakeholders and a range of participant experiences has led to ongoing collaborations. For example, my co-edited journal symposium “Looking for justice from the health industry” (Schroeder & Cook, 2019a; 2019b, not included in portfolio) focussed on the under-researched area of the role of private industry in maintaining ethical conduct in international health research, with four industry-led submissions from contributors involved in TRUST’s fora.

4.3.2. Preventing ethics dumping: "The challenges for Kenyan research ethics committees".

(Chatfield, Schroeder, Guantai et al., 2021)

This co-authored article drew further on data from TRUST's multi-stakeholder engagement (Section 4.3.1), literature, and case studies. Kenya has been an important focus for TRUST as it is an LMIC with a sophisticated research governance system. This study identified 11 specific challenges for Kenyan RECs in preventing ethics dumping: variations in governance standards; resistance to double ethics review (in external researchers' institution and host setting); resource constraints; management of biological samples; management of primary data; informed consent procedures; cultural insensitivity; standards of care; feedback to research communities; power differentials which facilitate exploitation of local researchers, and lack of local relevance and/or affordability of resultant products.

While broadly familiar, these issues always manifest in a specific context, and cannot be solved 'top-down' from 'outside' by HIC researchers. This article acknowledged these tensions, and pioneered an innovative model of collaborative and inclusive research *and* publication, to demonstrate how researchers from HICs and LMICs can work together with research participants from vulnerable populations, to identify both setting-specific and general solutions to ethics dumping challenges (Fig. 4.2).

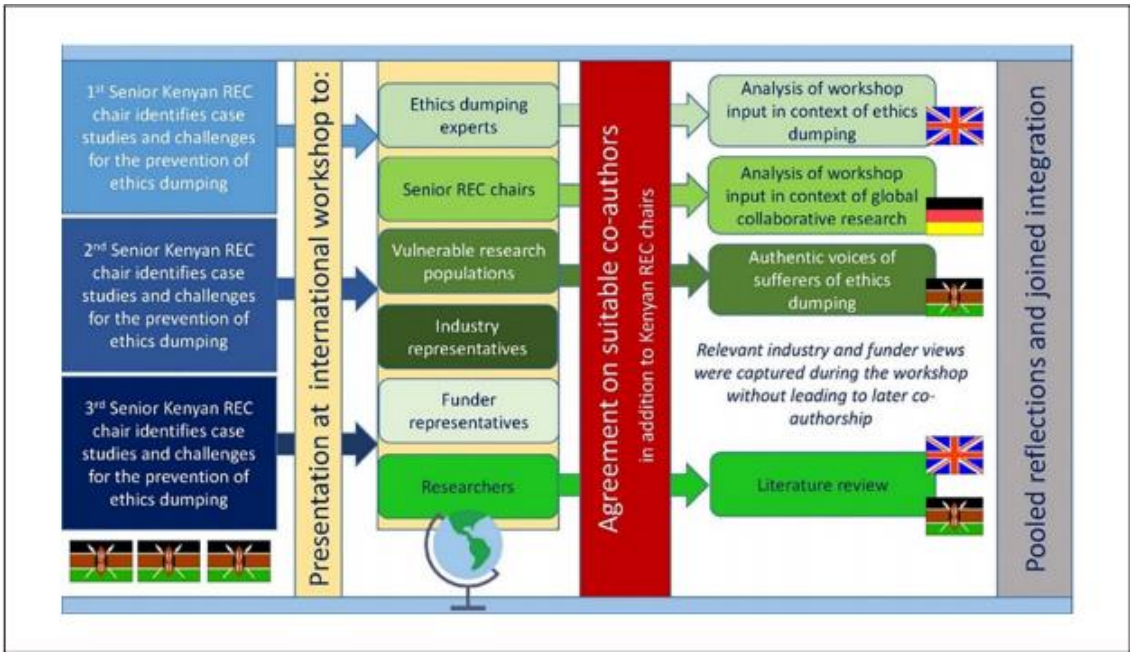


Figure 4.2.*Co-production and co-authorship on preventing ethics dumping in Kenya. (Chatfield, Schroeder, Guantai et al., 2021, p. 27)*

This process relied on mutual respect and the creation of long-term trusting relationships, such as those established during San-Khoba!, GenBenefit, and TRUST. My previous work is cited throughout the paper, in background, results and discussion. My methodological experience with the **curated comparative analysis of case studies** helped to frame the ethics dumping themes and analytical structure. I also made critical and theoretical contributions to the innovative method, particularly around publishing controversial or 'exposing' examples in a safe way, based on my experience editing *Ethics Dumping* (**Schroeder, Cook, Hirsch et al., 2018a**).

4.4. Reflection

The use of curated case studies as an analytical method was enhanced in TRUST through the active inclusion of multiple stakeholder voices in the co-creation of research outputs, including governance guidance. This enriched both the findings and their impact. However, while I continued to leverage an (eco)feminist understanding or sightline in relation to ethics dumping, it will be clear that gender aspects were not foregrounded in TRUST. I have subsequently begun to address this, as discussed in Section 5.

SECTION 5

"AVOIDING GENDER EXPLOITATION AND ETHICS DUMPING IN RESEARCH WITH WOMEN" (COOK, 2020)

The final publication in my portfolio is a sole-authored journal article. It drew on the theoretical feminist foundations discussed in Sections 2 and 3, and the methodological approach to empirical data from Sections 3 and 4. I first seeded this idea in **Alvarez Castillo & Cook Lucas (2009, pp. 163-4)**, which noted that "risk … becomes, additionally, a gender issue, when all of the participants in the study are female."

In **Cook (2020)**, I argued that strategies to redress the historical under-representation of women in biomedical and health research, as researchers, participants, or beneficiaries (known as a Fix the Numbers of Women; Fix the Institutions; Fix the Knowledge approach) (e.g., Schiebinger et al., 2011-20) have resulted in hidden risks of exploitation for women participants. As there had been no opportunity to address gender as a category of analysis/theme in *Ethics Dumping* (**Schroeder, Cook, Hirsch et al., 2018a**), I linked these issues here, following the operational and policy-driven approach established throughout my portfolio work.

I selected two *Ethics Dumping* case studies with 100% female cohorts; "Human Food Trial of a Transgenic Fruit" (van Niekerk & Wynberg, 2018), and "Cervical Cancer Screening in India" (Srinivasan et al., 2018). Using the curated comparative analysis of case studies method, with gender as the Axis of Analysis I identified a range of gendered Exploitation Risks (Appendix S: Ethics Dumping Case Studies. Selected Gender Indicators for Comparison, 2020). Analysis of these case studies revealed that women were differentially vulnerable to exploitation in research, both in relation to men (e.g., financial coercion due to gender pay gap), and to other (groups of) women (e.g., illiteracy), due to contextual pre-existing and structural gender-based inequalities. This reinforced my previous findings in GenBenefit regarding gendered vulnerabilities (**Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009**; **Alvarez Castillo & Cook Lucas, 2009**). Connecting with TRUST's orientation, here I argued that enriched understanding of the patterns which underlie ethics dumping can support more robust ethics review of research. For example, exploitative research designs and practices may be missed by reviewers without a nuanced understanding of gender-based harms. Based in my experience as an ethics reviewer, my recommendations provided practical tools for REC/IRB[14] members (Fig. 5.1).

[14] US Research Ethics Committees are known as Institutional Review Boards (IRB).

IRBs/reviewers should:

- Note single gender cohorts as a 'red flag':

  > There should be an expectation that researchers will include a justification for single gender cohorts in their application for ethics approval.

- Feel confident to ask questions or challenge the appropriateness of a single gender research design: What research purpose does this serve, and what benefits could it have for this gender?
- Relate ethics approval for single gender cohorts to the mitigation of risks *in the research context*:

  > Taking gender inequity as a starting point, in what ways are this participant group vulnerable in their community or society - how might participation in the proposed study exploit those conditions, or exacerbate them?
  >
  > IRB/ethics review should (where appropriate) consider opinions or input from local/host ethics committees, and patient and public involvement in research design, including advocates/representatives, to help assess and mitigate potential gender-based harms for research participants.

Figure 5.1.

*Recommendations for REC/IRB Reviewers to Avoid Ethics Dumping in Single Gender Cohorts (**Cook, 2020**)*

This approach connects with that outlined by Margaret Little early in the development of feminist bioethics, suggesting the field was:

> useful in ways that far outstrip the particular policy recommendations that feminists might give to some standard checklist of topics. For one thing, feminist reflection may change the checklist, altering what questions people think to ask, what topics they regard as important, what strikes them as a puzzle in need of resolution ... what dangers one is alerted to watch for. (1996, p. 2).

Throughout my portfolio outputs, my work has been about 'changing the checklist' of what dangers one is alerted to watch for. I have recently revisited the GenBenefit gender data, using curated comparative analysis (Appendix T: 2021: Reflection on 2009/13 gender indicators - Traditional Knowledge Cases; Appendix U: 2021: Reflection on 2009/13 gender indicators – Human Samples Cases). It is clear from this reflexive exercise that there are now (2021) more frameworks and protections in place for vulnerable research participants in international research, but also that my own understanding of the potential for gender-based harms and how to locate them has developed considerably.

Attention to gender nuances across the various fields within bioethics (e.g., health care, biotechnology) is increasingly a policy focus. For example, *Integrating a Gender Equality Perspective*, an expert report for the Council of Europe Committee on Bioethics, concludes that one overall goal should be to:

> decrease the data gap for women (their 'invisibility') in biomedical research. (Wagner, 2020, p. 34).

However, this does not acknowledge the hidden risks of involvement in biomedical research for vulnerable women (Persampieri, 2019). The need to embed a gender dimension in research ethics and our understanding of ethics dumping remains, so:

> perhaps it is time that discussions about the gendered ethical issues raised by these case studies … became embedded in … broader debate on the conditions under which research on women only should take place. (**Cook, 2020**).

SECTION 6

BIOETHICS AT THE INTERSECTIONS

In **Cook** (**2020**) I noted the intersections of policy frameworks around international women's rights (e.g., UN Women) and sustainability (UN Millennium Development Goals 2000–2015; UN Sustainable Development Goals 2016–30), and how it is now recognized that sustainable development cannot be achieved without the empowerment of all women and girls (UNDP, 2021; Ryder & Boone, 2021). It is therefore no longer necessary to constantly defend the 'women and environment' point.

However, accepting this link has never implied an *eco*feminist orientation (Section 2). Despite current interest in ecofeminism, it remains on the academic margins, with ecofeminist philosophy categorised as a subset of feminist environmental philosophy (McAfee, 2018).

There is however a well-established field of feminist bioethics (Tong, 1997; Tong, 2001; Donchin & Dodds, 2004; Scully et al., 2010), which questions how research is conducted and arguments are framed:

> Feminist bioethics is characterized by shared theoretical and political orientations that favor certain methodological approaches, including a focus on empirical experience; attention to the effects of social, political or epistemic power; and a commitment to influencing social and political change. (Donchin & Scully, 2015).

There have been calls to broaden the focus of feminist bioethics to engage with other feminisms including ecofeminism, and encompass environmental concerns and environmental justice (Twine, 2010b).

The work in my portfolio takes a recognisably feminist bioethical approach. But from its initial concern with benefit sharing to broader ethics of international research, it also links directly to ecofeminist commitments to 1. exploring intersections between women and the environment/'nature', and 2. including a plurality of voices in building ethics and practice (Gaard, 1993a, p. vii; **Cook, 1998**; Warren, 2000; Kheel, 2008, p. 215; **Cook Lucas, 2009**). The inclusion of empirical data is understood as central to this configuration (Warren, 1997b; Schiebinger et al., 2011-20). In my work, this has taken shape within the contemporary research methodology of empirical ethics.

This approach has enabled development of an original method of curated analysis of case studies in applied ethics. This method has not only become embedded in CPE's ongoing work; in terms of impact, its use in gender analyses played a direct role in debates around the content

of the 2010 *Nagoya Protocol*, and it was foundational for the *Ethics Dumping* collection (**Schroeder, Cook, Hirsch et al., 2018a**), on which considerable further work has been based.

Research into prevention of ethics dumping connected strongly with my ecofeminist commitments, evidencing how such exploitation occurs between some of the most vulnerable people globally (e.g., the Southern African San; sex workers in Nairobi; illiterate women in rural India), and some of the most powerful (e.g., world-leading scientists funded by the US National Institutes of Health; the Bill & Melinda Gates Foundation). Paying attention to the quality of the relationship between researcher and researched has influenced widely adopted recommendations to prevent ethics dumping (Section 4).

The materialist ecofeminist perspective I bring pays attention to the connections between vulnerable people and their bodies/labour as, for example, resources for scientific endeavours. In my sole-authored work this has culminated in highly specific recommendations for research ethics reviewers to avoid gender exploitation and ethics dumping in research with women (Section 5). A challenge for me now is to expand our understanding of ethics dumping to incorporate gender issues.

The emphasis on identification of gendered differential vulnerability to risk has thus become central to my approach, and links directly to intersectionality. This orientation gives me a specific sightline along which to locate exploitation risks in international research. This idea of a sightline resonates with Crenshaw, who recently described intersectionality as:

> basically a lens, a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other. (TIME, 2020).

For me, this enables the application of a distinctively *eco*feminist approach to bioethics. My work demonstrates one way of approaching what Plumwood called:

> the key justice (north/south) issue of relationship with other communities ... Taking responsibility for remote places requires strong institutional and community networking arrangements. The responsibility principle is compatible with some forms of exchange, and with the desirability of some exchange of goods and bads between places, provided this meets the ecojustice criterion of making one or both places involved in the exchange better and no places worse. (2008, p. 9).

Revisiting **Cook** (**1998/2016**) from an academic perspective has required some reflection on the double-edged role of academic activism, and especially the ongoing risk of appropriation and de-politicisation of discourses (Mies, 1993; Bilge, 2013). Being reminded of how I and other activist ecofeminists experience(d) misrepresentation and exclusion encourages me towards more respectful methodologies. My work has included curated activities and analyses which aim for authentic inclusion of multiply marginalised people in the creation of research outputs. This

extends to co-authorship, and I look forward to developing this early-stage methodology with the input of those whose voices most need to be heard.

As I complete this thesis, I have a role in a new Wellcome Trust-funded project in the Centre for Professional Ethics; *Leaving No-one Behind in Research* (2021-5) (UCLan, 2021), where I am continuing to develop the application of ecofeminist intersectional theory to resist the exploitation of vulnerable populations in global research, alongside those who are most affected by it.

REFERENCES

Adams, C. J. (1990). *The sexual politics of meat: A feminist-vegetarian critical theory*. Polity.

Adams, C. J. (Ed.) (1993). *Ecofeminism and the sacred*. Continuum.

Alvarez Castillo F., & Feinholz D. (2006). Women in developing countries and benefit sharing. *Developing World Bioethics*, *6*(3), 113-21.

Alvarez Castillo, F., & Cook Lucas, J. (2009). Fairness and gender in benefit sharing: Learning from the Kani, San, Nigerian, Kenyan and Icelandic cases for moving forward. *UP Manila Journal, Special Issue,* 140-173. **(Alvarez Castillo & Cook Lucas, 2009**)

Alvarez-Castillo, F., Cook Lucas, J., & Cordillera Castillo, R. (2009). Gender and vulnerable populations in benefit sharing: an exploration of conceptual and contextual points. *Cambridge Quarterly of Health Care Ethics, 18*(2), 130-37. **(Alvarez-Castillo, Cook Lucas & Cordillera Castillo, 2009)**

Andanda, P. (2009). Vulnerability: Sex workers in Nairobi's Majengo slum. *Cambridge Quarterly of Healthcare Ethics*, *18*(2), 138-46.

Andanda, P., & Cook Lucas, J. (2007). *Majengo HIV/AIDS research case*. www.uclan.ac.uk/genbenefit **(Andanda & Cook Lucas, 2007)**

Andanda, P., Schroeder, D., Chaturvedi, C., Mengesha, E., & Hodges, T. (2013). Legal frameworks for benefit sharing: From biodiversity to human genomics. In D. Schroeder & J. Cook Lucas, (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 33-64). Springer.

Arnason, G., (2007). *Icelandic biobank: A report for Genbenefit*. http://ris.org.in/images/RIS_images/pdf/IcelandicCase.pdf

Arnason, G., & Schroeder, D. (2013). Exploring central philosophical concepts in benefit sharing: Vulnerability, exploitation and undue inducement. In D. Schroeder & J. Cook Lucas (Eds.). *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 9-31). Springer.

Bayertz, K. (2002). Self-enlightenment of applied ethics. In R. Chadwick & D. Schroeder (Eds.), *Applied ethics Vol 1* (pp. 36-51). Routledge.

Beauchamp, T. (2008). The nature of applied ethics. In R. G. Frey & C. H. Wellman (Eds.), *A companion to applied ethics* (pp. 1-16). Wiley.

Biehl, J. (1991). *Rethinking ecofeminist politics*. South End Press.

Bilge, S. (2013). Intersectionality undone: Saving intersectionality from feminist intersectionality studies. *Du Bois Review: Social Science Research on Race*, *10*(2), 405-424.

Braidotti, R., Charkiewicz, E., Hausler, S., & Eieringa, S. (Eds.). (1994). *Women, the environment and sustainable development*. Zed Books.

Braidotti, R. (2012). Interview. In R. Dolphijn & I. van der Tuin, *New materialism: Interviews & cartographies* (pp. 19-37). Open Humanities Press. Retrieved October 18, 2021, from http://hdl.handle.net/2027/spo.11515701.0001.001

Buege, D. J. (1994). Rethinking again: A defense of ecofeminist philosophy. In K. J. Warren (Ed.), *Ecological feminism* (pp. 42-63). Routledge.

Burns, K. (1992). *Population: An ecofeminist perspective*. Women's Environmental Network.

Caldicott, L., & Leland, S..(1983). *Reclaim the Earth: Women speak out for life on Earth*. The Women's Press.

Carlassare, E. (1994). Destabilising the criticism of essentialism in ecofeminist discourse. *Capitalism, Nature, Socialism*, *5*(3), 50–66.

Carr, G. (2011). Foreword. In D. A. Vakoch (Ed.), *Ecofeminism and rhetoric: Critical perspectives on sex, technology and discourse* (p. ix). Bergahn Books.

Chatfield, K., Schroeder, D., Guantai, A., Bhatt, K., Bukusi, E., Adhiambo Odhiambo, J., Cook, J., & Kimani, J. (2021). Preventing ethics dumping: The challenges for Kenyan research ethics committees. *Research Ethics, 17*(1), 23-44. Published online May 24, 2020. **(Chatfield, Schroeder, Guantai et al., 2021)**

Chaturvedi, S. (2007). *Kani case: A report for GenBenefit*. http://www.ris.org.in/images/RIS_images/pdf/Kani_Case.pdf

Chennells, R. (2007). San *Hoodia case: A report for GenBenefit.* http://www.ris.org.in/images/RIS_images/pdf/San_Case.pdf

Chinyavanhu, T. (2021, March 18). *Hands off women at the frontline of environmental activism*. https://www.greenpeace.org/africa/en/press/13285/hands-off-women-at-the-frontline-of-environmental-activism/

Collard, A., & Contrucci, J. (1988). *The rape of the wild*. The Women's Press.

Convention on Biological Diversity (CBD). (1992). https://www.cbd.int/convention/

Convention on Biological Diversity (CBD). (2002). *Bonn Guidelines on access to genetic resources and fair and equitable sharing of the benefits arising out of their utilization*. https://www.cbd.int/doc/publications/cbd-bonn-gdls-en.pdf

Convention on Biological Diversity (CBD). (2010a). *Decision adopted by the conference of the parties to the convention on biological diversity at its tenth meeting.* https://www.cbd.int/doc/decisions/cop-10/cop-10-dec-01-en.pdf

Convention on Biological Diversity (CBD). (2010b). *Nagoya Protocol on access to genetic resources and the fair and equitable sharing of benefits arising from their utilization to the CBD* (CBD, 2010 https://www.cbd.int/abs/

Convention on Biological Diversity (CBD). (2010c). *The Convention on Biological Diversity: Year in Review 2009*. https://www.cbd.int/doc/reports/cbd-report-2009-en.pdf

Convention on Biological Diversity (CBD). (2011) : ABS theme, factsheet: The Bonn Guidelines. https://www.cbd.int/abs/infokit/revised/web/factsheet-bonn-en.pdf

Convention on Biological Diversity (CBD). (2012). *Gender equality and the Convention on Biological Diversity: A compilation of decision text*. www.cbd.int/gender/doc/compilation-CBD-GE-COP-decision-text.pdf

Cook, J. (1990). Review of: Adams, J. (1990). The Sexual Politics of Meat. *The Vegan, 6*(3), p. 24. (Cook, 1990)

Cook, J. (1991a). Toxic shock syndrome. *Primary Health Care*, *1*(6), 22-3.

Cook, J. (1991b). *Sanitary protection: Women's health and the environment.* Women's Environmental Network.

Cook, J. (1993). *Sanitary protection: Women's health and the environment.* Women's Environmental Network.

Cook, J. (1994). Review of: Mellor, M. (1992). Breaking the boundaries: Towards a feminist green socialism. *Environmental Values, 3*(3), 278-279. **(Cook, 1994)**

Cook, J. (1998). The philosophical colonization of ecofeminism. *Environmental Ethics, 20*(3), 227-246. (Translated and anthologised, 2016.) **(Cook, 1998)**

Cook, J. (2000). Review: Cuomo, C. J. (1998). Feminism and ecological communities: an ethic of flourishing. *Environmental Values, 9*(3), 398-399. **(Cook, 2000)**

Cook, J. (2016). (Translated by Noteris, E.). La colonisation de l'écoféminisme par la philosophie. In E. Hache (Ed.), *Reclaim - Recueil de textes écoféministes* (pp. 285-318). Cambourakis. **(Cook, 2016)**

Cook, J. (2020). Avoiding gender exploitation and ethics dumping in research with women. *Cambridge Quarterly of Healthcare Ethics, 29*(3), 470-479. **(Cook, 2020)**

Cook, J., Chatfield, K., & Schroeder, D. (2018). Promoting equity and preventing exploitation in international research: The aims, work and output of the TRUST project. In Z. Koporc (Ed.), *Ethics and integrity in health and life sciences research* (pp. 11-31). Emerald. **(Cook, Chatfield & Schroeder, 2018)**

Cook Lucas, J. (2009). Review: Kheel, M. (2008). Nature ethics: An ecofeminist perspective. *Environmental Values*, 18(2), 247-249. **(Cook Lucas, 2009)**

Cook Lucas, J. (2010). Review: Salleh, A. (Ed.). (2009). Eco-sufficiency and global justice: Women write political ecology. *Environmental Values*, *19*(1), 136-139. **(Cook Lucas, 2010)**

Cook Lucas, J. & Castillo, F. (2013). Fair for women? A gender analysis of benefit sharing. In D. Schroeder & J. Cook Lucas (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 129-151). Springer. **(Cook Lucas & Castillo, 2013)**

Cook Lucas, J., Schroeder, D., Chennells, R., Chaturvedi, S., & Feinholz, D. (2013). Sharing traditional knowledge: Who benefits? Cases from India, Nigeria, Mexico and South Africa. In D. Schroeder & J. Cook Lucas (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 65-93). Springer. **(Cook Lucas, Schroeder, Chennells et al., 2013)**

Cook Lucas, J., Schroeder, D., Arnason, G., Andanda, P., Kimani, J., Fournier, V., & Krishnamurthy, M. (2013). Donating human samples: Who benefits? Cases from Iceland, Kenya and Indonesia. In D. Schroeder & J. Cook Lucas (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 95-127). Springer. **(Cook Lucas, Schroeder, Arnason et al., 2013)**

Costello, A., Vallely, B., & Young, J. (1989). *The sanitary protection scandal*. Women's Environmental Network.

Council for International Organizations of Medical Sciences (CIOMS). (2002/2016). *International ethical guidelines for health-related research involving humans*. Fourth Edition 2016. https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf

Cox, C. (1993). *Chocolate unwrapped: The politics of pleasure*. Women's Environmental Network.

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*(6), 1241-1299.

Cuomo, C. J. (1998). *Feminism and ecological communities: an ethic of flourishing*. Routledge.

Dankelman, I., & Davidson, J. (1989) *Women and the environment in the third world*: *Alliance for the Future.* Routledge.

Davion, V. (1994). Is ecofeminism feminist? In K. J. Warren (Ed.), *Ecological feminism* (pp. 8-28). Routledge.

Diamond, I., & Orenstein, G. F. (Eds.). (1990). *Reweaving the world: The emergence of ecofeminism*. Sierra Club Books.

Donchin, A., & Dodds, S. (Eds.). (2004). *Linking visions: Feminist bioethics, human rights, and the developing world*. Rowman & Littlefield.

Donchin, A., & and Scully, J. (Winter 2015 ed.). Feminist Bioethics. In E.N. Zalta (Ed.), *The Stanford encyclopedia of philosophy*. https://plato.stanford.edu/archives/win2015/entries/feminist-bioethics/

DuBois, J. M. (2009). What counts as empirical research in bioethics and where do we find the stuff? *American Journal of Bioethics, 9*(6-7), 70-72.

Ebneyamini, S., & Sadegh, M. R. S. (2018). Toward developing a framework for conducting case study research. *International Journal of Qualitative Methods, 17*, 1-11.

Ervin, J. (2018, November 27). *In defense of nature: women at the forefront*. https://www.undp.org/blog/defense-nature-women-forefront

Estévez-Saá, M., & Lorenzo-Modia, M. J. (2018). The ethics and aesthetics of eco-caring: Contemporary debates on ecofeminism(s). *Women's Studies*, *47*(2), 123-146.

European Commission. (n.d.). *Horizon 2020, the EU framework programme for research and innovation: Ethics 2016*. https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics

European Commission. (2010). *European Textbook on Ethics in Research*. https://op.europa.eu/en/publication-detail/-/publication/12567a07-6beb-4998-95cd-8bca103fcf43

European Commission. (2015). *Horizon 2020 Work Programme 2014-2015.* https://ec.europa.eu/research/participants/data/ref/h2020/wp/2014_2015/main/h2020-wp1415-swfs_en.pdf

Feinholz Klip, D., Garcia Barrios, L., & Cook Lucas, J. (2009). The limitations of good intent: Problems of representation and informed consent in the Maya ICBG. In R. Wynberg, D. Schroeder & R. Chennells (Eds.)*, Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case* (pp. 315-331). Springer. **(Feinholz Klip, Garcia Barrios & Cook Lucas, 2009)**

Field, T. (2000). Is the body essential for ecofeminism? *Organization & Environment*, *13*(1), 39-60.

Foster, E. (2021). Ecofeminism revisited: Critical insights on contemporary environmental governance. *Feminist Theory*, *22*(2), 190-205.

Francisco, G., & Antrobus, P. (2009). Mainstreaming trade and Millennium Development Goals? In A. Salleh (Ed.). *Eco-sufficiency & global justice*: *Women write political ecology* (pp. 157-164). Pluto.

Frey, R. G., & Wellman, C. H. (Eds.) (2008). *A companion to applied ethics*. Wiley.

Frith., L. (2010). Empirical ethics: a growing area of bioethics. *Clinical Ethics, 5*(2), 51-53.

Fuss, D. (1990). *Essentially speaking: Feminism, nature and difference*. Routledge.

Gaard, G. (Ed.). (1993a). *Ecofeminism: Women, animals, nature.* Temple University Press.

Gaard, G. (1993b). Living interconnections with animals and nature. In G. Gaard (Ed.), *Ecofeminism: Women, animals, nature* (pp. 1-12). Temple University Press.

Gaard, G. (2002). Vegetarian ecofeminism: A review essay. *Frontiers, 23*(3), 117-146.

Gaard, G. (2011). Ecofeminism revisited: Rejecting essentialism and re-placing species in a material feminist environmentalism. *Feminist Formations*, *23*(2), 26-53.

Gaard, G., & Gruen, L. (1993). Ecofeminism: Toward global justice and planetary health. *Society and Nature*, *2*(1), 1-35.

Gaebl, G. (2018). On the liberation of all women: Socialist feminism and materialist ecofeminism. *Acta Cogitata: An Undergraduate Journal in Philosophy*, *5*(2), 1-7.

The Gale Review. (2019, March 20). *Challenging the stereotype: The Greenham Common protests*. Date of retrieval 18.10.21, from https://review.gale.com/2019/03/20/challenging-the-stereotype-greenham-common/

Gates, B. (1996). A root of ecofeminism: Ecoféminisme. *Interdisciplinary Studies in Literature and Environment,* 3(1), 7-16.

Grosz, E. (1994). Sexual difference and the problem of essentialism. In N. Schor and E. Weed (Eds.), *The essential difference* (pp. 82-96). Indiana University Press.

Grunwald, A. (2021). *Living technology: Philosophy and ethics at the crossroads between life and technology*. Jenny Stanford Publishing.

Hache, E. (Ed.), (2016a). *Reclaim: Recueil de textes écoféministes*. Cambourakis.

Hache, E. (2016b). Introduction. In E Hache (Ed.), *Reclaim: Recueil de textes écoféministes* (pp. 13-58). Cambourakis.

Harcourt, W. (Ed.). (1994). *Feminist perspectives on sustainable development*. Zed Books.

Heyes, C. (Fall 2020 ed.). Identity politics. In E. N. Zalta (Ed.), *The Stanford encyclopedia of* philosophy. https://plato.stanford.edu/entries/identity-politics/

International Labour Organization (n.d.). *Who are the indigenous and tribal peoples?* https://www.ilo.org/global/topics/indigenous-tribal/WCMS_503321/lang--en/index.htm

Jabeen, N. (2020). Women, land, embodiment: A case of postcolonial ecofeminism. *Interventions*, *22*(8), 1095-1109.

Kheel, M. (2008) *Nature ethics: An ecofeminist perspective*. Rowman & Littlefield.

Kings, A. E. (2017). Intersectionality and the changing face of ecofeminism. *Ethics and the Environment*, *22*(1), 63-87.

König, H., Baumann, M., & Coenen, C. (2021). Emerging technologies and innovation: Hopes for and obstacles to inclusive societal co-construction. *Sustainability* **forthcoming.**

Koporc, Z. (Ed.). (2019). *Ethics and integrity in health and life sciences research*. Emerald.

Kubar, O. Hepatitis B study with gender inequalities. In D. Schroeder, J. Cook, F. Hirsch, S. Fenet & V. Muthuswamy (Eds.), *Ethics dumping: Case Studies from North-South research collaborations* (pp. 61-66). Springer.

Lauwers, M. (2016). Angles and "*limes*" in American studies: Ecofeminism in the research field. *Angles*, *3*. http://journals.openedition.org/angles/1649

Little, M. O. (1996). Why a feminist approach to bioethics? *Kennedy Institute of Ethics Journal, 6*(1), 1-18.

Mackay, F. (2021). *Don't write off radical feminism – it's always been ahead of its time.* https://www.theguardian.com/commentisfree/2021/oct/17/radical-feminism-social-justice

McAfee, N. (Winter 2018 ed.). Feminist Philosophy. In E. N. Zalta (Ed.), *The Stanford encyclopedia of* philosophy. https://plato.stanford.edu/archives/fall2018/entries/feminist-philosophy/

McAfee, N., & Howard, K. B. (Winter 2018 ed.). Feminist political philosophy. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy*. https://plato.stanford.edu/archives/win2018/entries/feminism-political/

McHenry, K. A. (2017). Fracking women: A feminist critical analysis of hydraulic fracturing in Pennsylvania. *International Journal of Feminist Approaches to Bioethics*, *10*(2), 79-104.

Mellor, M. (1992). *Breaking the boundaries: Towards a feminist green* socialism. Virago.

Mellor, M. (1997). *Feminism and ecology*. Polity.

Merchant, C. (1980). *The death of nature: Women, ecology and the scientific revolution*. Harper & Row.

Merchant, C. (1995). *Earthcare*. Routledge.

Mies, M. (1993). Feminist research: Science, violence and responsibility. In M. Mies & V. Shiva (Eds.), *Ecofeminism* (pp. 36-54). Zed Books.

Mies, M., & Shiva, V. (1993). *Ecofeminism*. Zed Books.

Molewijk, B., & Frith, L. (2009). Empirical ethics: Who is the Don Quixote? *Bioethics, 23*(4), pp ii–iv.

Moore, N. (2004). Ecofeminism as third wave feminism? Essentialism, activism and the academy. In S. Gillis, G. Howie & R. Munford (Eds.), *Third wave feminism, a critical exploration* (pp. 227-239). Palgrave Macmillan.

Moore, N. (2008). Eco/feminism, non-violence and the future of feminism. *International Feminist Journal of Politics*, *10*(3), 282-298.

Moore, N. (2011) Eco/feminism and rewriting the ending of feminism: From the Chipko movement to Clayoquot Sound. *Feminist Theory*, *12*(1), 3-21.

Moore, N. (2016). *The changing nature of eco/feminism: Telling stories from Clayoquot Sound*. University of British Columbia Press.

Noor, K. B. M. (2008). Case study: A strategic research methodology. *American Journal of Applied Sciences, 5*(11) (pp. 1602-1604).

Pandey, A. (2013). Globalization and ecofeminism in the South: keeping the 'Third World' alive. *Journal of Global Ethics*, *9*(3), 345-358.

Persampieri, L. (2019). Gender and informed consent in clinical research: Beyond ethical challenges. *BioLaw Journal – Rivista di BioDiritto, 19*(1), 65-87.

Phillips, M. (2016). Embodied care and planet Earth: Ecofeminism, maternalism and postmaternalism. *Australian Feminist Studies*, *31*(90), 468-485.

Prentice, S. (1988). Taking sides: What's wrong with eco-feminism? *Women and Environments*, *10*(3), 9-10.

Plant, J. (Ed.). (1989). *Healing the wounds: the promise of ecofeminism*. Green Print.

Plumwood, V. (1986). Ecofeminism: An overview and discussion of positions and arguments, *Australasian Journal of Philosophy*, *64*, (120-38).

Plumwood, V. (1991). Nature, self, and gender: Feminism, environmental philosophy, and the critique of rationalism. *Hypatia*, *6*(1), 3-27.

Plumwood, V. (1992). Feminism and ecofeminism: Beyond the dualistic assumptions of women, men and nature. *The Ecologist*, *22*(1), 8-13.

Plumwood, V. (1993). *Feminism and the mastery of nature*. Routledge.

Plumwood, V. (2008). Shadow places and the politics of dwelling. *Australian Humanities Review*, *44*, 139-150.

Ryder, S. S. (2017). A bridge to challenging environmental inequality: Intersectionality, environmental justice, and disaster vulnerability. *Social Thought & Research, 34*, 8-115.

Ryder S., & Boone K. (2021). Intersectionality and sustainable development. In W. Leal Filho, A. Azul, L. Brandli, P. Özuyar & T. Wall. (Eds.). *Gender Equality. Encyclopedia of the UN Sustainable Development Goals*. Springer.

Salleh, A. (1984). Deeper than deep ecology: the ecofeminist connection. *Environmental Ethics*, *6*(1), 339-345.

Salleh, A. (1991). Review of Shiva, V. (1989). *Staying Alive*. In *Hypatia*, *6*(1), 206-214.

Salleh, A. (1997). *Ecofeminism as politics: Nature, Marx and the postmodern*. Zed Books.

Salleh, A. (Ed.). (2009a). *Eco-sufficiency & global justice*: *Women write political ecology*. Pluto.

Salleh, A. (2009b). Preface and Acknowledgements. In A. Salleh (Ed.), *Eco-sufficiency & global justice*: *Women write political ecology* (pp. ix-xii). Pluto.

Salleh, A. (2009c). Ecological debt: Embodied debt. . In A. Salleh (Ed.), *Eco-sufficiency & global justice*: *Women write political ecology* (pp. 1-40). Pluto.

Schiebinger, L., Klinge, I., Paik, H. Y., Sánchez de Madariaga, I., Schraudner, M., & Stefanick, M. (Eds.). (2011-2020). *Gendered Innovations in Science, Health & Medicine, Engineering, and Environment*. http://genderedinnovations.stanford.edu/what-is-gendered-innovations.html

Schroeder, D., & Arnason, G. (Eds.). (2009). Vulnerability revisited [special section]. *Cambridge Quarterly of Health Care Ethics*, *18*(2), 110-111.

Schroeder, D., & Cook Lucas, J. (Eds.). (2013a). *Benefit sharing in theory and practice: From biodiversity to human genetics.* Springer. **(Schroeder & Cook Lucas, 2013a)**

Schroeder, D., & Cook Lucas, J. (2013b). Benefit sharing: From biodiversity to human genetics – an introduction. In D. Schroeder & J. Cook Lucas (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 1-7). Springer. **(Schroeder & Cook Lucas, 2013b)**

Schroeder, D. & Cook Lucas, J. (2013). Towards best practice for benefit sharing involving access to human biological resources: Conclusions and recommendations. In D. Schroeder & J. Cook Lucas (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 217-229). Springer. **(Schroeder & Cook Lucas, 2013c)**

Schroeder, D., Cook, J., Hirsch, F., Fenet, S., & Muthuswamy, V. (Eds.). (2018). *Ethics dumping: Case studies from North-South research collaborations*. SpringerOpen: at http://www.springer.com/in/book/9783319647302 **(Schroeder, Cook, Hirsch et al., 2018a)**

Schroeder, D., Cook, J., Hirsch, F., Fenet, S., & Muthuswamy, V. (2018). Ethics dumping: Introduction. In D. Schroeder, J. Cook., F. Hirsch, S. Fenet, & V. Muthuswamy (Eds.), *Ethics dumping: Case studies from North-South research collaborations* (pp. 1-8). SpringerOpen: at http://www.springer.com/in/book/9783319647302 **(Schroeder, Cook, Hirsch et al., 2018b)**

Schroeder, D., Chatfield, K., Singh, M., Chennells, R., & Herissone-Kelly, P. (2019). *Equitable research partnerships: A global code of conduct to counter ethics dumping.* Springer.

Schroeder, D., Chennells, R., Louw, C., Snyders, L., & Hodges, T. (2020). The Rooibos benefit sharing agreement – Breaking new ground with respect, honesty, fairness, and care. *Cambridge Quarterly of Healthcare Ethics, 29*(2), 285–301.

Schroeder, D., & Cook, J. (Eds.). (2019a). Symposium on ethics dumping [Special section]. *Cambridge Quarterly of Health Care Ethics*, *28*(1).

Schroeder, D., & Cook, J. (2019b). Looking for justice from the health industry. *Cambridge Quarterly of Health Care Ethics*, *28*(1), 121-123.

Schroeder D., & Gefenas, E. (2009). Vulnerability: Too vague and too broad? *Cambridge Quarterly of Healthcare Ethics*, *18*(2), 113-121.

Scully, J. L., Baldwin-Ragaven, L., & Fitzpatrick, P. (2010). *Feminist bioethics: At the center, on the margins*. The John Hopkins University Press.

Shiva, V. (1989). *Staying alive: Women ecology and development*. Zed Books.

Shiva, V. (1997). *Biopiracy*. South End Press.

Singer, P. (1975). *Animal liberation: A new ethics for our treatment of animals*. Random House.

Singer, P. (1980). *Practical Ethics*. Cambridge University Press.

Sontheimer, S. (Ed.). (1991). *Women and the environment: A reader*. Earthscan.

Starhawk. (1990). *Dreaming the dark: Magic, sex and politics*. Unwin.

Spretnak, C. (Ed.). (1982). *The politics of women's spirituality*. Doubleday.

Srinivasan, S., Johari, V., & Jesani, A. (2018). Cervical cancer screening in India. In D. Schroeder, J. Cook, F. Hirsch, S. Fenet & V. Muthuswamy (Eds.), *Ethics dumping: Case Studies from North-South research collaborations* (pp. 33-47). Springer.

Stake, R. E. (1995). *The art of case study*. Sage.

Stanford University. (2020, October 5). *Clayman Conversations: Three scholars examine the TERF Industrial Complex.* https://gender.stanford.edu/news-publications/gender-news/clayman-conversations-three-scholars-examine-terf-industrial-complex

Stanley, E., & Wise, S. H. (2000). But the empress has no clothes: some awkward questions about the 'missing revolution' in feminist theory. *Feminist Theory*, *1*(3), 261-288.

TIME. (2020, February 20). *She Coined the Term 'Intersectionality' Over 30 Years Ago. Here's What It Means to Her Today*. https://time.com/5786710/KIMBERLE-CRENSHAW-INTERSECTIONALITY/

Sturgeon, N. (1997). *Ecofeminist natures: Race, gender, feminist theory and political action*. Routledge.

Thompson, C. (2006). Back to nature? Resurrecting ecofeminism after post-structuralist and third-wave feminisms. *Isis*, *97*(3), 505-512.

Tong, R. (1997). *Feminist approaches to bioethics*: *Theoretical reflections and practical applications*. Westview Press.

Tong, R. (2001). Towards a feminist global bioethics: Addressing women's health concerns worldwide. *Health Care Analysis, 9*, 229–246.

Tong, R. (2015). *Feminist thought, student economy edition*. Routledge.

Tong, R. & Botts, T. F. (2018). *Feminist thought: A more comprehensive introduction*. Routledge.

Torrijos, E. R. (2013). Ecofeminist visions: Recent developments and their contribution to the future of feminism. *Feminismo/s*, *22*, 17-46.

TRUST. (2018). *Global code of conduct for research in resource-poor settings.* https://www.globalcodeofconduct.org/

Twine, R. (2001). *Ecofeminisms in Process*. http://richardtwine.com/ecofem/ecofem2001.pdf

Twine, R. (2010a) Intersectional disgust? Animals and ecofeminism. *Feminism and Psychology*, *20*(3), 397-406.

Twine, R. (2010b). Broadening the feminism in feminist bioethics. In J. L. Scully, L. E. Baldwin-Ragaven & P. Fitzpatrick, (Eds.), *Feminist bioethics: At the center, on the margins* (pp. 45-59). Johns Hopkins University Press.

University of Central Lancashire (UCLan). (2021, May 25). *UK-Africa collaboration aims to establish level playing field for vulnerable populations in research*. https://www.uclan.ac.uk/news/uk-africa-collaboration-aims-to-establish-level-playing-field-for-vulnerable-populations-in-research

UNESCO. (2005). *Universal declaration on bioethics and human rights.* http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html

United Nations (UN). (1948). United Nations Declaration of Human Rights. https://www.un.org/en/about-us/universal-declaration-of-human-rights

United Nations (UN). (2015). *Paris Agreement*. https://unfccc.int/sites/default/files/english_paris_agreement.pdf

United Nations (UN). (n.d.). *Millennium Development Goals and beyond 2015*. https://www.un.org/millennium goals/

United Nations (UN). (n.d.). *Sustainable Development: The 17 goals.* https://sdgs.un.org/goals

United Nations Development Programme (UNDP). (1995). *Human development report 1995: Gender and human development.* http://hdr.undp.org/en/content/human-development-report-1995

United Nations Development Programme (UNDP). (2005). *Human development report 2005: International cooperation at a crossroads - Aid, trade and security in an unequal world*. http://hdr.undp.org/en/content/human-development-report-2005

United Nations Development Programme (UNDP). (2016). *How to conduct a gender analysis: A guidance note for UNDP staff.* https://info.undp.org/sites/bpps/SES_Toolkit/SES%20Document%20Library/Uploaded%20October%202016/UNDP%20Guidance%20Note%20how%20to%20conduct%20a%20gender%20analysis.pdf

United Nations Development Programme (UNDP). (2021). *The Sustainable Development Goals Report*. https://unstats.un.org/sdgs/report/2021/

van Niekerk, J., & Wynberg, R. (2018). Human food trial of a transgenic fruit. In D. Schroeder, J. Cook, F. Hirsch, S. Fenet & V. Muthuswamy (Eds.), *Ethics dumping: Case Studies from North-South research collaborations* (pp. 91-98). Springer.

Vermeylen, S. (2009). The struggle for indigenous peoples' land rights: The case of Namibia. In Wynberg, R., Schroeder, D. & Chennells, R. (Eds.), *Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case* (pp. 143-162). Springer.

Vermeylen, S. (2009a). Trading traditional knowledge: San perspectives from South Africa, Namibia and Botswana. In Wynberg, R., Schroeder, D. & Chennells, R. (Eds.), *Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case* (pp. 193-208). Springer.

Vermeylen, S., & Walker, G. (2011). Environmental justice, values and biological diversity: The San and the Hoodia benefit sharing agreement. In J. Carmin & J. Agyeman (Eds.), *Environmental inequalities beyond borders: Local perspectives on global injustices* (pp. 105-128). MIT Press.

Wagner, I. (2020). *Integrating a gender equality perspective: Expert report for the DH-BIO*. Council of Europe. https://rm.coe.int/inf-2020-1-ina-wagner-report-on-gender-equality-e-pdf/1680a13a58

Wambebe, C. (2007). *NIPRISAN case: A report for GenBenefit*. https://docplayer.net/122716739-Niprisan-case-nigeria-a-report-for-genbenefit-2007.html

Warren, K. J. (1987). Feminism and ecology: making connections. *Environmental Ethics*, *9*(1), 3-20.

Warren, K. J. (1990). The power and the promise of ecological feminism. *Environmental Ethics*, *12*(2), 125-146.

Warren, K. J. (Ed.). (1994a). *Ecological feminism*. Routledge.

Warren, K. J. (Ed.). (1994b). Introduction. In K. J. Warren (Ed.), *Ecological feminism* (pp. 1-7). Routledge.

Warren, K. J. (Ed.). (1997a). *Ecofeminism: Women, culture, nature.* Indiana University Press.

Warren, K. J. (1997b). Taking empirical data seriously: An ecofeminist philosophical perspective. In K. J. Warren (Ed.). *Ecofeminism: Women, culture, nature* (pp. 3-14). Indiana University Press.

Warren, K. J. (2000). *Ecofeminist philosophy; A Western perspective on what it is and why it matters.* Rowman & Littlefield.

Warren, K. J. (2002). Response to my critics. *Ethics and the Environment*. *7*(2), 39-59.

World Economic Forum. (2019). *Global gender gap report 2020*. http://www3.weforum.org/docs/WEF_GGGR_2020.pdf

World Medical Association (WMA). (2013) *Declaration of Helsinki - ethical principles for medical research involving human subject*s. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Wynberg, R., & Chennells, R. (2009). Green diamonds of the South: An overview of the San-*Hoodia* case. In R. Wynberg, D. Schroeder & R. Chennells (Eds.), *Indigenous Peoples, Consent and Benefit Sharing* (pp. 89-124). Springer.

Wynberg, R., Chennells, R., & Schroeder, D. (2009). Conclusions and recommendations: Towards best practice for community consent and benefit sharing. In R. Wynberg, D. Schroeder & R. Chennells (Eds.), *Indigenous Peoples, Consent and Benefit Sharing* (pp. 335-350). Springer.

Wynberg, R., Schroeder, D., & Chennells, R. (Eds.). (2009). *Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case*. Springer.

Wynberg, R., Schroeder, D., Williams, S., & Vermeylen, S. (2009). Sharing benefits fairly: Decision-making and governance. In R. Wynberg, D. Schroeder & R. Chennells (Eds.), *Indigenous Peoples, Consent and Benefit Sharing* (pp. 231-257). Springer.

Yin, R. K. (2018). *Case study research and applications: Design and methods* (6th ed.). Sage.

Zainal, Z. (2007). Case study as a research method. *Jurnal* [sic] *Kemanusiaan, 5*(1), pp. 1-6.

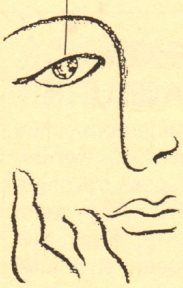
Appendix A

Women's Environmental Network (WEN)

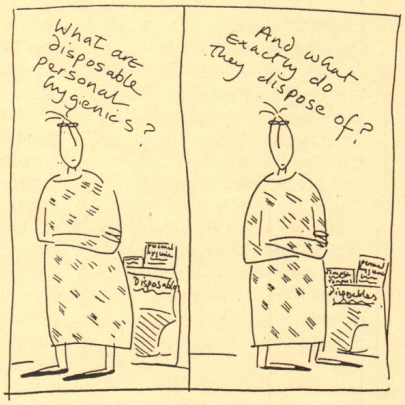
Sanitary Protection: Women's Health and the Environment

(1991; 1993 not in portfolio)

The Women's Environmental Network



Sanitary Protection: Women's Health and the Environment



There are around fourteen million menstruating women in the UK. In 1989 we spent £150 million on disposable, one use only, sanitary products. There is no doubt we **need** sanitary protection, but we also **need** to be aware of the profound environmental implications of the manufacture and disposal of these products, and the risks they may pose to our health.

Some progress has already been made. Since 1989 when the Women's Environmental Network highlighted the dangers of chlorine bleaching pulp for use in sanitary products, disposable sanitary towels and babies' nappies have started to be produced using non-chlorine bleached pulp. However, the environmental hazards resulting from the disposal of sanitary products are still pressing. Millions of strips of plastic from sanitary towels are dumped into our seas via sewage outfalls, where they remain in the environment indefinitely, causing visible pollution and harming wildlife. Tampons contain no plastic, but can still take 6 months to biodegrade at sea. Despite this, manufacturers still advise us to simply flush both towels and tampons away. Meanwhile, overpackaging of sanitary products uses vast amounts of energy and resources and adds to the non-biodegradeable waste in landfill sites.

Tampons might not necessarily be a safe alternative. They are made from a mixture of cotton grown with the use of pesticides, and rayon, made by breaking down wood-fibres with chlorine thus giving rise to dioxins. There is concern about pesticide residues in tampons, as well as about possible links between dioxin residues and some cancers in women. Research has shown many other health risks associated with tampon use, not least Toxic Shock Syndrome which has killed at least three young women in Britain since mid-1989. Little information is available to women about these risks to enable them to make informed choices about using tampons.

In recent years many new 'feminine hygiene' products have become available, including 'everyday protection' items which encourage us to use these products habitually. Meanwhile, many women are now using or considering reusable sanitary protection as a practical and symbolic step towards lessening the impact we, as women, have on the environment.

The Women's Environmental Network is a non-profit organisation educating, informing and empowering women who care about the environment.

The WEN Information Department answers enquiries, produces briefings, papers and other information related to women and the environment.

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Sanitary Towels

PRODUCTION

Until recently disposable sanitary towels were made from chlorine-bleached pulp. This process gives rise to highly dangerous chemicals including dioxins and up to 1,000 other organochlorine compounds. These are released into seas and rivers when the paper pulp is produced. Tiny concentrations remain in the products themselves. Since these dangers were publicised manufacturers have started to produce sanitary towels using alternative pulp. Chemo Thermo Mechanical Pulp **(CTMP),** is an environmentally safer, semi-mechanical process which uses hydrogen peroxide to bleach the pulp. Other methods (sometimes called **oxygen bleaching**) involve chlorine dioxide which contains a residual amount of chlorine gas, so that organochlorine pollution, is reduced but not eliminated. Some companies are starting to use recycled pulp to produce sanitary towels.

Sanitary towels have plastic inner linings, usually made from polythene. There are also strips of pressure-sensitive adhesive covered with siliconised treated paper on the back. The non-woven fabric covering is generally made from polypropylene or rayon. The towels are then packaged in plastic or cardboard, sometimes in individually wrapped packets.

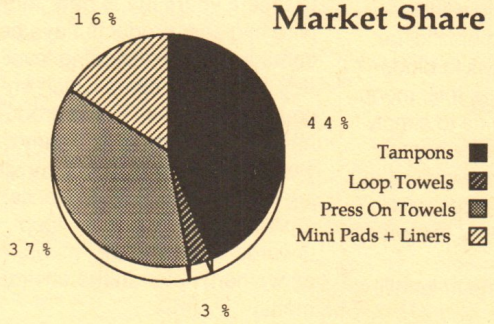
DISPOSABLE?

The **1936 Public Health Act** forbids disposal through the sewage system of any article which may block the flow. Sanitary protection manufacturers recommend however that their products are flushed away, and have indicated that their responsibility ceases with this 'disappearance', even though one estimate suggests that 75% of blocked drains are caused by sanitary products. No other European country permits the flushing away of sanitary wear. In the UK, more than 50% of sewage, including sanitary towels and tampons, is pumped untreated or only partially treated straight out to sea.

Even with treatment, the plastic liners still pollute beaches and enter the seas, where they will remain indefinitely. Plastic particles can be ingested by sea-birds, fish and marine mammals such as turtles and whales. Bacterial contamination of used sanitary products is also a health risk.

Pollution problems are left to water authorities or local councils who unblock drains and dispose of sewage. We all suffer from the wider environmental effects.

1989 Sanitary Protection Market Share



TAMPON MANUFACTURE

Tampons are made from cotton or a cotton/rayon mix. **Cotton** is a cash crop which uses 5% of the world's productive land in countries such as Brazil, Egypt and the Sudan. Instead of natural systems, chemical pesticides are used to control pests. The list is enormous and includes many which are restricted for use in the UK. Pesticides contaminate drinking water and kill natural predators as well as affecting the health of cotton workers and local residents. Further pollution is caused by the fossil fuels used in cotton-production machinery. The whole process uses large amounts of water and causes soil degradation. Nitrates used as fertilizers can discolour the cotton. Traditionally chlorine has been used to make cotton white, but alternatives are being sought, and British tampons are now oxygen bleached.

Rayon is made mainly from eucalyptus trees from plantations in countries such as Indonesia and South Africa, as well as trees from temperate zones in Canada and the USA, and from rainforests. Eucalyptus plantations deplete water resources as each tree can soak up 400 litres a day. Rayon production requires chlorine or chlorinated compounds to delignify (break down) the wood fibres, causing dioxin and other organochlorine pollution around the rayon mills.

A Safe Alternative?

POSSIBLE HEALTH RISKS

Dioxins and furans (a family of chemicals closely related to dioxins) have been found in British tampons, although they are oxygen bleached. This is probably because of the use of chlorine in rayon production. In Sweden experts disagree about the absorption of dioxins into the body through the vagina. Some argue that there may be a link between dioxins in tampons and uterine cancers. There is also concern about the health effects of pesticide residues in tampons. However, little research has been undertaken in this area although it has been known since 1918 that toxins can be absorbed into the body through the vagina.

PROVEN HEALTH RISKS

Tampons have been shown to cause vaginal dryness, as they absorb only 65% menstrual blood and 35% other vaginal secretions. This can cause **epithelial layering** (peeling of the mucous membrane) leading to **micro-ulcerations** and in extreme cases, **vaginal ulcers**. Fibres from tampons have also been found incorporated into vaginal walls, causing inflammation.

Did You Know?

In spite of their appearance and individual packaging, tampons and sanitary towels have NOT been sterilised.

TOXIC SHOCK SYNDROME

Tampon-related Toxic Shock Syndrome (TSS) was first made public in 1980 in the USA. The disease is related to tampon absorbency.

TSS is a rare illness caused by a toxin (TSST-1) produced by a strain of the bacteria **Staphylococcus aureus**, which is found naturally in the vagina of many women. However, tampon use can create a biological environment which encourages production of the toxin. There is little information available about TSS in Britain but it is estimated that there are up to 15 TSS cases per 100,000 menstruating women, with a much higher risk for women under 34 than for older women. Two-thirds of TSS cases occur in the under 25s. The fatality rate may be as high as 13%. 3 young women have died in Britain since summer 1989, and many more have been hospitalised. It is also possible to suffer from 'mild', recurring TSS, and women who have had the condition are likely to get it again.

EARLY SYMPTOMS OF TSS

are flu-like and include;

- **A high temperature, around 102° F**
- **Vomiting**
- **Diarrhoea**
- **Sore throat**
- **Aching muscles**
- **Headache and stiff and tender neck**
- **Dizziness and fainting**
- **Sunburn-like peeling rash, especially on hands and feet, or on the trunk.**

The acute phase progresses with a rapid loss of blood pressure (hypotension), toxins oozing from orifices, shedding skin (desquamation), respiratory failure and kidney failure. Necrosis (a decay of cells caused by the poor blood supply) can cause the loss of fingers and toes. After-effects include hair and fingernail loss, double vision, headaches, a loss of concentration and arthritis. These can last for months or even years.

WHAT YOU CAN DO

- Dispose of sanitary towels and tampons carefully and **never** flush them away, even if the label says 'fully flushable'.
- Choose towels made from unbleached or non-chlorine bleached pulp.
- Look for towels without plastic liners.
- Choose products with minimum packaging.
- Try reusable sanitary towels, perhaps starting overnight.

The only way to completely eliminate the risks of tampon-related Toxic Shock Syndrome and other tampon-related health problems is to avoid using tampons altogether. However, there are other steps you can take to minimise the risks of developing these conditions:

- Avoid high absorbency tampons - use the lowest absorbency that works for you, and change every 4-6 hours. The longer a tampon is kept in, the higher the risk.
- Alternate tampons and sanitary towels as much as possible.
- Use a sanitary towel overnight.
- If you have any of the symptoms of TSS, remove your tampon and consult a doctor immediately - take this briefing with you.
- If you feel you may have suffered from TSS, please write to us at WEN and let us know, to help us raise awareness of the condition.

FURTHER READING

The Sanitary Protection Scandal, Alison Costello, Bernadette Vallely, Josa Young. The Women's Environmental Network, London, 1989. ISBN 0 951 4297 01. Available from WEN at £6.95 plus £1.00 p&p.

REUSABLE SANITARY PRODUCTS

- **Natural sponges** are a reusable form of internal protection, but they have also been linked to TSS.
- **Ecofem** - machine washable, reusable sanitary towels which simply need a pre-wash soak are available from Ganmill Ltd, 38-40 Market Street, Bridgwater, Somerset, TA6 3EP.
- **A reusable rubber menstrual cup** is marketed in the USA. Information from The Keeper, Box 20023, Cincinatti, Ohio, USA.

DISPOSABLE SANITARY TOWELS

Vespre and **Vespre Silhouette** by Johnson & Johnson are non-chlorine bleached, but contain plastic liners. There is no on-pack environmental information.

The **Simplicity** range of sanitary towels by Kimberley Clark are non-chlorine bleached and contain no Optical Brightening Agents. The packs are flashed 'environmentally friendly pulp'. All towels have plastic liners.

Sainsbury's own brand sanitary towels are oxygen bleached and flashed 'environment friendlier'. All towels contain plastic.

Boots own brand sanitary towels are chlorine-free, with a label on the packet. The looped towels do not have plastic liners.

Tesco regular and super towels, mini pads, slim towels and pant liners are non-chlorine bleached.

Co-op own brand sanitary towels are either oxygen bleached, or made from CTMP. There is clear on-pack information about this.

Superdrug own brand sanitary towels are oxygen bleached. The **Green Options** towel has a waxed tissue moisture-resistant barrier instead of a plastic liner.

Sancella's **Bodyform, Libra** and **Pennywise** ranges are all chlorine-free, and the packs say '100% non-chlorine bleached'. They are made exclusively from pulp produced by CTMP. None of these towels are plastic-free.

Safeway's own 'Feminine Hygiene' products are all oxygen bleached.

Dr White's, and **Poise** towels by Smith & Nephew are non-chlorine bleached and most packs indicate this. The **Ecosense** towel is oxygen bleached, 97% biodegradeable and contains no plastic or Optical Brightening Agents. 50% of the pulp used is recycled, as is 50% of the packaging.

Asda own brand sanitary products contain non-chlorine bleached pulp. The packs indicate this. All towels contain plastic.

Natracare sanitary towels by Bodywise (UK) are oxygen bleached with no optical whiteners or perfumes. The pack advises not to flush because of plastic liners. Boxed in recycled card.

The Women's Environmental Network is one of Britain's leading environmental pressure groups. We are a non-profit organisation funded by membership and donations. WEN aims to educate, inform and empower women who care about the environment.

Membership entitles you to receive our quarterly newsletter and to be informed of all events.

Subscription rates

Founder	£20	Ordinary	£10
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April 1991

Sanitary Protection:
Women's Health and the Environment

The Women's Environmental Network

We as women, menstruate on average 4 to 5 days each month for about 35 years, spending a possible total of 6.5 years bleeding. Most women in the world have no access to the luxury of disposable sanitary towels and tampons, while the average 'western' woman uses about ten thousand such items during her life.

Western society's concealment of menstruation has given rise to expensive, wasteful, polluting sanitary products which bring unnecessary health and period problems for women.

There are 13.4 million menstruating women in the UK. In 1990, we spent £160 million on 3,000,000,000 disposable, one-use-only sanitary towels and tampons. In Britain, sanitary products are subject to VAT, yet there are no legal safeguards governing their manufacture or labelling; only voluntary agreements exist between the Department of Health, Department of Trade and the Association of Sanitary Protection Manufacturers (ASPM). This does not represent all manufacturers.

Since 1989 Women's Environmental Network has highlighted the dangers of chlorine-bleached pulp for use in sanitary protection products. Disposable sanitary towels have started to be made using alternative pulp, although the problem of organochlorine pollution has not been eliminated.

The disposal of sanitary products also creates serious environmental hazards. Millions of plastic strips from sanitary towels are dumped into the sea via sewage outfalls, where they remain in the environment indefinitely, causing visible pollution and harming wildlife. Tampons can take 6 months to biodegrade in the sea and plastic lasts indefinitely. As a result of pressure to change disposal instructions, manufacturers are increasingly recognising the problems caused by flushing and are moving towards recommending disposal through household waste. However some manufacturers still give us the option to flush.

Overpackaging of sanitary products is increasing, wasting energy and resources, and adding to the non-biodegradable waste in landfill sites. Despite product-whiteness and the trend towards individual packaging, sanitary protection products are **not** sterile.

Tampons are convenient and contain no plastic, but are **not** necessarily safe. Made from cotton grown with the use of pesticides, many tampons also contain rayon, the production of which uses chlorine gas, and gives rise to dioxins. Concern is growing about the health effects of pesticide residues in tampons, as well as about possible links between dioxin residues and some cancers in women. Research has shown many other health risks associated with tampon use.

Tampon-related Toxic Shock Syndrome (TSS), has killed at least 12 women in Britain since it was first identified in 1978. Following pressure from the Women's Environmental Network, tampon manufacturers have now agreed to provide on-pack warnings about TSS, starting from March 1993. However, little independent information is available about the risks, meaning that women cannot make informed choices about using tampons.

In recent years many new disposable 'feminine hygiene' products have become available, including items marketed for 'everyday protection', encouraging us to use them even when we are not bleeding. Meanwhile there is a growing movement of women who are trying out and making reusable forms of sanitary protection, as a practical , symbolic step towards lessening the impact we have, on our environment.

The Women's Environmental Network Trust is a Registered Charity educating, informing and empowering women who care about the environment.

The WEN Trust Information Department answers inquiries, produces briefings, papers and other information related to women and the environment.

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The Sanitary Protection Market

The first commercial disposable sanitary towel was made in the 1880s, costing the same price as a pair of shoes. Nurses returning from the First World War later popularised the use of disposable dressings for menstruation, but this was still regarded as an expensive luxury. In 1933 the disposable tampon was patented, but many British women still used homemade, washable protection well into the 1950s. By 1990 however, the UK market for disposable towels and tampons was worth £160 million, with virtually nobody using reusable ones.

With a declining population, the number of menstruating women in Britain has fallen, yet we are buying more sanitary protection today than ever. The 1992 market is worth £200 million. The highest unit cost per towel is almost 20p compared to about 8p in 1989. This is partly due to the increasing cost of advertising.

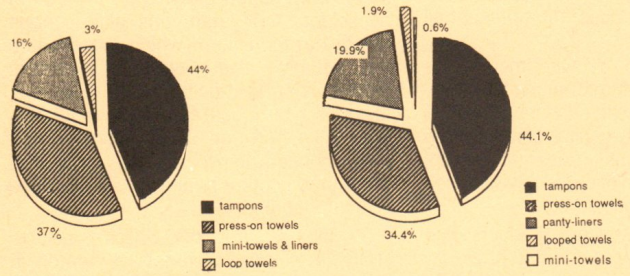
Menstruation products have always been advertised in the women's press. TV advertising was prohibited until 1986. Now it is commonplace, but restrictions on 'offence' grounds mean that blood is portrayed as *blue*. Women's complaints about embarrassment led the Independent Television Commission to restrict such advertising to non-family viewing times from May 1992.

Overall, the market is split between 55% external and 45% internal sanitary products, with 60% of women keeping to the same brand.

Patterns of sanitary protection-use change throughout women's lives, and differ among various groups of women, depending on age, class and ethnicity. For example, women aged between 18 to 24, together with those in the highest socio-economic groups, generally choose tampons, unlike younger teenagers. But women who have recently given birth, or who are close to the menopause, prefer towels.

Product innovation also has an influence on our purchasing habits. With the introduction of sanitary towel 'wings,' the market is again changing,reaching saturation point. Panty-liners represent the only dynamic area of growth, so that their introduction has swelled the external sanitary protection market by 25% since the early '80s. Many women suffer from mild stress-incontinence, for example when coughing. Often women use panty-liners continuously, instead of seeking medical help for this curable problem.

Sanitary Production Market for 1989 and 1992



Super-absorbents

The new generation of super-thin towels contains super-absorbent materials such as polyacrylate gels, which are also used in disposable nappies. The non-biodegradable gel absorbs many times its own weight in liquid which cannot flow out again, even under pressure. LD50 tests on animals, and human trials, have led to claims that the toxicity is low, but health risks are involved for those working in the manufacture of these gels. Contact with the eyes may cause irritation and temporary corneal injury. Inhalation may cause lung damage. No independent research exists concerning the effects on women's health. Alternatives to gels include processed sphagnum moss, extraction of which depletes endangered ecosystems.

Rayon

Many tampons are made from a blend of cotton and rayon, providing a more absorbent mix. Rayon is also used in some towels. This is a synthetic fibre, made from woodpulp obtained from eucalyptus plantations in countries like Indonesia and South Africa, and trees in temperate rainforests of the Pacific Northwest as well as tropical rainforests. The pulp is processed by delignification which breaks down fibres and removes oils. This normally involves chlorine gas or chlorinated compounds which cause dioxin and other organochlorine pollution around rayon mills.

Traces of dioxins have been found in British tampons. Although other rayon processing technologies are available, there is no evidence that any British sanitary ware contains chlorine-free rayon.

Sanitary Towels

Until 1989 disposable towels were made from 100% chlorine-bleached paper pulp. This bleaching process gives rise to highly dangerous chemicals, including dioxins and up to one thousand other organochlorine compounds. The US Government Environmental Protection Agency (EPA) has recently concluded that dioxin does cause cancer in humans, and that some responses to dioxin may have no safe level.

When paper pulp is produced, organochlorine compounds are released into seas and rivers, and tiny concentrations remain in the products themselves. Since these dangers were publicised, manufacturers have started to produce towels using alternatively bleached pulp. Various processes are now used, but product-labelling is unclear. Chemo Thermo Mechanical Pulp (CTMP) is an environmentally safer process, using hydrogen peroxide as a bleach. Other methods, sometimes confusingly called *'oxygen-bleaching'*, use chlorine dioxide which contains up to 10% residual chlorine gas, so that organochlorine pollution is reduced, not eliminated. Some companies have started to use recycled pulp in towels, although this usually means using pre-consumer waste from the production process.

Towels generally have leakproof, plastic backing strips. The non-woven, fabric covering on the outside called the coverstock, is generally made from non-biodegradable polypropylene and / or polyethylene, and sometimes with other fibres like cotton. Increasingly towels are individually wrapped in polyethylene and card, which rarely have a high recycled content.

Cotton

All tampons and some towels contain cotton. Some tampons are 100% cotton. As a cash crop, cotton takes up 5% of the world's productive land, half the area of non-food crops in more than 70 countries including the USA and the Sudan.

Intensive cotton production causes soil degradation. Integrated pest management systems based on ecological understanding are making slow progress among cotton growers. Little organic cotton is available. In the developing world, 50% of pesticides are used on cotton but resistant pests have multiplied. Meanwhile pesticide poisoning of workers is common, with sprays drifting to surrounding areas, contaminating soil, groundwater and other crops. Many pesticides used in developing countries such as organochlorines like DDT and carbamates, are banned elsewhere. Some are known carcinogens.

Cotton used in British tampons is bleached with hydrogen peroxide and sodium hypochlorite.

Disposable?

It is offence to discharge into sewers anything that *'interferes with the free flow'* of its contents (Section 27(a) of the Public Health Act). However with a few exceptions, sanitary product labelling gives instructions to dispose by flushing. Manufacturers have indicated that their responsibility ends with the '*disappearance*' of their product. One estimate suggests that 75% of blocked drains are caused by sanitary products, as 66% of UK women flush away towels and tampons, unlike other European countries where flushing is rare. Water and sewage authorities are spending more money removing growing amounts of sanitary products from sewage. The cost is passed on to the public.

Increasingly smaller sewage screens and maceration processes are required to remove tampons and towels and to ensure that the plastic liners or other recognisable debris, do not reach watercourses or remain in sewage sludge. Cleaned sewage screenings are incinerated in some areas, but are usually sent to landfill sites.

Some sewage sludge is used on agricultural land as fertiliser. Sewage treatment facilities vary greatly around the country. Sanitary products block narrow pipes. Heavy rain can cause premature discharge of raw sewage intended for treatment, directly into watercourses. In some areas untreated sewage is pumped directly into rivers and the sea. While tampons will eventually biodegrade, plastic liners from towels remain in the environment indefinitely. Plastic tampon applicators pose a similiar hazard. Five million sea birds and 100,000 marine mammals including turtles and whales are estimated to die each year from swallowing plastic. Water authorities are now suggesting it would be better to dispose of sanitary products directly through household waste. If all towels were disposed of this way, they would make up only 0.03% of household waste. Incineration of used sanitary products is not a safe option as the burning of rubbish is a major source of dioxins in the environment.

Tampon Absorbency

If you are using tampons, the lowest possible absorbency for your flow, is an essential safety step. However in the UK, tampon absorbencies are not regulated or standardised, unlike the USA Canada and Australia. This means that British tampons cannot be compared across brands for absorbency, although some manufacturers have started to display their own absorbency tables on packs, in grammes of liquid absorbed per tampon.

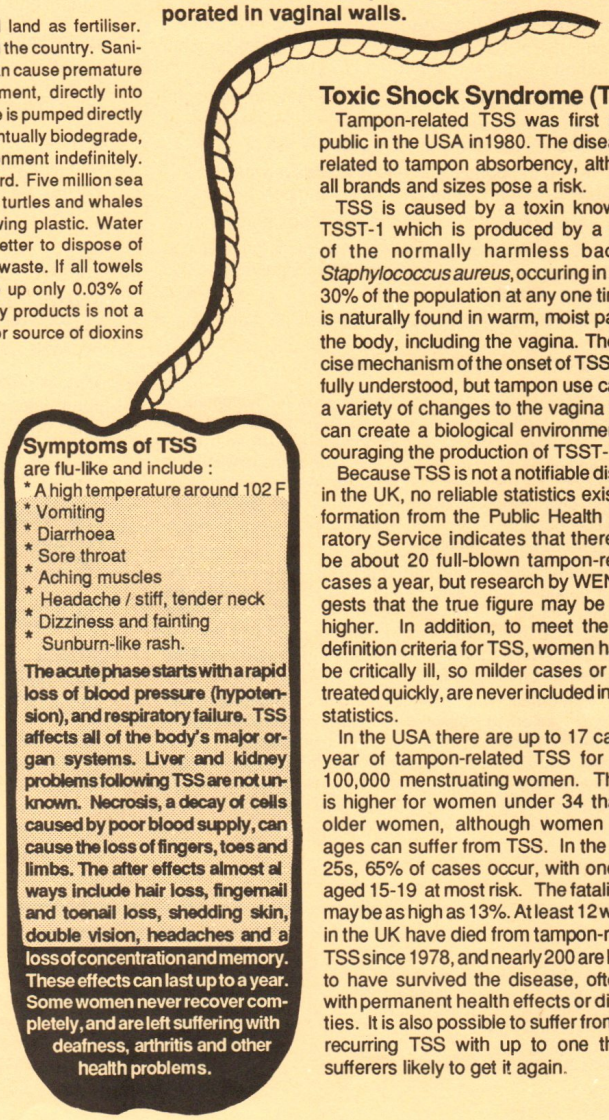
Tampons

Possible Health Risks

Since 1918 it has been known that toxins can be absorbed into the body through the vagina. Little is known about the possible health effects of dioxin and pesticide residues in tampons. No British tampon manufacturer has released the results of pesticide residue tests. Experts have voiced concern about possible links between dioxin residues and uterine cancers.

Proven Health Risks from Tampons

Tampons absorb about 65% menstrual blood and 35% other vaginal secretions. They cause vaginal dryness which can lead to epithelial layering, (peeling of the mucous membrane). Up to 1 in 5 tampon users may suffer from micro-ulcerations. This appears to be a transient effect, healing between monthly bleeding, but little is known about the long term effects of such recurring damage. Micro-ulcerations can develop into vaginal ulcers and can increase bleeding. Prolonged tampon use and higher absorbencies increase the risk of ulceration and up to 75% of women experience some form of alteration to the mucous membrane. Fibres shed from tampons have been found incorporated in vaginal walls.



Symptoms of TSS

are flu-like and include :

* A high temperature around 102 F
* Vomiting
* Diarrhoea
* Sore throat
* Aching muscles
* Headache / stiff, tender neck
* Dizziness and fainting
* Sunburn-like rash.

The acute phase starts with a rapid loss of blood pressure (hypotension), and respiratory failure. TSS affects all of the body's major organ systems. Liver and kidney problems following TSS are not unknown. Necrosis, a decay of cells caused by poor blood supply, can cause the loss of fingers, toes and limbs. The after effects almost always include hair loss, fingernail and toenail loss, shedding skin, double vision, headaches and a loss of concentration and memory. These effects can last up to a year. Some women never recover completely, and are left suffering with deafness, arthritis and other health problems.

Toxic Shock Syndrome (TSS)

Tampon-related TSS was first made public in the USA in1980. The disease is related to tampon absorbency, although all brands and sizes pose a risk.

TSS is caused by a toxin known as TSST-1 which is produced by a strain of the normally harmless bacteria *Staphylococcus aureus*, occuring in about 30% of the population at any one time. It is naturally found in warm, moist parts of the body, including the vagina. The precise mechanism of the onset of TSS is not fully understood, but tampon use causes a variety of changes to the vagina which can create a biological environment encouraging the production of TSST-1.

Because TSS is not a notifiable disease in the UK, no reliable statistics exist. Information from the Public Health Laboratory Service indicates that there may be about 20 full-blown tampon-related cases a year, but research by WEN suggests that the true figure may be much higher. In addition, to meet the case definition criteria for TSS, women have to be critically ill, so milder cases or those treated quickly, are never included in these statistics.

In the USA there are up to 17 cases a year of tampon-related TSS for every 100,000 menstruating women. The risk is higher for women under 34 than for older women, although women of all ages can suffer from TSS. In the under 25s, 65% of cases occur, with one third aged 15-19 at most risk. The fatality rate may be as high as 13%. At least 12 women in the UK have died from tampon-related TSS since 1978, and nearly 200 are known to have survived the disease, often left with permanent health effects or disabilities. It is also possible to suffer from mild, recurring TSS with up to one third of sufferers likely to get it again.

TSS Warnings

Since 1981 British tampon leaflets have included information about TSS. In 1990 the ASPM introduced packaging notices to remind women to read these leaflets. In July 1992, following parliamentary concern, consumer pressure and independent moves by Natracare and the Co-op, the ASPM announced that its member companies would introduce clear on-pack warnings about TSS, bringing the UK into line with the USA, Canada, Australia and New Zealand.

How to Avoid Tampon-related TSS:

The only way to eliminate the risk of developing tampon-related TSS or any other tampon-related health effect is to avoid using tampons altogether. There is no completely safe way to use tampons.

- **Avoid** high-absorbency tampons which carry a higher risk of TSS. Use the lowest absorbency tampon. Change it every 4 to 6 hours, during the night too.
- **Use** a sanitary towel instead of a tampon overnight.
- **Alternate** towels and tampons as much possible. Continuous tampon use increases the risk of TSS.
- **Keep** tampons clean and dry. Always wash your hands before and after changing a tampon.
- **Always** read the leaflet in a new box of tampons.
- **If** you experience any of these symptons remove your tampon. Consult a doctor immediately. Take this briefing with you!
- **Never** use a tampon when not having a period.

Reusable Sanitary Protection

For some years there has been a growing movement of women in the USA and Canada interested in reusable sanitary protection. This is echoed in the UK with overwhelming demand for the one available brand of washable sanitary towel on the market. Other women are making their own towels in favourite colours and fabrics. This makes periods more pleasurable and creative, is cheaper, and more environmentally friendly.

Another popular, reusable form is the natural sea sponge, but sponges have also been linked to TSS as they are absorbent and worn internally. The harvesting of this living creature damages the marine environment and there is concern about chemical residues in sponges, which filter sea water in order to feed.

An internally worn rubber cup, cap or diaphragm, can also be used to collect or temporarily block menstrual bleeding. However, the safety of such practices is unclear. Diaphragms have also been linked with TSS, and although there is little research available about this, women in Australia are being advised not to use diaphragms for more than four hours while menstruating.

What You Can Do

- **If** you suffer from painful periods, try not using tampons for a while and see if things improve.
- **Choose** towels with minimum packaging and avoid individually wrapped products.
- **Look** for chlorine-free products and those without plastic liners or applicators.
- **Dispose** of your towels or tampons carefully, and never flush or incinerate them.
- **Pelvic** floor exercises are fun! Ask at your doctor's surgery or contact women's health organisations for details on how to improve muscle tone to help control or avoid incontinence.
- **Try** reusable sanitary towels.
- **Always** check on-pack information carefully. Write to the companies for clarification if you wish.
- **If** you have experienced TSS or any other problem with tampons, contact WEN and let us know. This will help us to raise awareness of these issues.

Further Reading

The Sanitary Protection Scandal: Costello, Vallely, Young. Women's Environmental Network, 1989. Available from WEN at £6.95 plus £1 p&p.

Why Me God? Miriam Murphy, a survivor of tampon-related Toxic Shock Syndrome. 1992. Available from WEN at £5 plus £1 p&p.

Chlorine, Pollution and our Environment: WEN briefing. Send an SAE to WEN.

The Wise Wound: Penelope Shuttle and Peter Redgrove. Paladin. Published 1978. Revised edition 1986.

Reusable Sanitary Protection

Ecofem washable sanitary towels are available from Ganmill Ltd, 38-40 Market Street, Bridgwater, Somerset TA6 3EP.

The Keeper, a reusable rubber menstrual cup is marketed in the USA. Write to: The Keeper, Box 20023, Cincinatti, Ohio, USA.

The Women's Environmental Network Trust is one of Britain's leading environmental charities. WEN aims to educate, inform and empower women who care about the environment.

Membership entitles you to receive our quarterly newsletter and to be informed of all events.
Subscription rates :
Supporting £30 Affiliation £35
Individual £13 Overseas £20
Unwaged £7

Acknowledgements:
Researched and written by Julie Cook and assisted by Ann Link and Sue Tibballs. Illustrated by Angela Martin. Edited and desk top published by Yolanda Christian.

April 1993

Appendix B

Women's Environmental Network (WEN)

Population: An Ecofeminist Perspective

(1992 not in portfolio)

The Women's Environmental Network

Population: An Ecofeminist Perspective

Exploding the Myth

In 1987 the World's Population reached 5 000 million. Every year at least another 95 milion people are added to this total, and by the year 2000 the total is expected to reach 6 250 million. The rate of growth is increasing at an exponential rate, and it is not expected to stabilize until it reaches 10 000 million in the middle of the next century. Some people argue that this "population explosion" is a great threat to the survival of the planet.

This issue indeed is potentially explosive: the countries with the fastest growing populations are amongst the world's poorest. People seek scapegoats, and the extremist solution of state "population control" has been experimented with in some countries. Controversy rages over the development of genetic engineering, and the morality of abortion. Economic development, so often taken as the only yardstick to measure a country's well-being, is cited as the way to stem the overflowing tide of humanity. Sadly, the search for a small-family solution has all but ignored one significant social factor: the empowerment of women, through education, available contraception and economic independence. This would give all women a genuine choice regarding motherhood and the control of her own fertility.

Demographic Transition

Population growth has been an issue of concern for a long time: in 1798 Thomas Malthus forecast doom in "An Essay on Population". Since that time, when there was less than a fifth of the people there are now, many countries started to count their inhabitants in censuses every 10 years. The industrialisation of countries in the global North (in particular Western Europe and North America) had an impact on the level of population growth known as the demographic transition.

In Europe during the 18th Century both birth and death rates were high: the total population level rose and fell marking out periods of famine, epidemics and wars. Since infant mortality was very high, couples would have large families; it was a kind of insurance policy to ensure that some children were around to support the parents in their old age. In the 19th Century improvements in sanitation, education and medical knowledge helped to reduce the death rate. The birth rate remained high for a while, and consequently the number of people (in these countries) expanded rapidly. In the early twentieth century the population level stabilised when the birth rate fell due to continued improvements in the standard of living and in the position of women in society.

The Women's Environmental Network is a Registered Charity, educating, informing and empowering women who care about the environment.

The WEN Information Department answers enquiries, produces briefings, papers and other information related to women and the environment.

For further details contact:
Information Officer
WEN
Aberdeen Studios
22 Highbury Grove
London
N5 2EA

Tel: 071 354 8823
Fax: 071 354 0464

Printed on recycled paper.

The WEN Information Department gratefully acknowledge the support of the Joseph Rowntree Charitable Trust and the Department of the Environment.

The poorest regions of the world occupy most of the equatorial and southern land masses; they have been described as the "developing countries", the "Third World", or by their geographical location: the South. It was expected that the pattern of demographic transition experienced in the global North would be repeated in the South. However, the pattern of development in the South has not been the same, so many poor people continue to have large families.

Power for the Poor

Children are a very valuable asset to poor people in many countries. Children make an important contribution to the household income. In Peru girls of six or seven can look after younger siblings whilst their mother sells wares in the marketplace. In Java a boy can start caring for the family's animals when he is seven years old. From the age of twelve he may be able to work for wages, and by the time he is fifteen his labour will have repaid the investment his family has made in him. A twelve year old girl in India will spend up to ten hours a day picking tea during the harvest time.

In cities, the birth of each child provides another step towards the family goal: despite the odds, there is hope that this child might be bright enough to get an education and land a city job. With such a career they could support the rest of the family. A child can help younger siblings climb the educational ladder, so each successive son or daughter will bring added income, status and security to the family. In many parts of the world, both North and South, access to heath care and nutritious food is only available at a price. Many people are too poor to afford to eat healthy food, and they do not have access to land to grow it.

The development process has left many people disenfranchised: they have lost land rights. In poor countries, with no system for social welfare parents know that their offspring are their only security. They rely on children to look after them in their old age.

Infant Mortality

The threat of death hangs constantly over the poorest families. With no access to health care, the chance of children surviving to see their fifth birthday may be as low as 75%. Having many children is the only way to ensure that some will survive to adulthood. Studies by the World Health Organisation show that death of offspring and the fear of their deaths will encourage couples, however well off, to have many children.

Education

A United Nations report has discovered that women with at least four years of secondary education have fewer children. Their offspring are noted to be healthier, better nourished, and they tend to become better educated themselves. Education helps to increase awareness and it can provide opportunities for women to find paid work, and take part in other activities away from the home and family.

Many Third World women would like to limit the number of children they bear. However, a woman who wants to avoid or delay pregnancy risks the wrath of her partner. The man may find it such a challenge to his virility, that he resorts to violence. The lack of support from the state, the dogma of male-centred religious and social customs are further barriers to a woman who wants to control her fertility. 300 million couples in the Third World would stop having children if they had reliable contraception.

Son Preference

Patriarchal tradition in many parts of the world means that male children are given a higher status than females. There is an enormous pressure for women to continue having children until at least one son is born. The use of amniocentesis, to determine the sex of unborn babies has caused a worrying trend in parts of India, where daughters hold much less status than male offspring. Researchers in Bombay revealed that of 8 000 abortions studied, all but one were female foetuses.

The Myths of Overpopulation

It is often argued that poverty is the main cause of over-population. The industrialised nations went through the process of demographic transition as they developed economically. Some people argue that this is the solution for the so-called "developing" nations: they think that the wealth created from large technological schemes, mineral exploitation and monocultural crop plantations will trickle down to benefit everyone, and the birth rate will then fall. The solution is not that simple. Sustainable growth, not unlimited growth is the answer.

Another myth is that the inhabitants of the poor South, have lots of children, therefore they must be causing the most damage to the environment.

It *seems* to make sense that the more people there are, the greater the pressure on the planet. However, the impact on the global environment of each individual depends on his or her lifestyle.

25% of the world's population uses 75% of the world's energy. An average baby in the United States will use 25 times more resources than an average baby in India.

The inhabitants of the wealthy global North produce a great deal of pollution. There is a saying that the two greatest enemies of the environment are the richest billion and the poorest billion inhabitants of the planet. It is certainly true that the rich are harming the planet, but the poor are far too destitute to cause any comparable damage.

The poorest of the poor, often blamed for the population problems of the planet are single, widowed and divorced mothers. They do not own any land to degrade, and they are the group least able to clear and destroy patches of rainforest, or overgraze land with large herds of cattle.

The Poorest Tread the Lightest

It is possible for anyone who uses the land to abuse soils to some extent, but the poorest farmers are most likely to realise the problems they are causing early on if crops begin to fail on poor soil. Only the wealthier land owners and consortiums can afford machinery, chemicals and large-scale agribusiness farms and plantations. They therefore have a much greater potential to destroy vulnerable soils than bare hands and simple tools.

Urban poverty usually means an existence in the most degraded, polluted environment. Destitute city-dwellers have to tolerate high levels of air and water pollution. They are not the cause of environmental problems but they are the people who suffer most from the hazards created. Shanty towns themselves are dangerous to live in and look unsightly but they are much less damaging to the natural environment than the affluent suburbs.

The more wealth we have, the greater the harm we can do to our planet. Low-tech solutions can help improve the quality of life of the world's poorest inhabitants as well as having a more beneficial impact on the environment. For instance, women in Kenya were able to make terraces to prevent soil erosion and increase their yield of maize.

Population and Hunger

In *The Population Bomb* (1968) Paul Ehrlich forecast doom: the world's fast-growing population was overwhelming the planet's capacity to feed its inhabitants. He forecast mass starvation: famines would cause hundreds of millions of deaths during the 1970s.

In more recent years his supporters have swung the argument toward the idea that population expansion is threatening the environment. Some writers take the neo-Malthusian perspective further toward biological determinism. They argue that our biology drives us to reproduce at a rate faster than resources can sustain.

However, there is no correlation between population density and hunger. For instance, China has only half as much cropped land as India, but its population is much better fed. Effective government policies kept food affordable in Sri Lanka, a country which has half the farmland per head that Bangladesh has. Cuba has the highest life expectancy of any country in the global South and the infant mortality rate is low.

Contraception

The use of artificial methods to prevent pregnancy is the source of much controversy . Demographers who follow "people versus resources" perspective tend to advocate "birth-control" as the only solution to the problem of rapidly increasing populations. The Catholic church has taken a stance against the use of any unnatural means of contraceptive, and they condemn abortions. This means that women who do not want to have children have no reliable option except abstaining from sexual intercourse. In many societies, both in the North and the South, many young people have not been informed about the possible consequences of sexual intercourse. Without sex education, access to contraception, or recourse to abortion, many parents end up in a desperately unhappy circumstances. All too often, the woman is left holding the baby, and she can face many years of struggle as a single parent.

Abortions

It is women who must bear the burden when things go wrong. Abortion is not an easy choice for any woman, but making abortion illegal is no solution. In countries where abortion is illegal, countless back street abortions take place. The annual worldwide death toll from illegal abortions is 200 000, most of these required by poor, illiterate Third World women. The unavailability of contraception coupled with a lack of sex education also causes problems when adolescents start to explore relationships. Unwanted pregnancies are tragically common for teenage girls in many parts of the world.

Infertility and Genetic Engineering

In rich and poor nations alike, there is an inherent expectation that women should bear children. Some women choose alternative lifestyles, and this choice should be respected. Other women cannot have children: infertility may be the result of stress and pollution so prevalent in industrial society.

We often look to science and technology for solutions to the problems which they often caused. The promise of in-vitro fertilisation (IVF) is often a false one: it has a 5% success rate, and when it does work there is a high risk of multiple pregnancy. Like a lottery, several eggs are taken for test-tube fertiliation, to increase the chances of successful fertilisation: the result may be sextuplets for one mother, whilst other women remain childless. IVF is extremely costly; an inequitable use of scarce resources whilst so many are struggling for survival.

The growing science of genetic engineering is a dangerous field. Recently, in the United States a doctor was convicted of gross malpractice; it was revealed that he had fertilised the eggs of at least 75 women with his sperm, without their consent. The potential for unethical conduct is enormous. Some scientists have even openly admitted that they are seeking to develop the perfect human form, a "master race". Such ideas have been used to prevent black, disabled and other disadvantaged people from having children.

Genetic research threatens animal well-being as well as human ethics. The so-called progress of science depends on the use of animals since most experiments would not be allowed on human beings. Scientists attempt to cross fertilise species, and there is even a case where a foetus was implanted into a male baboon. One day we may look back at such experimentation, with the same horror as we see the Nazi holocaust.

Species Extinction

It is estimated that the earth is home to between 10 million and 100 million species. For many thousands of years, human beings had little influence on the natural rate of extinction, since the average person comparatively little. Today, however, UNFPA has estimated the current rate of extinction at 108,000 per year. It is forecast that between a quarter and a half of ALL species will have been wiped out by the middle of the next century. Whilst some people point to the growing number of human beings threatening the survival of other living creatures, it is our over consumption which poses the greatest threat to the world's other inhabitants.

Demographic Theories: another point of view

Some people have looked at population growth from a strictly human-centred perspective. They believe that there is no problem whatever the birth rate is. Julian Simon in the *Ultimate Resource* thinks that additional people will stimulate higher productivity in the long term. If it has happened in the Western industrial nations, Simon argues, why can't it happen for the rest of the world? He argues that no solution is needed: market forces will spur human creativity to discover or create new resources.

Family Planning

There must be a clear distinction between access to contraception and enforced population control. The misguided belief of many international agencies and Third World governments has led to the widespread use of incentives and disincentives to promote family planning. Payments to people for their sterilisation are coupled with restrictions on maternity leave, limits on social services, and the imposition of higher taxes on families with more than a certain number of children. Until recently medical staff in Bangladesh received money for performing sterilisations, whilst a commission would be given to anyone who motivated someone have such an operation. The so-called voluntary programs in many Asian nations have often used the provision of food as a means to coerce a population suffering from malnutrition and hunger.

The claim that the poorest people of the South are causing the greatest threat to the environment through their overpopulation, is used to promote population control. However, this perception amounts to implicit racism; everyone deserves the human right to choose whether to have children or not. Coercive sterilisation takes away the mother's choice to become pregnant, and it takes away the only security known to many people: their offspring.

Conclusion

It is a myth that excess population causes environmental degradation. The affluent inhabitants of the North are causing much more environmental havoc through their excessive use of resources and the consequential high levels of pollution. "Overpopulation" is not the greatest threat to the planet; much more ominous is the development of artificial industrially dependent environments. The EC's Common Agricultural Policy and other artificial pricing structures distort the cultivation and availability of food. Some landowners are paid to grow nothing, whilst starving homeless people scavenge for food and beg for money in nearby cities.

Everyone deserve a right to a comfortable life, but not at the expense of someone else's suffering. No other species inflicts as much suffering on it's own kind as human beings. It is wrong and hypocritical for the North to demand the South to reduce population whilst they continue to pour money and resources into genetic engineering and reproductive research. The average child in the North has the lifetime potential to use many times more resources than an average child born in the South.

Every woman should have a right to choose the size of her family. Women need to have equal opportunity in terms of education, work, financial resources and ownership of land. We have a long way to go: currently women own a mere 1% of land. Women are burdened with 60% of work done in return for 40% of wages paid out. When all women are given a reasonable level of economic security and the means to control their own their fertility there will be an improvement to the health and well-being of all members of society and the planet.

What you can do

- Become aware of your own personal contribution to the production and use of the world's resources
- Celebrate children: think about your family as valued members of society who enrich the whole world, not simply as 'family property'.
- Don't be afraid of sex education: it enables teenagers to learn how their body works, and how to take responsibility for their behaviour.
- Promote communication and informed decision making. It is important for every woman to learn about her own needs and develop personal strategies.
- Support empowerment programmes which educate and inform women.

Further Reading

Frances Moore Lappe and Rachel Schurman, *Taking Population Seriously*; Earthscan Publications, 1989.

Paul Harrison, *The Third Revolution: Environment, Population and a Sustainable World*; I.B.Tauris & Co, London,1992.

Perdita Huston, *The Right To Choose: Pioneers in Women's Health and Family Planning;* Earthscan Publications, London, 1992.

Jocelynne A Scutt ed., *The Baby Machine: Reproductive Technology and the Commercialisation of Motherhood*; Green Print, London 1990.

Gita Sen and Caren Grown, Development, Crises and Alternative Visions: Third World Women's Perspectives; Earthscan Publications, London, 1987.

Vandana Shiva, *Staying Alive*; Zed Books, London 1989.

Laurence Roche, *Forestry and Famine: Arguments Against Growth Without Development* The Ecologist Vol 19 No 1 Jan/Feb 1989, MI, USA.

The Women's Environmental Network is one of Britain's leading environmental pressure groups. We are a non-profit organisation funded by membership and donations. Our aim is to educate, inform and empower women who care about the environment.

Subscription rates
Supporting £30 Ordinary £13
Unwaged £7, Overseas £20,
Affiliation £35

Membership entitles you to receive our quarterly newsletter and to be informed of all public meetings, seminars and events.

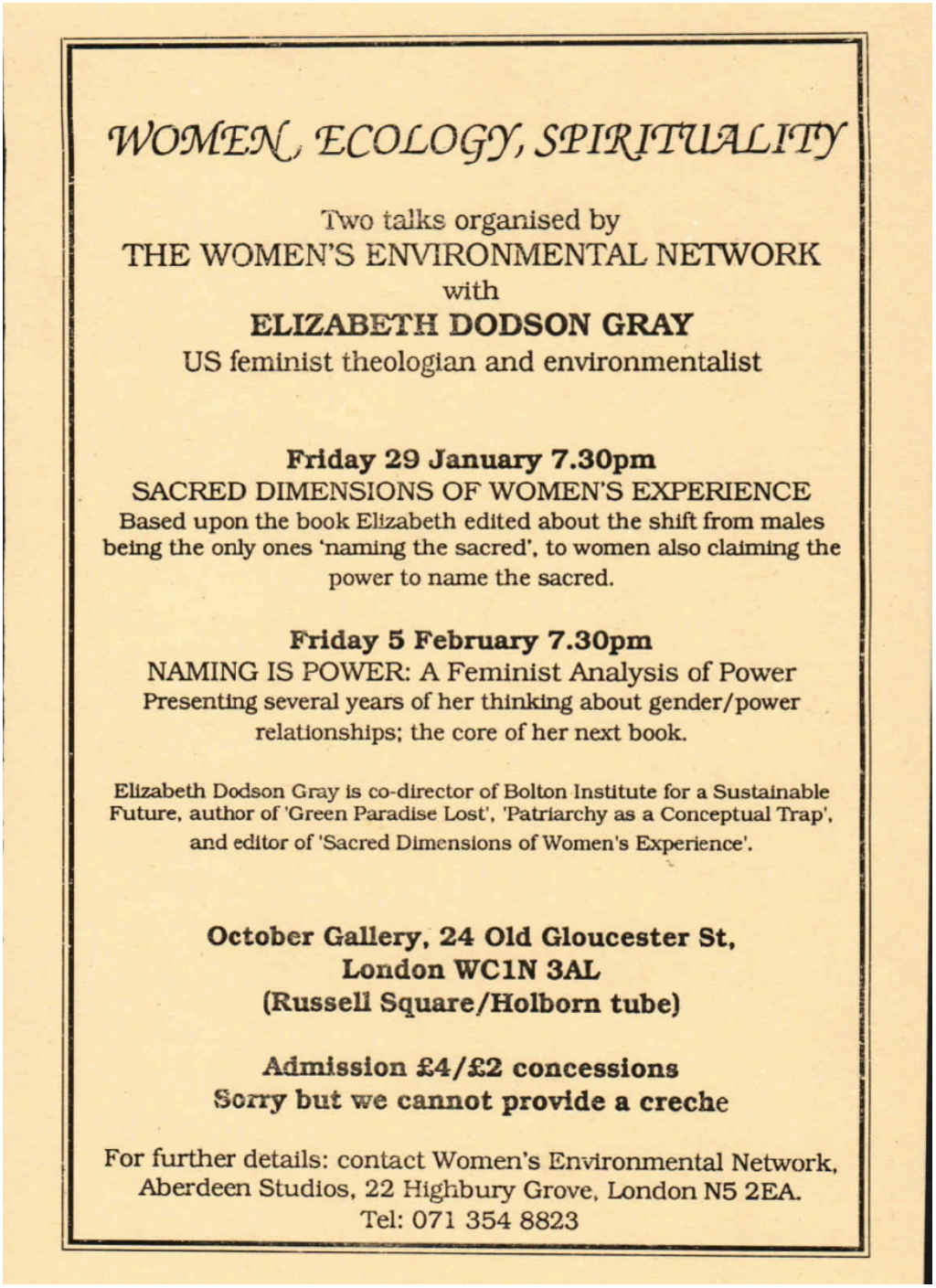
Acknowledgements:
Researched and written by Kirsty Burns with editing and guidance from Julie Cook, Naomi Diamond, Bernadette Vallely, Claire Flenley, Cat Cox, and other members of the WEN staff.

June1992

Appendix C

Ecofeminism Lecture Series

January 1993, and September – October 1993



WOMEN, ECOLOGY, SPIRITUALITY

Two talks organised by
THE WOMEN'S ENVIRONMENTAL NETWORK
with
ELIZABETH DODSON GRAY
US feminist theologian and environmentalist

Friday 29 January 7.30pm
SACRED DIMENSIONS OF WOMEN'S EXPERIENCE
Based upon the book Elizabeth edited about the shift from males being the only ones 'naming the sacred', to women also claiming the power to name the sacred.

Friday 5 February 7.30pm
NAMING IS POWER: A Feminist Analysis of Power
Presenting several years of her thinking about gender/power relationships; the core of her next book.

Elizabeth Dodson Gray is co-director of Bolton Institute for a Sustainable Future, author of 'Green Paradise Lost', 'Patriarchy as a Conceptual Trap', and editor of 'Sacred Dimensions of Women's Experience'.

October Gallery, 24 Old Gloucester St,
London WC1N 3AL
(Russell Square/Holborn tube)

Admission £4/£2 concessions
Sorry but we cannot provide a creche

For further details: contact Women's Environmental Network, Aberdeen Studios, 22 Highbury Grove, London N5 2EA.
Tel: 071 354 8823

WOMEN, ECOLOGY, SPIRITUALITY

A series of talks organised by
THE WOMEN'S ENVIRONMENTAL NETWORK

Thursday 24th September 7.30pm
THE GODDESS EMERGES with *MONICA SJOO*

Thursday 1st October 7.30pm
NIGHTMARE & VISION - Women, Science & Technology
with *LYNDA BIRKE AND SUE THOMAS*

Thursday 8th October 7.30pm
POLITICS & SPIRITUALITY OF THE LAND - Women's Heritage
with *BARBARA BENDER AND CHESCA POTTER*

Thursday 15th October 7.30pm
THE SPIRITUAL DIMENSION OF ECOFEMINISM
with *CHARLENE SPRETNAK*

Thursday 22nd October 7.30pm
SEASONS & CYCLES - Reweaving the Sacred
with *FAY WOMBWELL*

Thursday 29th October 7.30pm
ECOFEMINISM - Women's Action and Empowerment
with *CAT COX, JULIE COOK AND HELEN O'HARA*

Admission £4/£2 concessions or book all talks for £20 in advance.
Creche facilities available - please book at least 1 week in advance.

Conway Hall, Red Lion Square, London WC1. (Holborn Tube).

For further details/bookings contact
Women's Environmental Network,
Aberdeen Studios, 22 Highbury Grove, London N5 2EA.
Tel: 071 354 8823

Appendix D

Ecofeminism Course at Birkbeck College (1994-5)

BIRKBECK COLLEGE
UNIVERSITY OF LONDON
Centre for Extra-Mural Studies

Ecofeminism

Tuesday 21 September 1994, 6.30pm - 8.30pm

at the FEMINIST LIBRARY
5 Westminster Bridge Road, London SE1

LECTURERS: Cat Cox and Julie Cook

FEE: £85.00/£28.00 concessions

This course is one of several in the Certificate and Diploma in Applied Women's Studies. It is also open to women who wish to take it as a single subject.

The Certificate and Diploma courses are open to all and require no previous qualifications. The Certificate can be used as a way of getting back into study or for those women who have never had any further education experience.

This Ecofeminism course runs for twelve weeks and examines women's reflections on the ecological crisis. Contemporary issues from the environment to reproductive technologies, are presented in an historical, political and philosophical context.

To gain the Certificate in Applied Women's Studies, students must complete three courses, with assessment based on the submission of a course folder at the end of each course.

For further details of the Ecofeminism course and the rest of the programme, please contact Elaine Kitteringham at the address/telephone number below.

TO ENROL: please complete the form below and return it with your payment to
Elaine Kitteringham, Centre for Extra-Mural Studies
Birkbeck College, 26 Russell Square, London WC1B 5DQ
Telephone 071-631 6674 Fax 071-631 6688

ENROLMENT FORM **Ecofeminism** **C46I01**

Please enrol me for the above course, I enclose the fee of £........ (£85/£28 concessions). Please enclose a copy of documentation if claiming a concessionary fee. Cheques/postal orders to be made payable to **'Birkbeck College'.**

Name ______________________

Address ______________________

____

Telephone: (Day) ______________ **(Evening)** ______________

Access/Visa Card No ______________ **Expiry Date of Card** ______________

Signed ______________ **Date** ______________

Complete and return to Elaine Kitteringham, Centre for Extra-Mural Studies, Birkbeck College, 26 Russell Square, London WC1B 5DQ. Telephone 071-631 6674. Fax 071-631 6688.

All courses are offered on condition that enrolments reach a satisfactory level by the fourth meeting and maintain a good average attendance. Unfortunately classes that do not do so will have to be closed. This year the minimum number is 13 students for each course except for certain courses for which a lower minimum number may apply.

BIRKBECK COLLEGE
UNIVERSITY OF LONDON
Centre for Extra-Mural Studies

Ecofeminism

Beginning Tuesday 10 January 1995

6.30pm - 8.30pm for twenty-four meetings

at the
Centre for Extra-Mural Studies
32 Tavistock Square, London WC1

LECTURERS: Cat Cox and Julie Cook

FEE: £85.00/£28.00 concessions

This course examines one of the most vital and exciting developments in Women's Studies, the exploration of women's reflections on the ecological crisis.

From the environment to reproductive technology, contemporary issues and concerns will be presented in an historical and political framework, with an examination of how women are offering alternative considerations to the ecology debate.

'Ecofeminism' is one of several courses in the Certificate and Diploma in Applied Women's Studies, which can also be taken as a single course.

These courses are open to all and require no previous qualifications. The Certificate can be used in various ways: as a first step to higher education, as preparation for postgraduate research or to assist women who wish to incorporate equal opportunities perspectives into their work.

For further details of this and other courses in Women's Studies, and how to enrol please contact Elaine Kitteringham, Centre for Extra-Mural Studies, Birkbeck College, 26 Russell Square, London WC1B 5DQ.
Tel 0171-631 6674. Fax 0171-631 6688.

BIRKBECK COLLEGE University of London
CENTRE FOR EXTRA-MURAL STUDIES

COURSE OUTLINE

Course Code: C46I02

Academic Year 1994-95

Subject area: Women's Studies

Course title: Ecofeminism

Type of course: Certificate & Diploma in Applied Women's Studies

Centre: Extra-Mural Studies

Class venue: 32 Tavistock Square, London WC1

Day of week: Tuesday

First meeting: 10/01/95

Time: 6.30-8.30pm

COURSE LECTURER: Cat Cox, BSc & Julie Cook BA

COURSE OUTLINE:
This course will explore ecofeminism as a development of feminism which arises from women's reflections on the ecological crisis. It will examine contemporary issues and concerns, from our environment to reproductive technologies, presenting these in an historical, political and philosophical context. It will further explore the ways women are redressing the balance and revisioning the future, through creativity, spirituality and action.

Term 1:
Feminisms - putting ecofeminism in a feminist context
Seventeenth Century Scientific Revolution and the Death of Nature - the historical and philosophical development of dualism
Women & Nature - what is the relationship?
Ecological Crisis - from an ecofeminist perspective
Animal Rights - as part of the ecofeminist movement
Genetic Engineering - the manipulation of nature - biotechnology and reproductive technologies

Term 2:
Community - alternative social systems from separatist women's space to ecological community
Women's Creativity - revisioning our world, from women's fiction to visual art
Healing - the history of women and healing and its value for contemporary ecofeminism
Body Parables - revaluing women's bodies
Women's Spirituality
Creating new systems through thought and action.

Previous/current experience: Students are required to have a basic knowledge of gender relations and the ability to read and write English in order to complete the course work.

Teaching methods: A mixture of lecture, discussions, individual and group work.

Assessment: Students need to complete 3 pieces of course work, 2 of 1,000 words, one of 2,000.

Course work: Includes reading and essays.

AIMS: (a) to introduce students to ecofeminist theory
(b) to enable students to critically evaluate theory through discussion and course work
(c) to explore diverse contemporary issues through an ecofeminist perspective
(d) to create a positive learning environment where students can explore new ideas
(e) to empower women beyond the classroom.

OUTCOMES:
By the end of the course students should have:

(a) gained an understanding of ecofeminism

(b) developed an ability to critically evaluate ideas and evidence in relation to personal knowledge and experience, and locate those ideas within an analytical and theoretical framework

(c) successfully completed the course and gained accreditation for their Certificate.

BLOCK 1: WEEKS 1-6

Ecofeminist Theory

Looking at ecofeminism as a development of feminist theory, and examining some of its key themes, which include:

The historical and philosophical development of dualism, and the challenge it faces from ecofeminism today; an examination of the theme of women and nature - what is the relationship?

Course work: 1000-word essay evaluating an aspect of ecofeminist theory to be handed in by week 12.

BLOCK 2: WEEKS 7-12

Contemporary issues in Ecofeminism

We will examine a diverse range of contemporary issues from the ecological crisis to reproductive technologies.

Course work: 1000-word essay exploring an issue of interest to the student from an ecofeminist perspective, to be handed in by week 14.

BLOCK 3: WEEKS 13-17

Shifting the paradigm

We will explore the alternative paradigm offered by ecofeminism, which reinterprets power relationships and social relations in new ways; and we will examine the contribution of women's spirituality to this change.

Course work: 2000-word project (written or verbal presentation). A personal interpretation/appreciation of the value of ecofeminism. To be completed by week 22.

BLOCK 4: WEEKS 18-23

Windows on new worlds

We shall investigate facets of women's experience which reflect the growing integration of ecofeminist values into contemporary society, including women's creativity, revaluing our bodies and ecological action.

BLOCK 5: WEEK 24

Synthesis

Bringing together all facets of the course material, including course review and evaluation.

Basic reading list:

Carolyn Merchant	*The Death of Nature: Women, ecology and the scientific revolution*, Harper & Row, 1990 edition
Judith Plant (ed)	*Healing the Wounds: The promise of ecofeminism*, Green Print, 1989
Maria Mies & Vandana Shiva	*Ecofeminism*, Zed Books, 1993
Andree Collard with Joyce Contrucci	*The Rape of the Wild: Man's Violence against animals and the earth*, Women's Press, 1988
Starhawk	*Dreaming the Dark*, Mandala, 1982
Marge Piercy	*Women on the Edge of Time*, Women's Press, 1976

Appendix E

Impact: Ecofeminism and Ethics Dumping

This appendix reflects on the citation and readership impact of the included publications in two areas – Ecofeminism (Section 2), and *Ethics dumping: Case studies from North-South research collaborations* (**Schroeder, Cook, Hirsch et al., 2018a**) (Section 4).

These are not only different areas thematically, but also in terms of the shape of the publications' impact, offering a useful perspective on the different trajectories of published academic output.

Ecofeminism (Section 2)

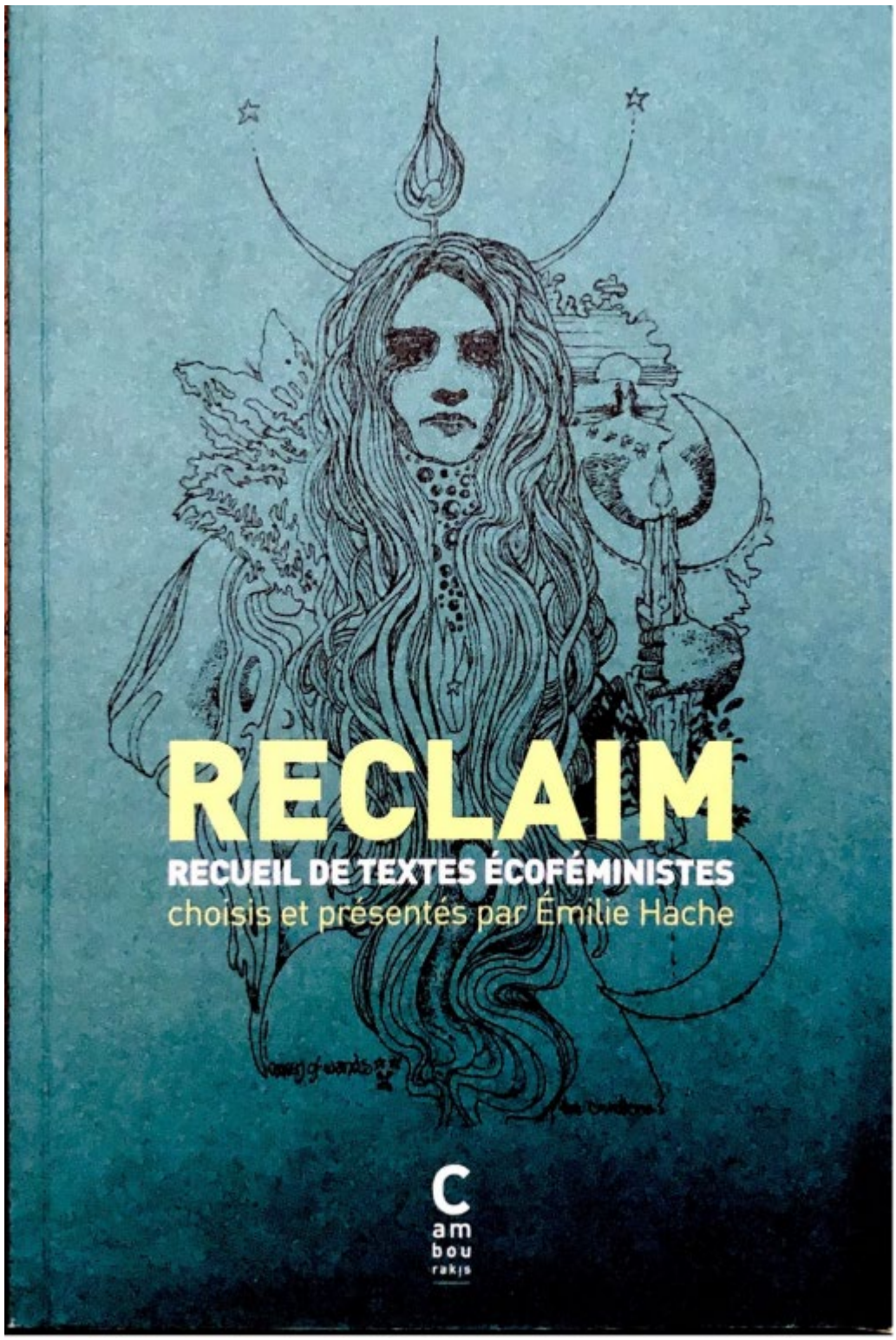
> **Cook, J**. (1998). The philosophical colonization of ecofeminism. *Environmental Ethics*, *20*(3), 227-246. (Translated and anthologised, 2016.) (**Cook, 1998**)

This paper was a slow-burn in terms of impact for many years. I was told by Val Plumwood, who had been one of the peer-reviewers for *Environmental Ethics*, that its controversial nature meant it was unlikely to be cited much. Although this is not possible to assess, there were indeed few citations for a long time, except in very specific area of interest, which included theological approaches to ecofeminism, or amongst UK and Australian ecofeminists. I consider this is likely related to a) my resistance to the theoretical move to 'essentialise' anything that appealed to any value or experience beyond 'reason', including 'spiritual' activism, or b) (related), some deep differences at this time between US academic feminism and global activism with a political focus.

No doubt my withdrawal from the field (see Section 2) and lack of follow-up also contributed to this.

I was therefore both surprised and delighted to be contacted by the publisher Cambourakis on behalf of Emilie Hache in 2015, to ask if the article could be included in a French translation of "a selection of hard-to-find Eco-feminist texts and to make them accessible to the wider public", to coincide with the Paris Climate Agreement events.

This publication, which became *Reclaim* (Hache, 2016), saw **Cook** (**1998**) included as a "rare activist voice" (p. 27) alongside high-profile ecofeminists such as Susan Griffin, Vandana Shiva, Ariel Salleh and Starhawk, whose work has been important both to me personally, and to my own work.


RECLAIM
RECUEIL DE TEXTES ÉCOFÉMINISTES
choisis et présentés par Émilie Hache
Cambourakis

TABLE

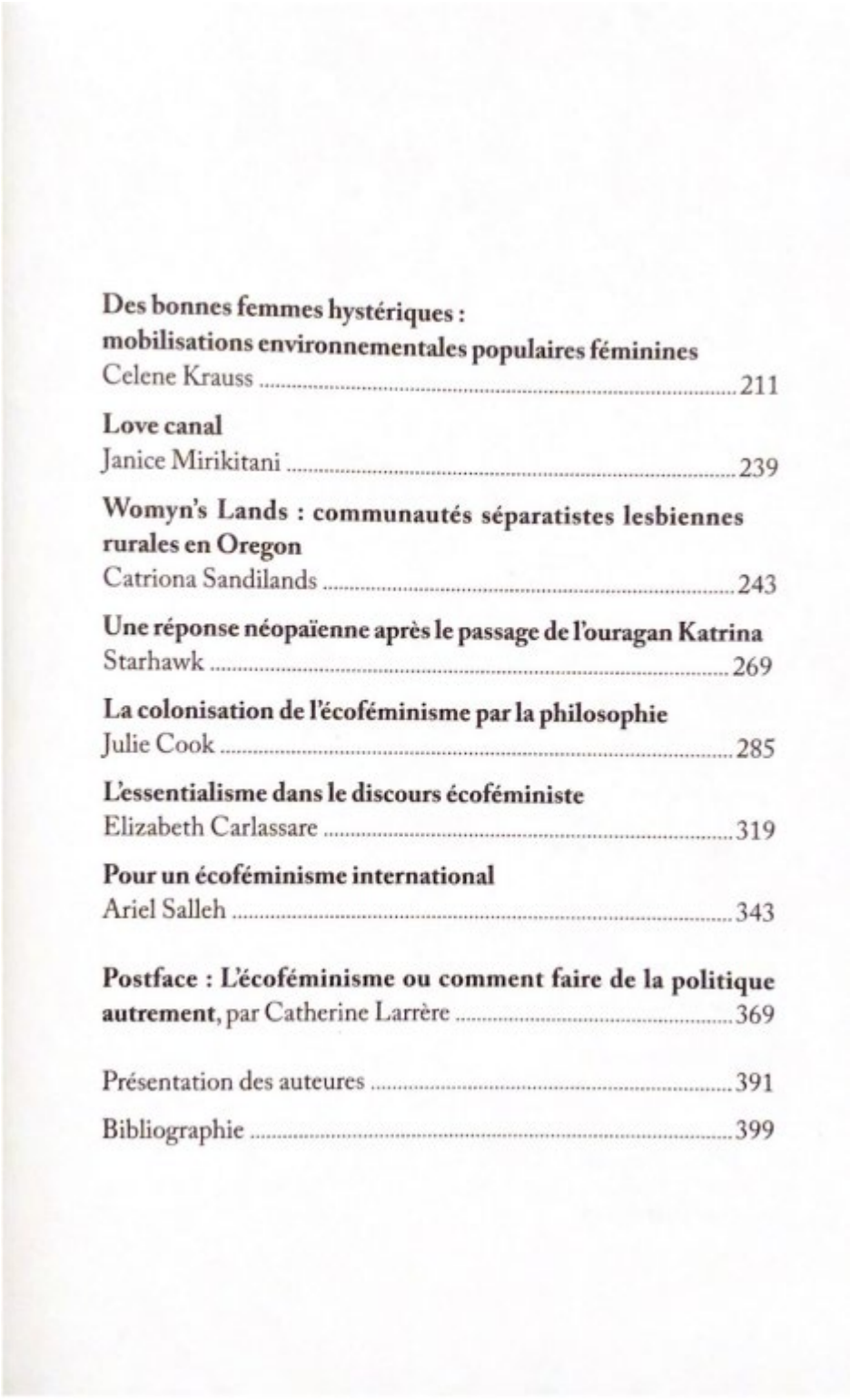
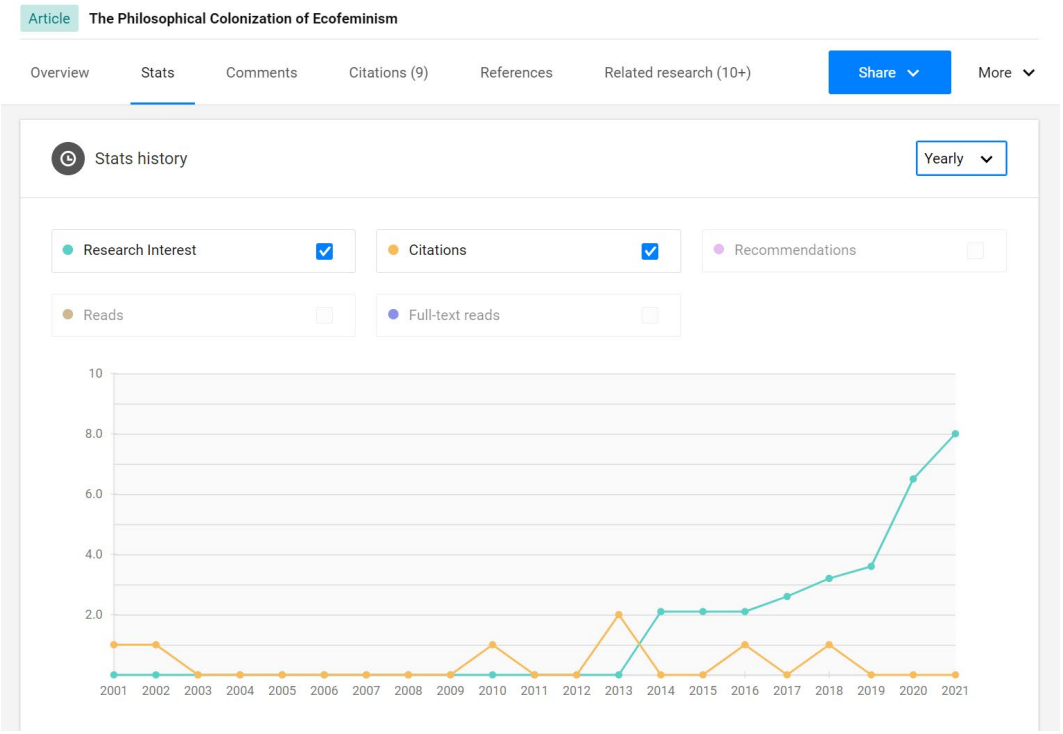
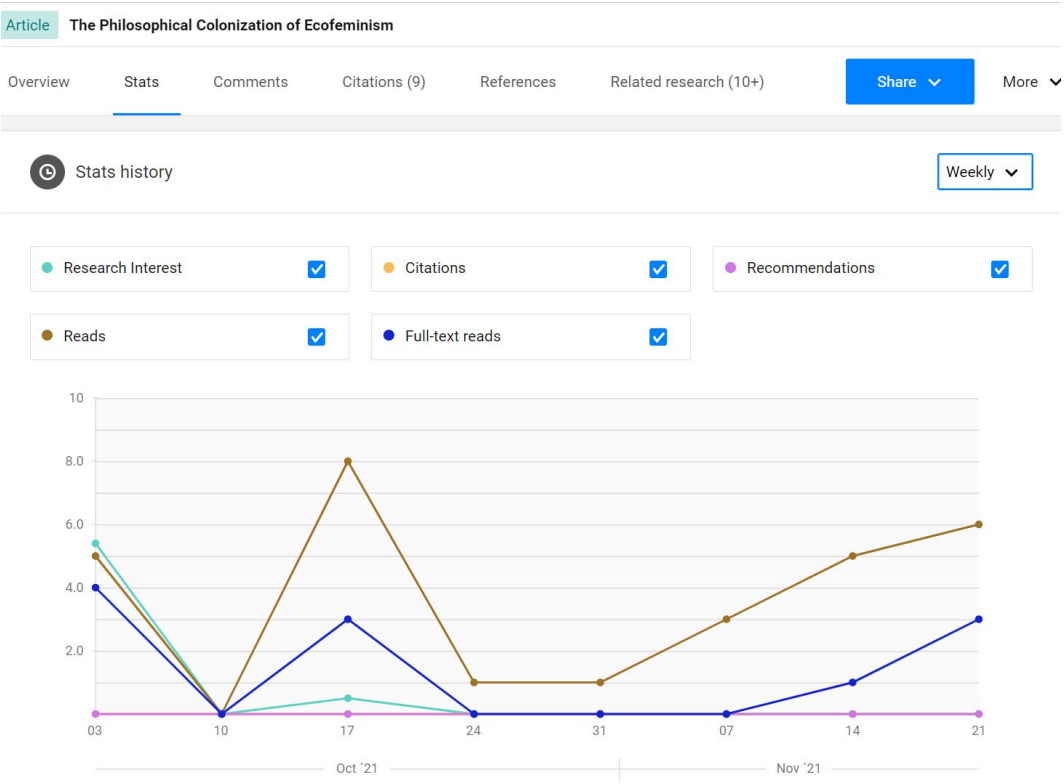


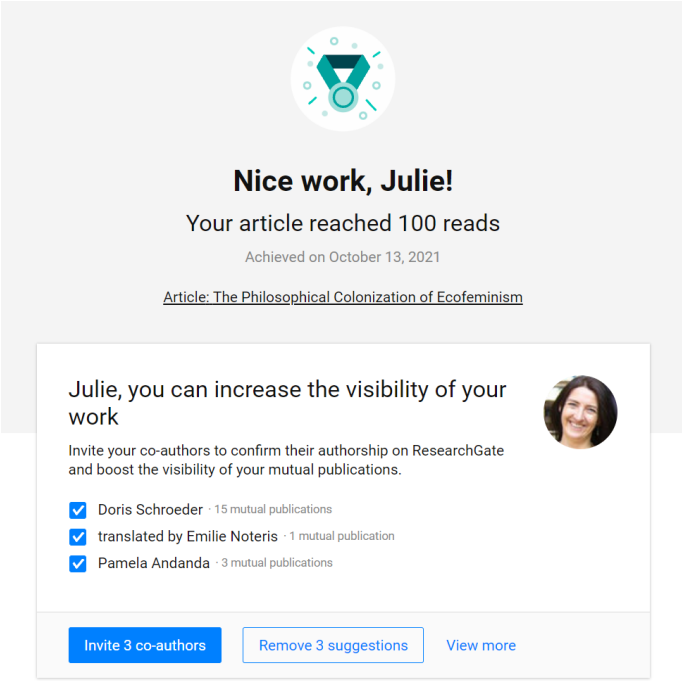
Figure E.1.

Reclaim *(Hache, 2016) cover and Contents*

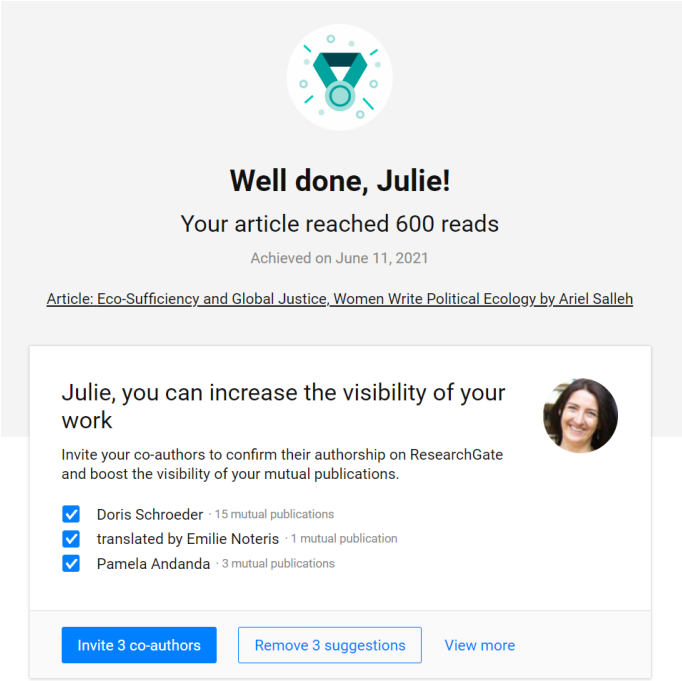
As part of the publication process, I learned from *Environmental Ethics* that I held the copyright to **Cook** (**1998**). As the paper is still not freely available online from the journal, I therefore created a Researchgate account and added a copy of the original paper to my profile, in the hope that those who could not read it in French might find it there. It has subsequently attracted increasing research attention and recently reached 100 reads, with weekly activity currently being quite buoyant.







I have also added the ecofeminist book reviews from *Environmental Values* (**Cook, 1994**; **Cook, 2000**; **Cook Lucas, 2009**; **Cook Lucas, 2010**) to Researchgate, where they receive a steady stream of reads, particularly for Salleh (2009).



The Researchgate activity is possibly related to the inclusion of **Cook** (**1998**) as a resource in a number of university reading lists, for example as further reading in ecofeminism for Theorising Gender 2 at the University of Leeds.

Google scholar citations are still low (31), but range through student dissertations, articles and books across disciplines from theology to philosophy to environmental sciences to post-colonialism.

The article is pleasingly referenced in the "Ecofeminism" chapter in pioneering bioethicist Rosemarie Tong's classic, *Feminist thought, student economy edition* (2015), and in the revised *Feminist Thought: A More Comprehensive Introduction* (Tong & Botts, 2018).

It has a growing presence online, for example on *encyclopedia.com*
https://www.encyclopedia.com/science/encyclopedias-almanacs-transcripts-and-maps/environmental-ethics-iv-ecofeminism

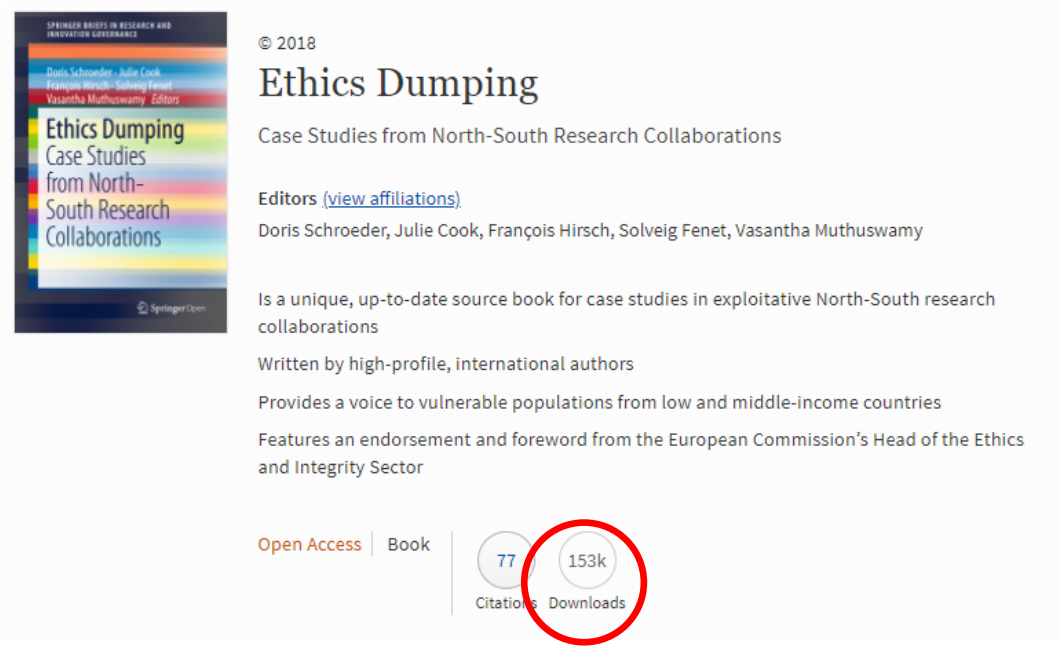
And I can be found listed as a "known ecofeminist author" on Wikipedia's Ecofeminism page, although I have yet to populate my waiting page

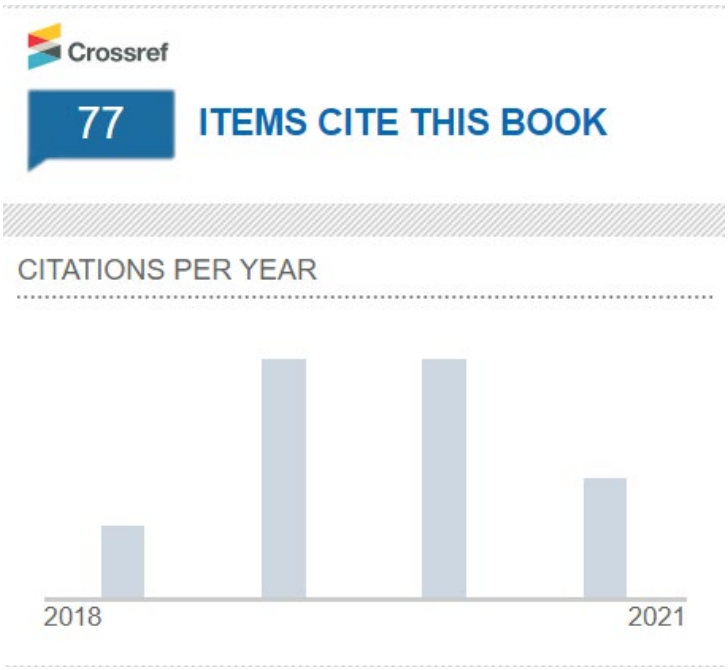
https://fr.wikipedia.org/wiki/%C3%89cof%C3%A9minisme

My ecofeminist work has not of course ever been funded in any way. This provides a useful and historical comparison of both the impact of high-profile funding on research outputs, and the changes in academic publishing and the accessibility of academic outputs over the timespan of this thesis.

By contrast, *Ethics dumping: Case studies from North-South research collaborations* (**Schroeder, Cook, Hirsch et al., 2018a**) has had huge impact in terms of reads and citations in the three years since its publication in November 2018.

Due to the European Commission funding for the TRUST project, *Ethics Dumping* was published gold open access, meaning that it can be downloaded freely direct from Springer's site. This has facilitated its impact and reach, and at the time of writing (20.11.21) it has achieved 153,000 downloads, with 77 recorded citations for the book.

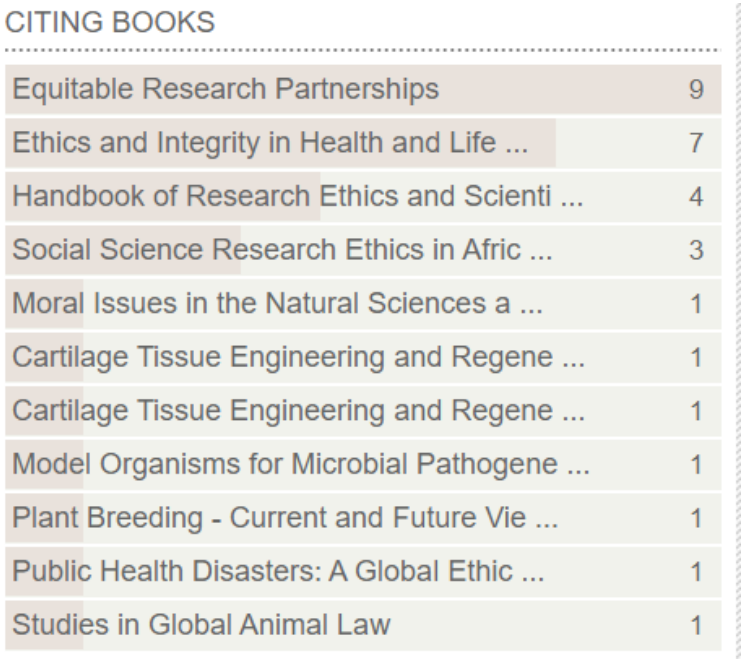




The list of citing books and journals provided by Crossref (https://www.crossref.org/ 20.11.21) demonstrates the interdisciplinary reach of the collection.

CITING JOURNALS

Research Ethics	10
BMJ Global Health	3
Cambridge Quarterly of Healthcare Ethic ...	3
Science	2
Wellcome Open Research	2
AAS Open Research	1
AAS Open Research	1
Alternatives to Laboratory Animals	1
Annals of Applied Biology	1
Annual Review of Genomics and Human Gen ...	1
BMC Medical Ethics	1
BMC Medical Genomics	1
Development	1
Evolutionary Anthropology: Issues, News ...	1
F1000Research	1
Human Molecular Genetics	1
Indian Journal of Public Health	1
Information, Communication & Society	1
International Health	1
International Journal of Molecular Scie ...	1
International Journal of Qualitative Me ...	1
Journal of Anthropological Research	1
Journal of Empirical Research on Human ...	1
Journal of Forensic Sciences	1
Medicine, Health Care and Philosophy	1
Nature Genetics	1
Nature Reviews Genetics	1
NeuroImage	1
Nursing Ethics	1
Philosophy & Technology	1
Revista Latinoamericana de Bioética	1
The CRISPR Journal	1
Therapeutic Innovation & Regulatory Sci ...	1
Veteriner Farmakoloji ve Toksikoloji De ...	1



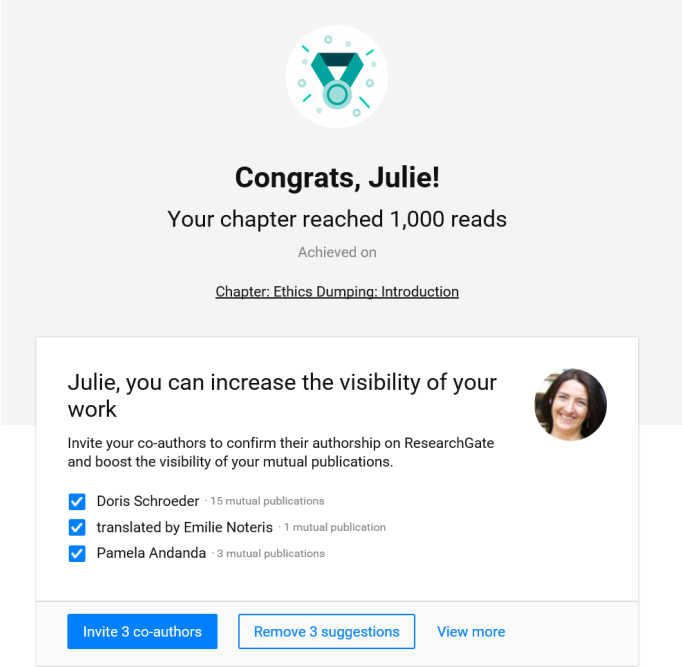
Google Scholar also provides citations for the individual chapters / cases in the book. The sources of these citations again evidence the broad appeal and use of these case studies for those involved in a range of research disciplines and endeavours, but perhaps indicate some gaps in interest (gender).

Table E.1.

Current citations for individual ethics dumping cases

Chapter / Case study		Google Scholar citations 20.11.21
1	Introduction	8
2	Social science research in a humanitarian emergency context	6
3	International genomics research involving the San people	24
4	Sex workers involved in HIV/AIDS research	5
5	Cervical cancer screening in India	17
6	Ebola vaccine trials	9
7	Hepatitis B Study with Gender Inequities	1
8	Healthy volunteers in clinical studies	4
9	An international collaborative genetic research project conducted in China	11
10	The use of non-human primates in research	14
11	Human food trial of a transgenic fruit	3
12	ICT and mobile data for health research	3
13	Safety and security risks of CRISPR/Cas9	16
14	Seeking retrospective approval for a study in resource-constrained Liberia	5
15	Legal and Ethical Issues of Justice: Global and Local Perspectives on Compensation for Serious Adverse Events in Clinical Trials	1

However, verifying these figures is always contentious, as Researchgate currently records a further 1000 reads of the book's "Introduction" via my pages. This has also brought me a number of useful contacts and potential collaborators in academic activism for the future.



Conference output

I presented TRUST's Ethics Dumping results at UCLan's *4th International Health & Wellbeing Research with Real Impact Conference* on 4.2.18. My presentation, "How to Counter 'Ethics Dumping' in International Health Research", presented the overall ethics dumping concept illustrated by data from two case studies from the curated collection: "Cervical Cancer - Clinical Trials In India", and "Seeking Retrospective Ethical Approval for Ebola Research in Liberia".

Teaching

I have also used the case study research and overarching 'ethics dumping' analysis to provide 'research-informed teaching' on post-graduate Health modules at UCLan. I have taught "Ethics and Governance Processes" on the module *Design and Interpretation of Clinical Trials*, and I teach an ongoing single session each semester, "Linking Research Ethics with Critical Evaluation" on the module *Evidence for Practice*. This too relies on specific case study examples from the collection.

Appendix F

GenBenefit International Conference: New Delhi, March 2008

Agenda

DAY 1: Thursday, March 6, 2008

09.30 **Registration**

10.00 to 10.40 **Inaugural Session**

Welcome Remarks by
Dr. Nagesh Kumar, Director General, RIS, New Delhi

Inaugural Address by
Shri B. S. Parsheera, Additional Secretary, Ministry of Environment and Forests (MoEF), Government of India

Remarks by
Prof. Doris Schroeder, Project Leader, GenBenefit, University of Central Lancashire, UK

Keynote Address
Access and Benefit Sharing (ABS) and International Trade and Legal Regimes

Prof. Thomas Pogge, Yale University, USA

Vote of Thanks
Dr. Vasantha Muthuswamy, Indian Council of Medical Research (ICMR), New Delhi

10.40-11.00 **Tea Break**

11.00-13.00 **Session I: Panel Discussion on Issues in ABS Debate**

Chair: *Mr. Timothy Hodges, Co-Chair, Working Group on Access and Benefit-Sharing (WGABS), UN Convention on Biological Diversity*

Panelists:
Overview of Negotiations at WTO Forum: *Mr. Sanjay Kumar, Former Director, Ministry of Commerce and Industry, Government of India*

Overview of Negotiations at CBD Forum: *Prof. Gurdial Singh Nijar, Malaysia*

ABS and Human Genetics: *Dr. Véronique Fournier, Director, CE Centre, Paris, France*

ABS and Gender Issues: *Prof. Fatima Alvarez-Castillo, University of Philippine, Manila, the Philippines*

13.00 to 14.00 ***Lunch Break***

14.00-15.30 **Session II: Indigenous Knowledge System, ABS and Evidence from Plant based Case Studies**

Chair: *Dr. Fernando Casas, International Affairs Advise, Co-Chair – Working Group on Access and Benefit-sharing, UN Convention on Biological Diversity*

San Hoodia Case and Access and Benefit Sharing: *Roger Chennells, Stellenbosch,, South Africa*

ABS and Kani Case: *Dr. Sachin Chaturvedi, RIS, New Delhi*

ABS Arrangements in Peru: *Bram De Jonge, Wageningen University, the Netherlands*

Panelists

Dr. Balakrishna Pisupati, UNEP, Nairobi

Mr. Atul Kaushik, Advisor (Projects), CUTS International, Jaipur

Dr. S. Rajasekharan, Head, Tropical Botanic Garden and Research Institute, Kerala

15.30-16.00 ***Tea Break***

16.00 to 17.30 **Session III: Emerging ABS Trends in Human Genetics**

Chair: *Prof. R. Kumar, Indian Institute of Science, Bangalore*

ABS Issues and Icelandic Biobank: *Dr. Gardar Arnason, Manchester University, UK*

Majengo HIV/AIDS Research Case: *Prof. Doris Schroeder and Dr. Pamela Andanda, University of the Witwatersrand, Johannesburg, South Africa*

Panelists

Dr. Vasantha Muthuswamy, Indian Council of Medical Research (ICMR), New Delhi

Dr. S. S. Agarwal, Professor of Eminence, Sanjay Gandhi Post Graduate Institute, Lucknow

Prof. Charles Obadiah Nimma Wambebe, Chief Executive Officer, International Biomedical Research in Africa, Nigeria

Dr. Joshua Kimani, University of Nairobi, Kenya

DAY 2: Friday, March 7, 2008

09.30 to 11.00 **Implementation of ABS and National Legal Regimes**

Co-Chair**:** *Prof. Madhav Menon, Member, Commission for Centre/State Relations, New Delhi**

Co-Chair**:** *Dr. R. S. Rana, Member, UNEP-CBD Tech Expert Group on Tech Transfer & Chair, Bio-Links, New Delhi*

Dr. Dafna Feinholz, Executive Director, National Commission of Bioethics, Mexico

Dr. Lifeng Guo, Researcher, China Academy for Science and Technology for Development (CASTED), China

Mr. Jack Beetson, Aboriginal Philosopher, Federation of Independent Aboriginal Education Providers, Australia

Dr. K. Venkataraman, Secretary, National Biodiversity Authority, Chennai

11.00-11.30 ***Tea Break***

11.30-13.30 **Valedictory Session: ABS Policy Lessons and Way Forward**

Chair: *Dr. Miltos Ladikas, University of Central Lancashire, UK*

Mr. Timothy Hodges, Co-Chair - WGABS, UN Convention on Biological Diversity

Dr. Fernando Casas, International Affairs Adviser, Co-Chair – WGABS

Dr. Sujata Arora, Director, MoEF, Government of India, New Delhi

Dr. S. K. Bhattacharya, Additional Director General, ICMR, New Delhi

13.30 **Lunch**

GenBenefit Core Group Meeting at RIS

Appendix G

Table G.1. *MAYA-ICBG – San-Hoodia Comparison 2009*

MAYA-ICBG / San-Hoodia Cases: Selected indicators for comparison (Feinholz Klip, Garcia Barrios & Cook Lucas, 2009)		Did not occur / NO Questionable/conflicted/challenged Occurred / YES
Research project	**MAYA_ICBG**	**San-*Hoodia***
Time Period	1998 - 2001	2003 - 2009
Country	Mexico	South Africa
Indigenous Peoples (IP)	Maya	San
Pharma products from plant Traditional Knowledge (TK)	✓	✓
External (international) research funding & design	USA public / Wales private	UK private
Local / national host research partners	ECOSUR public	SA CSIR public
IPs / TK holders involved in research design / project	X	X
R&D benefit sharing intention	✓	X
National CBD policy framework in place	X	X
Functioning implementation / operationalisation of existing policies	Q	X
Adequate processes and structures for negotiating CBD-style benefit sharing	X	X
TK holders identified	Q	X
Consent from TK holders to access biodiversity	Q	post-hoc
Stakeholders adequately represented in decision-making (around benefit sharing)	X	Following intervention
Local resistance to planned activities	Q	✓
Organised resistance within country to planned activities	✓	✓
International support for resistance to planned activities	✓	✓
Conflict between concepts / governance of community / relevant territories (land)	✓	✓
Stable / safe political situation	Post-Zapatista uprising. Militarisation, displacement	Historic genocide. Contemporary marginalisation
Conflict over nature of knowledge / IPR	✓	✓
Benefit sharing agreement reached	X	✓
Research enacted	X	✓
Benefits paid	X	✓

Appendix H

Timeline of CBD Cases 1987-2010

Table H.1.

Timeline of CBD Cases 1987-2010

	Interactions between benefit sharing case studies, CBD, and national frameworks / legislation to support implementation																			
	1987 ...	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
		Convention on Biological Diversity																		
														Bonn Guidelines on ABS						**Nagoya Protocol**
India: Kani Case		**Kani Jeevani case**																		
		Signs CBD		Ratifies CBD	Relevant legislation not in place							India Biological Diversity Act 2002								
Nigeria: Niprisan Case		**Niprisan case**																		
		Signs CBD		Ratifies CBD	Relevant legislation not in place									Nigerian Biodiversity Legislation enacted (various)						
South Africa: San Case							**South(ern) African San-*Hoodia* case**													
			Signs CBD		Ratifies CBD	Relevant legislation not in place							First NBSAP	South African Biodiversity Act 2004 (enacted 2008)						
Mexico: Maya_ICBG									**MAYA_ICBG**											
		Signs CBD	Ratifies CBD	Relevant legislation not in place						Mexico adopts first National Biodiversity Strategy Action Plan 2002										

Data as understood 2013

Appendix I

Methodological Approach for this Inquiry

Applied ethics

The methodological approach for the published research presented in this portfolio falls within applied ethics. 'Applied ethics' describes the use of philosophical methods to examine particular issues for the purpose of ethical decision-making. It emerged in the 1970s as a philosophical movement (Singer, 1980) to address "pressing moral problems in society" (Beauchamp, 2008, p2). The 'problems' in question may relate to issues such as reproductive choices, end-of-life, mental health care or racial and sexual equality. They may address personal (e.g. dietary: Singer, 1975) or professional conduct, or broader contemporary social and political issues such as technology (Grunwald, 2021), or climate change. Specifically in my thesis, the use of applied ethics is of broad value for informing research policy and practice.

Applied ethics often requires practical, feasible solutions to problems in addition to theoretical analysis of them (Bayertz, 2002). Therefore an applied ethics approach requires understanding of the specific fields it addresses, as well as the synthesis and analysis of information drawn from diverse sources, which can range through academic literature, empirical studies, philosophical enquiry, policy documents and so on (Frey and Wellman, 2008). There are no set rules about how to find the relevant information; the analysis of each case will be unique, therefore this type of analysis requires a flexible approach which can adapt to the topics under consideration.

Applied ethical analysis is most commonly desk-based, involving critical thinking and conceptual philosophical analysis of existing data, as well as dialogue and exchange with other scholars, expert informants etc. However, the use of empirical methods to actively obtain data that is then included in applied ethical analysis has become more widespread, and is often termed 'empirical ethics' (Molewijk & Frith, 2009).

Empirical ethics

Empirical research in ethics has been captured as relevant to determining what course of action is right or wrong, good or bad, respectful or disrespectful etc. It involves the collection and analysis of "ethically relevant empirical data" for making these decisions; "bioethicists may use empirical data to generate 'evidence-based' recommendations about how ethical principles should be realized in specific settings." (DuBois, 2009, p. 72). Empirical ethicists may therefore analyse data that has been collected via a wide variety of means, and methods. This may include their own empirical work, or other researchers' studies, information from civil society, or industry and media. Consequently, the approach to data collection for ethical analysis can draw upon any tradition or approach to obtain the ethically relevant data. In my trajectory from a campaigning perspective to academic research, this has been an appropriate method to develop, as it relies on the same skillset in locating and working with information from diverse sources, and a transferable critical perspective of 'What is relevant here?'.

The relationship between traditional social sciences and empirical ethics, including any distinctions between them, are ongoing matters of debate in this relatively new field (Frith, 2010). However, there is significant overlap and sharing of approaches, particularly in multi- or trans-disciplinary research projects, such as those reported in this thesis.

Case studies are a well-established method in the development of applied ethics, including for education, training and communication, particularly in transdisciplinary contexts, where they bring this 'real-life' empirical evidence to situations which demand ethical decision-making (European Commission, 2010).

The applied ethics research presented in Sections 2 and 3 is largely based on an empirical ethics method which made substantial use of case study data.

Case studies

Research case studies are usually (a combination of) exploratory, descriptive or explanatory (Zainal, 2007; Ebneyamini, 2018). Whilst often used in isolation, multiple (or collective) case studies can enhance generalized understandings of a topic (Noor, 2008).

Stake's work (1995) grounded the intention to capture complexity in case study research, with in-depth consideration of historical background, setting, and institutional and political factors.

Yin's (2018) description of case studies that investigate a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used, is close to the analytical approach I developed for the published work which is presented in Sections 2, 3, and 4.

I describe this as a **curated comparative analysis of case studies in applied ethics**.

Curated comparative analysis of case studies in applied ethics

The term **curation** represents my reflexive responsibility for organising the material to identify trends and themes to develop and present the resulting analysis and make recommendations. The method relied on my deep familiarity with the material under investigation through immersion over time. This helped to retain the individual character of each case within a complex international and theoretical context.

This approach connects to the need for "de-abstraction" when using such an analytical method. Complex mapping and synthesis of multiple evidence sources will produce general conclusions, about for example the (non)adoption of specific practices and their impacts (see Stage 2, *Cross-map findings with other case studies included in the collection*). However, the outcomes in each case are sensitive to and dependent on multiple and diverse contextual factors, which need to be identified and accounted for: "transferring 'evidence-based' conclusions to other cases requires de-abstraction in the sense of collecting detailed knowledge about these contextual factors that led to adoption of programmes and their outcomes under different conditions." (Konig et al., 2021, forthcoming).

The **curated comparative analysis of case studies in applied ethics** is a reflexive method which incorporates this understanding**.** Crucial contextual factors are identified early in Stage 1 of the method in order to establish the Situation, Context and Frameworks. This shapes the subsequent Axes of Analysis for each case study. These factors are then incorporated into the identification of comparative themes between and across the case studies, in Stage 2. Synthesis of the themes and contextual factors in Stage 3 generates nuanced but widely applicable conclusions and recommendations which take the contextual factors identified into account.

These recommendations can aim either to support and build such factors, or to resist or defend against them, dependent on the ethical orientation of the analysis. For example, in my analysis, identifying conditions in which ethics dumping flourishes (Section 3) enables recommendations which will counter these, as well as recommendations to support the factors which strengthen ways to resist ethics dumping.

A detailed indicative example of applying the steps in the **curated comparative analysis** method is shown in Appendix L.

Appendix J

Table J.1. *MAYA-ICBG – San-*Hoodia *– Kani – Nigeria Comparison 2013*

Did not occur / NO Questionable / conflicted / challenged Occurred / Yes	MAYA-ICBG / San-Hoodia / Kani - Jeevani / Nigeria - Niprisan cases: Selected indicators for comparison (Cook Lucas, Schroeder, Chennells et al., 2013)				
SITUATION					
Research project		**MAYA-ICBG**	**San-*Hoodia* (Updated 2013)**	**Kani (Jeevani)**	**Nigeria - Niprisan**
Time Period		1998 - 2001	2003 - 2013	1987 - (2013)	1992 - (2013)
Country		Mexico	South(ern) Africa	India	Nigeria
Indigenous Peoples (IP) / Traditional Knowledge	Updated 2013	Maya	San	Kani	Traditional health practitioner (THP) and family
Pharma products from plant TK		✓	✓	✓	✓
External (international) research funding & design		USA public / Wales private	Phytopharm /Pfizer / Unilever (private)	X	X
Local / national host research partners		ECOSUR public	SA CSIR public	AICPRE / TBGRI public	NIPRD public
IPs / TK holders involved in research design	Updated to 2 categories 2013	X	X	X	✓
IPs / TK holders involved in research project		Appropriateness challenged	X	✓	✓
Research enacted		X	✓	✓	✓

CONTEXT	MAYA-ICBG	San-*Hoodia*	Kani (Jeevani)	Nigeria - Niprisan
Local resistance to planned activities	THP organisations	✓	X	X
Organised resistance within country to planned activities	✓	✓	X	X
International support for resistance to planned activities	✓	✓	X	X
Conflict between concepts / governance of community / relevant territories (land)	✓	Live across Botswana, Namibia and South Africa	✓	X
Stable / safe political situation	X	Historic genocide. Marginalisation	Poor rural community; wide geographical area	✓
Conflict over nature of knowledge / IPR	✓	Formally consider IP a collective asse	✓	✓

FRAMEWORK		MAYA-ICBG	San-*Hoodia*	Kani (Jeevani)	Nigeria - Niprisan
R&D intention to abide by CBD-style benefit sharing principles	Adapted 2013	Good intentions overly naïve	✓	✓	Protection of TK as distinct from biodiversity concerns
National CBD policy framework in place		X	2008	X	X
Functioning implementation-operationalisation of relevant existing policies		Unclear system chaotically administered	X	✓	✓
Adequate processes and structures for negotiating CBD-style benefit sharing	Adapted 2013	X	✓	Late in process	✓
TK holders identified		Contested	✓	Generic	✓
Consent from TK holders to access biodiversity		Contested	ex post facto	Limited (individuals) became divisive	Did THP have exclusive rights over TK?
Benefit sharing agreement reached		X	2003 and 2010	✓	THP/researchers excluded from licensing negotiations
Structure for payment of benefits	Added 2013	Controversial Pro-MAYA	San-*Hoodia* Benefit Sharing Trust	Kerala Kani Samudya Kshema Trust	✓
Adequate governance structure for distribution of benefits	Added 2013	Top-down R&D driven	✓	✓	None distributed
Benefits paid		X	✓	✓	X
Stakeholders adequately represented in decision-making (around benefit sharing)	Replaced 2013	X	Following intervention	✓	

Appendix K

Table K.1. *Iceland – Kenya – Indonesia Comparison 2013*

Did not occur / NO Questionable/conflicted/challenged Occurred / YES	deCODE biobank / Kenya HIV-AIDS / Indonesia H5N1 cases: Selected indicators for comparison (Cook Lucas, Schroeder, Arnason et al., 2013)		
SITUATION			
Research project	**deCODE biobank**	**Kenya HIV-AIDS studies**	**H5N1 virus samples**
Time Period	1996 - 2009	1984 - 2013	2005 - 2011
Country	Iceland	Kenya	Indonesia
Human samples / data	✓	✓	✓
Export of human samples / data	Potentially. Not aim of study	Related to lack of national capacity	Shared internationally via WHO. Terms not honoured
Clinical trials	X	✓	X
External (international) research funding & design	deCODE genetics inc. (US private). Roche (private)	University of Manitoba. University of Oxford. Multiple international research partners and funders.	WHO global virus sharing system / Reference Laboratories
Local / national host research partners	Islenk erfoagreining (wholly owned subsidiary)	University of Nairobi (public)	Indonesian laboratories
Research enacted	Limited	✓	✓

CONTEXT	deCODE biobank	Kenya HIV-AIDS studies	H5N1 virus samples
Vulnerable Participants re frameworks	Vulnerable groups within HIC population	Extreme vulnerability	LMIC
Risk of inducement for individuals to participate compromising consent	X	Trading participation for health care	X
Organised resistance within country to planned activities	✓	X	Parliamentary / government
International support for resistance to planned activities	✓	Concern over potential exploitation of participants	✓
Stable / safe political situation	✓	Multiply marginalised community in LMIC	LMIC
Conflict over nature of ownership of samples / data	✓	Controversy over export of samples	Controversy over sample sharing outside agreed parameters to create inaccessible vaccines

FRAMEWORK	deCODE biobank	Kenya HIV-AIDS studies	H5N1 virus samples
International laws / regulations apply	Very few apply (vaguely) to this	Biomedical governance regime - non-binding	International research ethics guidelines although not appealed to
Functioning implementation-operationalisation of relevant existing national policies / governance	✓	New regulations introduced over time	✓
Benefit sharing intentions	Profit sharing with government	Runs counter to biomedical governance regime to reward participants	X
Potential alternative benefits in accordance with governance regimes	Free medicines	Multiple possibilities but concern over 'benefit' status	X
CBD-style benefit sharing appealed to	X	X	✓
Benefit sharing agreement reached with governance structure and payment schedule	deCODE & Roche / deCODE and government	X	X
Individual consent to access and use samples / data	Presumed consent	Informed individual consent	X
Dramatic parliamentary / legal intervention	Need to change law. Ruled unconstitutional 2003	X	Government stopped routine export of samples 2006
Benefits paid	X	Multiple activities but disagreement over 'benefit' status	2007 sample sharing resumed following negotiations. Sealed 2011 with PIP framework.

Appendix L

Table L.1. *Indicative example of curated comparative analysis of collective case studies in applied ethics*

Curated comparative analysis of collective case studies in applied ethics *(indicative example relates to fair benefit sharing in research)*			
Stage 1: Apply process to each individual case in the collection			
Step in process	**Purpose**	**Categories for analysis (*indicative examples*)**	**Shaping considerations**
Situation **This will focus and define the rest of the analysis**	**Who is doing what, to who?** Identify specifics: ▪ What is the topic/issue? ▪ What happened? ▪ Who are the stakeholders? ▪ What's the location? ▪ Establish the timeline.	Completely open	▪ Is this a paradigm/familiar case? ▪ Does it seem unusual or unique? ▪ What are its specific features? ▪ What is the existing context for analysis – evidence/literature/media coverage?
Applying additional gender lens	Enable baseline data collection for this analysis.	▪ Single gender cohorts	

		▪ Women's role in case ▪ Differential gender roles/status in case.	
Context **This will be dependent on the research question you bring – what are you interested in?**	What are the relevant key features?	▪ Single country ▪ HIC or LMIC ▪ Cross-border ▪ Disaster/conflict zone ▪ Indigenous people ▪ Pandemic	▪ Are there any (geo)political issues to be considered? ▪ Who or what is/has been funding, driving or opposing this case/project?
Applying additional gender lens	Enable contextual baseline data for the analysis.	▪ Single gender cohorts ▪ Women's roles/status in community of interest ▪ Specific data for women e.g., maternal mortality rate.	Differential gender status in community/country, e.g., gender pay gap/education.
Frameworks **Decisions made here set the analytical parameters e.g. human v non-human specimens.**	▪ What overarching frameworks apply here directly (e.g. CBD)? ▪ Could any others be relevant/comparable (e.g., *Declaration of Helsinki*)?	▪ Policy ▪ Legal ▪ Ethical ▪ Human rights	▪ What impact do/could these frameworks have if applied (in the case to the analysis)? ▪ What has been/will be the impact of not applying them in the case/to the analysis?

	▪ What specific frameworks have been put in place (e.g., consent/benefit sharing agreement)?	▪ Binding v non-binding/voluntary/aspirational ▪ Codes/statements	
Applying additional gender lens	▪ What overarching gender-based frameworks apply here directly? ▪ What gender-based aspects of overarching applicable frameworks (e.g., *Nagoya Protocol*) are relevant here? ▪ Could any others be relevant or comparable? E.g., Does the country have a Constitution? ▪ What specific frameworks have been put in place (e.g., in a consent/benefit sharing agreement)?	▪ National/international women's rights guidelines and commitments. ▪ Indigenous guidelines for women's political participation.	Could these frameworks help to identify e.g., gender-biased gaps in inclusion and participation, and offer support to underpin recommendations?
Identifying Lenses/Axes of Analysis **Based on the data, what lenses/axes are most**	▪ What are the patterns? ▪ What or who is missing or overrepresented? ▪ What have **you** noticed? (Your bias/specialism)	▪ Indigeneity ▪ Poverty ▪ Disease status ▪ Funding	This principle will influence/structure presentation of the whole analysis: ▪ e.g., a historical presentation will give pre-post *something* and indicate changes but the analysis of cause/effect/impact of any particular change is part of your *interpretation*.

appropriate for your research question?	▪ What are the sources of information? ▪ Might other lenses be helpful?	▪ Historical situation (colonisation) ▪ Vulnerability ▪ External perspectives: NGOs/media.	▪ e.g., a focus on impacts related to poverty as a mechanism will not *necessarily* look at the causes of poverty as part of the *interpretation*. That would require a further lens/axis.
Applying additional gender lens	▪ Identify where are the women. ▪ What are they doing / what is happening to them and why? ▪ Are there other impacted gender groups? ▪ What are the gender differentials?	▪ Women's participation in consent processes and negotiations. ▪ Women's role in identifying, managing or distributing benefits. ▪ Women's access to/share of benefits. ▪ Women's political participation in wider community.	Can findings/status quo be critiqued/triangulated against gender-based guidelines or normative comparisons?
Exploitation risks **These should emerge from the analysis.**	Identify and assess these in relation to the selected frameworks.	▪ Lack of appropriate consent procedures. ▪ Population vulnerable to coercion. ▪ Lack of effective governance.	Gauge against the story – what happened/when/how/who to/outcome – could that have been foreseen or mitigated?

Applying additional gender lens	Identify and assess these in relation to the selected frameworks.	▪ Coercion/consent made (or denied) on women's behalf. ▪ Unfair share of benefits. ▪ Exclusion from democratic (or other) process.	
Recommendations (individual case)	▪ To mitigate risks ▪ To model best practice	Completely open	▪ What could be done differently/better? ▪ Recommendations need to be contextual – who are they aimed at? ▪ Are they implementable by those (or any) parties? ▪ If not, what are the alternatives?
Applying additional gender lens	To ensure inclusion of women's needs/targets in recommendations.	Completely open	

Stage 2:
Cross-map findings with other case studies in the collection to identify comparative themes

Step in process	Points noted (*indicative examples*)	Counterpoints noted (*indicative examples*)	Themes (*indicative examples*)
Situation	*Biodiversity exported for R&D*	*R&D retained in country*	*Location of R&D shapes benefit sharing.*
Context	*Politically unstable setting/LMIC*	*Politically stable setting/HIC*	*The country setting underpins many capacity issues and exploitation risks.*

Frameworks	*Relevant local laws and regulations followed.*	*Cases subject to different international regimes, e.g., if CBD not yet promulgated in country.*	*Confusion about conflicting frameworks and expectations has a negative impact on outcomes.*
Lens / Axes of analysis	*Poverty*	*Wealthy population*	*Indicates potential vulnerabilities and risks e.g., coercion with a potential impact on informed consent.*
Exploitation risks	*Poor practice regarding export of samples is notable in cases with strong external research input.*	*Strong host involvement in research is reflected in more local involvement in research design and analysis.*	*Who designs and implements the research seems to be significant. General risk of poorer practice when HIC researchers conduct activities in LMICs.*

Stage 3. Synthesis produces recommendations which would be weaker, or missed altogether, based on an individual case study / limited set of case studies.

(*Example*) Recommendations

- *Need to build researcher capacity regarding benefit sharing theory and practice/frameworks and requirements, especially in international research settings.*
  - *Capacity-building needs and strategies will be very different for HIC or LMIC research settings.*
- *Need to build compliance with regulations through Research Ethics Committee structures to address exploitation risks within existing systems.*
  - *This requires support and capacity building, particularly in LMICs.*
- *Need to build participant capacity/empowerment , including development of community permission.*

Additional gender lens	*Address requirements for women's involvement at all relevant stages; build into compliance mechanisms and extend capacity-building initiatives in contextually sensitive ways.*

Appendix M

Gender Analysis: Selected Indicators 2009 (with 2021 comparison)

Indicator / Country	Iceland	Kenya	Nigeria	San (Southern Africa)	Kani (India)
% of Women in parliament **UN 2008 data**	34.9 (2000) 30.2 (2004)	3.6 (2000) 7.10 (2004) Men dominate political sphere.	3 (1999) 7 (2008) Women have a minimal role in politics despite a constitutional guarantee for equal rights.	Women's participation in political affairs dwindled with sedentarisation and women are marginalized in politics.	Women by tradition do not participate in political activities.
Maternal mortality rate (per 100,000 live births) **WHO 2006 data**	0 (2000)	1000 (2000)	800 (2000) Lack of female autonomy over reproduction.	No specific data available	Women lack autonomy over their fertility. Pregnancy-related health problems related to physical labour.
Life expectancy (years) **WHO 2004 data**	79 (men) 83 (women)	51 (men) 50 (women)	45 (men) 46 (women)	No specific data available	No specific data available
UN 2007/8 data	High #1	Medium #148	Low #158	No specific data available	No specific data available
Women in key benefit sharing decision-making bodies. *	Act on a Health Sector Database (1998) passed by a parliament with 25% women members. Women's participation in debates: 24% (TV); 39% (radio).	0	0	2/7 (San Trustees) WIMSA (no woman officer during negotiations)	2/11 (Kani Trust Executive Committee). Appointed by men as no woman would stand.

Table M.1. *2009. Comparison of selected indicators for gender analysis: women's participation in benefit sharing negotiations, management and distribution of funds.*

*Combined original data reproduced from: **(Alvarez Castillo & Cook Lucas, 2009):** Table 3. Gender Inequality in Kani society; Table 4. Gender inequality in San society; Table 5. Gender inequality in Nigerian society; Table 6. Gender inequality in Kenyan society; Table 7. Comparison of selected indicators in 3 non-indigenous social settings; Table 8. Women in bodies involved in 5 x benefit sharing decision making and GenBenefit aggregated data **(Cook Lucas & Castillo, 2013, p. 133)**.*

Table M.2.

Reflexive Analysis: Comparative Gender Data 2021

The Global Gender Gap Index 2020 **rankings***						**My comparative data**
Rank	**Country**	**Score (scale 0-1)**	**Rank change since 2018**	**Score change since 2018**	**Score change since 2006**	**Rank change since Alvarez Castillo & Cook Lucas (2009)**
1	**Iceland**	0.877	-	+0.018	/ +0.095	-
17	**South Africa**	0.780	+2	+0.025	+0.068	No data for San
109	**Kenya**	0.671	-33	-0.029	+0.023	+39
112	**India**	0.668	-4	+0.003	+0.066	No data for Kani
128	**Nigeria**	0.635	+5	+0.015	+0.025	+30

**Data from: Global Gender Gap Report*. (2019). World Economic Forum (p. 9)

Appendix N

GenBenefit Side-Event at the sixth meeting of the Ad-Hoc Open-Ended Working Group on Article 8(j) and Related Provisions in November 2009, Montreal

Genomics and Benefit Sharing with Developing Countries –

From Biodiversity to Human Genomics

Friday 6 November 2009

10.30 – 16.30

Fontaine Room D, Hilton Bonaventure,

900 de la Gauchetière Street West, Montréal

Agenda

10:00 -10:30	Registration & Refreshments
10:30	**Keynote address:**
	The importance of Benefit Sharing provisions for developing countries
	Tim Hodges; Co-Chair, Working Group on Access and Benefit Sharing, UN Convention on Biological Diversity
10:45-12:45	**Session I: Project Results**
	(Chair: Dr Veronique Fournier; Assistance Publique-Hopitaux de Paris, France)
10:45 - 11:00	GenBenefit: The Project (Prof. Doris Schroeder; Uclan, UK)
11:00 - 11:45	GenBenefit Project Results
	Case-study I: The San People and Hoodia (Roger Chennells; Hoodia Trust, South Africa)
	Case-study II: Nairobi's Majengo Slum Sex Workers and HIV / AIDS Research (Prof. Pamela Andanda; University of Witwatersrand, South Africa)
	Gender Aspects in Benefit Sharing (Prof. Fatima Alvarez Castillo, University of the Philippines Manila & Julie Cook Lucas, Uclan, UK)

GenBenefit is funded by the European Community's Sixth Framework Programme

11:45 - 12:15 Coffee Break

12:15 - 2:45 Public Discussion

12:45 -14:00 Buffet Lunch

14:00 - 14:40 **<u>Session II:</u>** **Project Recommendations**

(Chair: Dr Miltos Ladikas; Uclan, UK)

14:00 -14:20 Research Ethics Committee Guidelines (Prof. Doris Schroeder, Uclan, UK)

14:20 -14:40 International Regulations (Dr Sachin Chaturvedi, RIS, India)

14:40-15:30 **Panel Feedback**

Tim Hodges; Co-Chair, Working Group on Access and Benefit Sharing, UN Convention on Biological Diversity

Dr Vasantha Muthuswamy; Indian Council for Medical Research, India

Dr Balakrishna Pisupati; United Nations Environment Programme, Nairobi

Prof. Jack Beetson; University of New England, Australia

Dr Giorgio Sirugo; Medical Genetics Unit, San Pietro Hospital, Rome

15:30 -16:00 Tea Break

16:00 -16:30 Public Discussion

16:30 -16:40 Meeting Conclusions (Prof. Doris Schroeder, Uclan, UK)

16:40 Close of Meeting

To be followed by a book launch of **Indigenous Peoples, Consent and Benefit Sharing: Lessons from the San-Hoodia Case**, Edited by Rachel Wynberg, Doris Schroeder & Roger Chennells, Springer, Berlin, 2009.

GenBenefit is funded by the European Community's Sixth Framework Programme

Appendix O

Table O.1. *Comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) with curated analysis (Cook Lucas & Castillo, 2013)*

5 CASES: Comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) with curated analysis (Cook Lucas & Castillo, 2013): San-*Hoodia* / Kani (Jeevani) / Nigeria – Niprisan			Iceland / Kenya		
TK cases: themes where significant differentials applied for gender analysis (Kani / San / Nigeria)	**(Alvarez Castillo & Cook Lucas, 2009)**	**(Cook Lucas & Castillo, 2013): Gender dimensions considered in broader analysis**	**Human cases: Themes where significant differentials applied for gender analysis (Kenya / Iceland)**	**(Alvarez Castillo & Cook Lucas, 2009)**	**(Cook Lucas & Castillo, 2013): Gender dimensions considered in broader analysis**
SITUATION	**2009**	**2013**	**SITUATION**	**2009**	**2013**
Country	✓	✓	Country	✓	✓
Indigenous Peoples (IP)	Strong emphasis	Strong emphasis	Indigenous Peoples (IP)	Strong emphasis	This is developed with new data
Pharma products from plant TK	X	X	Human samples / data	X	Not explicitly presented as gender issue
External (international) research funding & design	X	In 2013, I discussed emerging funder expectations	External (international) research funding & design	n/a	In 2013 I discussed emerging funder expectations
Local / national host research partners	X	X	Local / national host research partners	X	X
IPs / TK holders involved in research design	✓	✓	Clinical trials	n/a	Not explicitly presented as gender issue
IPs / TK holders involved in research project	✓	✓	Export of human samples / data	n/a	X
Research enacted	X	X	Research enacted	X	X

CONTEXT	2009	2013	CONTEXT	2009	2013
Local resistance to planned activities	Only data from one case - collapsed into framework themes	Some emphasis on empowering women to say 'no' independently	Vulnerable Participants re frameworks	Addressed in general terms	Directly addressed re gendered dimensions
Organised resistance within country to planned activities	Only data from one case - collapsed into framework themes	Some emphasis on empowering women to say 'no' independently	Organised resistance within country to planned activities	Strong resistance in Iceland indicated potential gender dimension	Strong resistance in Iceland indicated potential gender dimension
International support for resistance to planned activities	Gender dimension notably missing, hence analysis here	E.g. NGO action not addressed here	International support for resistance to planned activities	Very few discussions considered gender analysis in Majengo, probably due to single gender cohort	Not explicitly presented as gender issue
Conflict between concepts/governance of community/territories (land)	✓		Risk of inducement for individuals to participate compromising consent	Not addressed directly	Gendered aspects addressed e.g. individual v community consent
Stable / safe political situation	✓	✓	Stable / safe political situation	I first introduced the idea that it was a gender issue when cohort is all female	✓
Conflict over nature of knowledge / IPR	Noted that Nigerian women with TK interest wren excluded	A more nuanced approach to IP cultures was included based on new data	Conflict over nature of knowledge / IPR	Not addressed directly as gender issue	Not addressed directly as gender issue

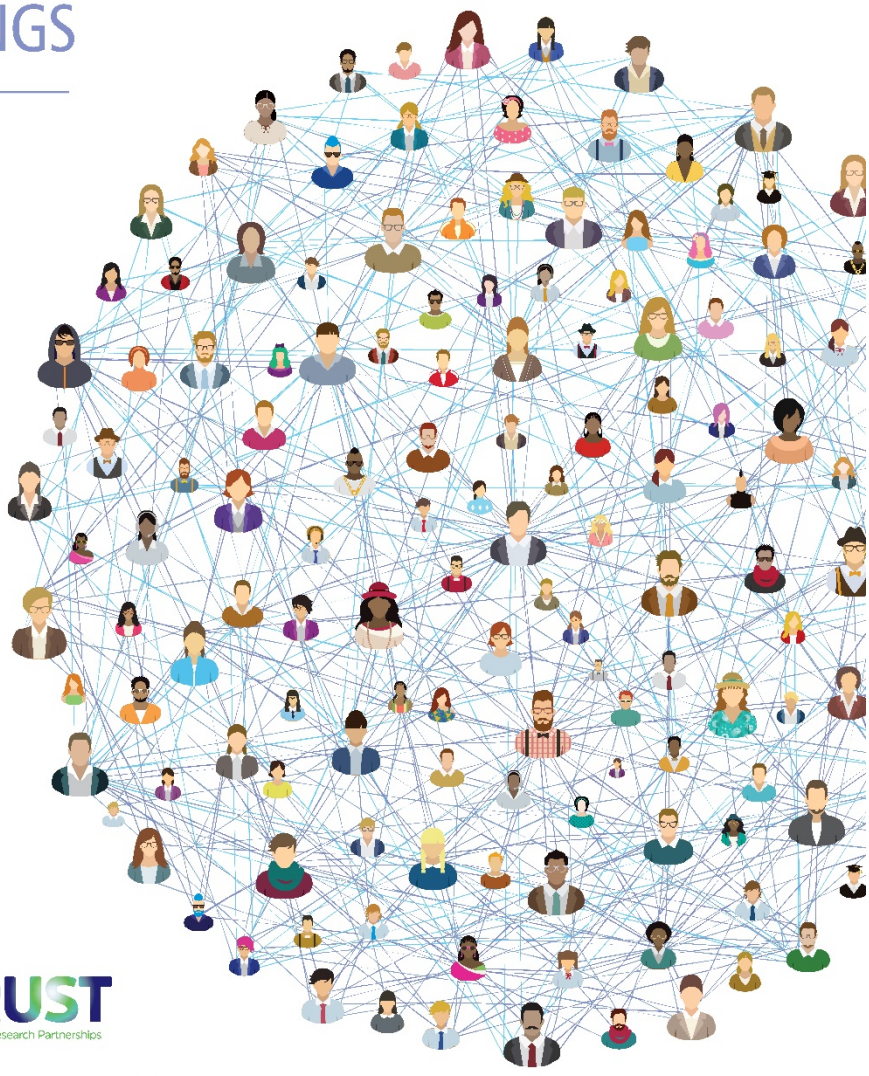
FRAMEWORK	2009	2013	FRAMEWORK	2009	2013
R&D intention to abide by CBD-style benefit sharing principles	X	X	Benefit sharing intentions	n/a	Addressed contextually. E.g. exclusion of women in Nigerian case
National CBD policy framework in place	X	X	International laws / regulations apply	Directly addressed	Relevance of international framework developed strongly
Functioning implementation of relevant existing policies	Situated critique applied	Strong focus	Functioning implementation of relevant existing policies	Directly addressed	Directly addressed and expanded
Adequate processes and structures for negotiating CBD-style benefit sharing	Regarding women's representation/participation in decision-making	A strong focus on this - Nagoya Protocol applied	Potential alternative benefits in accordance with governance regimes	Not addressed directly	Synthesis of 2009 indicators re better targeting funds
TK holders identified	Regarding women's representation/participation in decision-making	Nagoya Protocol applied			
Consent from TK holders to access biodiversity	Regarding women's representation/participation in decision-making	Additional emphasis on empowering women to say 'no' independently - Nagoya Protocol applied	Individual consent to access and use samples/data	Not addressed directly	✓
Benefit sharing agreement reached	Regarding women's participation in management, distribution and use of benefits	Synthesis of 2009 indicators re better targeting funds	Benefit sharing agreement reached with governance structure and payment schedule	Regarding women's representation/participation in decision-making, management, distribution and use of benefits	Extended discussion of participation and representation in decision-making in multi-level contexts
Structure for payment of benefits	Regarding women's control of and access to the benefits (given exclusion from previous stages)	Synthesis of 2009 indicators - Nagoya Protocol applied	Appeal to CBD-style benefit sharing	n/a	n/a
Adequate governance structure for distribution of benefits	Regarding women's participation in management, distribution and use of benefits	Synthesis of 2009 indicators - Nagoya Protocol applied	Dramatic parliamentary / legal intervention	Women's representation in parliament addressed	Women's representation in parliament addressed

Appendix P

Global Code of Conduct for Research in Resource-poor Settings

https://www.globalcodeofconduct.org/

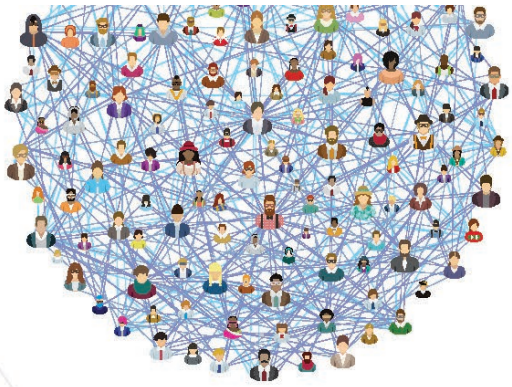
GLOBAL CODE OF CONDUCT FOR RESEARCH IN RESOURCE-POOR SETTINGS



TRUST
Equitable Research Partnerships

www.globalcodeofconduct.org/

GLOBAL CODE OF CONDUCT FOR RESEARCH IN RESOURCE-POOR SETTINGS



Research partnerships between high-income and lower-income settings can be highly advantageous for both parties. Or they can lead to ethics dumping, the practice of exporting unethical research practices to lower-income settings.

This Global Code of Conduct for Research in Resource-Poor Settings counters ethics dumping by:

- Providing guidance across all research disciplines
- presenting clear, short statements in simple language to achieve the highest possible accessibility
- focusing on research collaborations that entail considerable imbalances of power, resources and knowledge
- using a new framework based on the values of fairness, respect, care and honesty
- offering a wide range of learning materials and affiliated information to support the Code, and
- complementing the European Code of Conduct for Research Integrity through a particular focus on research in resource-poor settings.

Those applying the Code oppose double standards in research and support long-term equitable research relationships between partners in lower-income and high-income settings based on fairness, respect, care and honesty.

FAIRNESS

ARTICLE 1
Local relevance of research is essential and should be determined in collaboration with local partners. Research that is not relevant in the location where it is undertaken imposes burdens without benefits.

ARTICLE 2
Local communities and research participants should be included throughout the research process, wherever possible, from planning through to post-study feedback and evaluation, to ensure that their perspectives are fairly represented. This approach represents Good Participatory Practice.

ARTICLE 3
Feedback about the findings of the research must be given to local communities and research participants. It should be provided in a way that is meaningful, appropriate and readily comprehended.

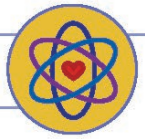
ARTICLE 4
Local researchers should be included, wherever possible, throughout the research process, including in study design, study implementation, data ownership, intellectual property and authorship of publications.

ARTICLE 5
Access by researchers to any biological or agricultural resources, human biological materials, traditional knowledge, cultural artefacts or non-renewable resources such as minerals should be subject to the free and prior informed consent of the owners or custodians. Formal agreements should govern the transfer of any material or knowledge to researchers, on terms that are co-developed with resource custodians or knowledge holders.

ARTICLE 6
Any research that uses biological materials and associated information such as traditional knowledge or genetic sequence data should clarify to participants the potential monetary and non-monetary benefits that might arise. A culturally appropriate plan to share benefits should be agreed to by all relevant stakeholders, and reviewed regularly as the research evolves. Researchers from high-income settings need to be aware of the power and resource differentials in benefit-sharing discussions, with sustained efforts to bring lower-capacity parties into the dialogue.

ARTICLE 7
It is essential to compensate local research support systems, for instance translators, interpreters or local coordinators, fairly for their contribution to research projects.

RESPECT



ARTICLE 8
Potential cultural sensitivities should be explored in advance of research with local communities, research participants and local researchers to avoid violating customary practices. Research is a voluntary exercise for research participants. It is not a mission-driven exercise to impose different ethical values. If researchers from high-income settings cannot agree on a way of undertaking the research that is acceptable to local stakeholders, it should not take place.

ARTICLE 9
Community assent should be obtained through recognized local structures, if required locally. While individual consent must not be compromised, assent from the community may be an ethical prerequisite and a sign of respect for the entire community. It is the responsibility of the researcher to find out local requirements.

ARTICLE 10
Local ethics review should be sought wherever possible. It is of vital importance that research projects are approved by a research ethics committee in the host country, wherever this exists, even if ethics approval has already been obtained in the high-income setting.

ARTICLE 11
Researchers from high-income settings should show respect to host country research ethics committees.

CARE

ARTICLE 12
Informed consent procedures should be tailored to local requirements to achieve genuine understanding and well-founded decision-making.

ARTICLE 13
A clear procedure for feedback, complaints or allegations of misconduct must be offered that gives genuine and appropriate access to all research participants and local partners to express any concerns they may have with the research process. This procedure must be agreed with local partners at the outset of the research.

ARTICLE 14
Research that would be severely restricted or prohibited in a high-income setting should not be carried out in a lower-income setting. Exceptions might be permissible in the context of specific local conditions (e.g. diseases not prevalent in high-income countries). If and when such exceptions are dealt with, the internationally acknowledged compliance commandment "comply or explain" must be used, i.e. exceptions agreed upon by the local stakeholders and researchers must be explicitly and transparently justified and made easily accessible to interested parties.

ARTICLE 15
Where research involvement could lead to stigmatization (e.g. research on sexually transmitted diseases), incrimination (e.g. sex work), discrimination or indeterminate personal risk (e.g. research on political beliefs), special measures to ensure the safety and wellbeing of research participants need to be agreed with local partners.

ARTICLE 16
Ahead of the research it should be determined whether local resources will be depleted to provide staff or other resources for the new project (e.g. nurses or laboratory staff). If so, the implications should be discussed in detail with local communities, partners and authorities and monitored during the study.

ARTICLE 17
In situations where animal welfare regulations are inadequate or non-existent in the local setting compared with the country of origin of the researcher, animal experimentation should always be undertaken in line with the higher standards of protection for animals.

ARTICLE 18
In situations where environmental protection and biorisk-related regulations are inadequate or non-existent in the local setting compared with the country of origin of the researcher, research should always be undertaken in line with the higher standards of environmental protection.

ARTICLE 19
Where research may involve health, safety or security risks for researchers or expose researchers to conflicts of conscience, tailored risk management plans should be agreed in advance of the research between the research team, local partners and employers.

HONESTY

ARTICLE 20
A clear understanding should be reached among collaborators with regard to their roles, responsibilities and conduct throughout the research cycle, from study design through to study implementation, review and dissemination. Capacity-building plans for local researchers should be part of these discussions.

ARTICLE 21
Lower educational standards, illiteracy or language barriers can never be an excuse for hiding information or providing it incompletely. Information must always be presented honestly and as clearly as possible. Plain language and a non-patronising style in the appropriate local languages should be adopted in communication with research participants who may have difficulties comprehending the research process and requirements.

ARTICLE 22
Corruption and bribery of any kind cannot be accepted or supported by researchers from any countries.

ARTICLE 23
Lower local data protection standards or compliance procedures can never be an excuse to tolerate the potential for privacy breaches. Special attention must be paid to research participants who are at risk of stigmatization, discrimination or incrimination through the research participation.

The code was drafted by the TRUST project under the leadership of Prof. Doris Schroeder. Existing guidelines have played an important role in formulating the code.

Please see the website for those we have taken substantial inspiration from and for further information on authorship and global engagement activities: http://www.globalcodeofconduct.org.

The Ethics and Research Integrity Sector, Directorate General for Research and Innovation, European Commission will propose the Code as a reference document for funding applications in the Framework Programme.

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COHRED Council on Health Research for Development

Inserm

PHDA Partners for Health and Development in Africa

UNESCO

TRUST Equitable Research Partnerships

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Appendix Q

Table Q.1.

12 Ethics Dumping Case Studies: Selected indicators for comparison:

(Schroeder, D., Cook, J., Hirsch, F., Fenet, S., & Muthuswamy, V. (Eds.). (2018))

Occurred / YES Questionable / conflicted / challenged Did not occur / NO or N/A	(12) Ethics Dumping Case Studies: Selected indicators for comparison: (Schroeder, D., Cook, J., Hirsch, F., Fenet, S., & Muthuswamy, V. (Eds.). (2018)											
THEME	Vulnerable Participants				Clinical Trials			Benefit Sharing	New & Emerging Technologies		Ethical & Governance Processes	
SITUATION												
Case study / Indicators	Social Science Research in a Humanitarian Emergency Context	International Genomics Research Involving the San People	Sex Workers in HIV/AIDS Research	Cervical Cancer Screening in India	Ebola Vaccine Trials	Hepatitis B Study with Gender Inequities	Healthy Volunteers in Clinical Studies	International Collaborative Genetic Research Project in China	Human Food Trial of a Transgenic Fruit	ICT and Mobile Data for Health Research	Seeking Retrospective Approval for a Study in Liberia	Compensation for Serious Adverse Events in Clinical Trials
Time period	Redacted	2010	Since 1985	Since 1998	2015	2014	Generic	1994-2007	2014	2006-11	2014	2006-13
Country	African country	Southern Africa	Kenya	India	African Country	Russia	LMICs	CHINA	USA	South Africa	Liberia	China
Indigenous Peoples / TK	X	✓	X	X	X	X	X	X	X	X	X	X
Human samples / data	Health-seeking behaviours	Genetic samples / data	Biological samples / data	Biological samples / data	Biological samples / data	Biological samples / data	Biological samples / data	Biological samples / data	Biological samples / data	Health data	Qualitative data	✓
Export of human samples / data	X	✓	Variable	✓	Actively unclear	✓	Variable	✓	X	Variable	✓	✓
Clinical Trials	X	X	✓	✓	✓	✓	✓	X	✓	X	X	✓
New / emerging technology	X	X	X	X	X	X	X	X	✓	Tele Health	X	X
External (HIC) research funding/design	International NGO (HIC). Dual purpose	Multiple international authors	Multiple international funders	Multiple international funders	✓	✓	Generic clinical studies	US University / science funder / pharma	HIC philanthropic funder	X	UN Public Health Agency	Global pharma company
Research discipline	Socio-anthropology	Human Genomics	Biomed (HIV-AIDS)	Biomed (Cancer)	Biomed (Ebola vaccine)	Biomed (Hep B vaccine)	Biomed	Biomed genetics	Biomed (Nutrition)	Service evaluation	Sociological research	Biomed (DVT drug)
LMIC host research partners	X	Limited	✓	✓	✓	✓	Variable	✓	X	✓	X	Unclear
Community involved in research design	X	X	Improving research literacy	X	X	X	X	X	X	X	X	X
Research enacted	✓	✓	✓	✓	Stopped during recruitment	Governance blocked trial	✓	✓	✓	✓	Retrospective ethical approval	✓

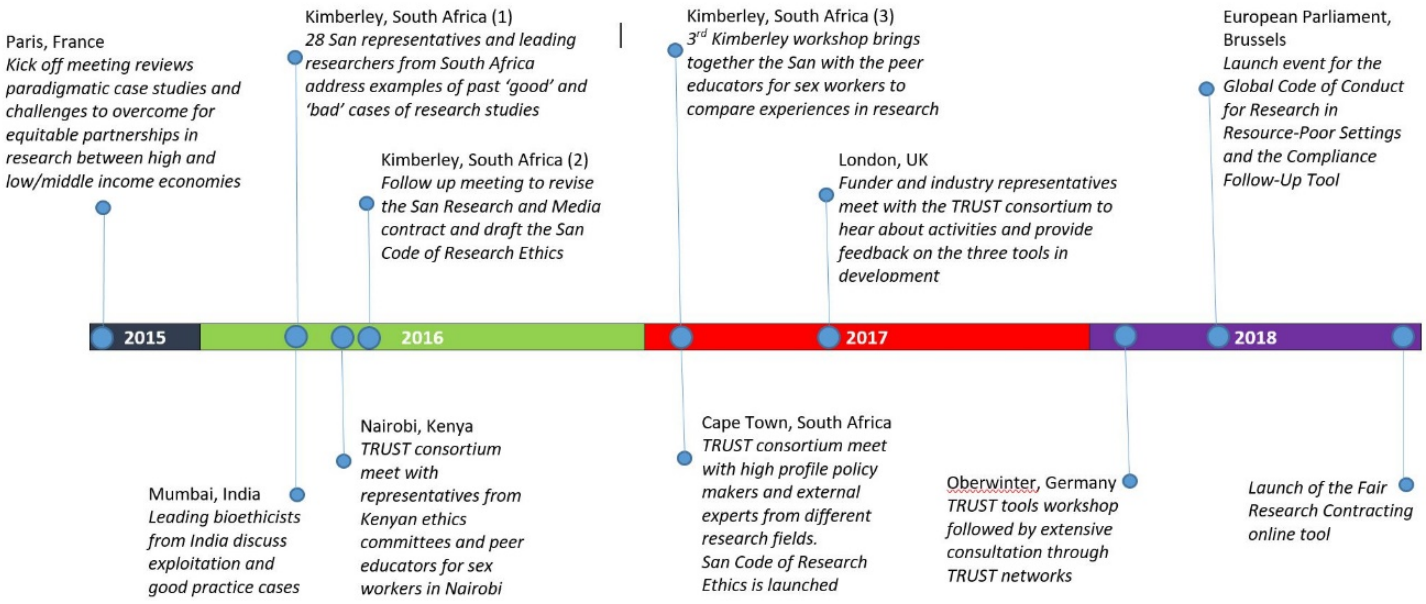
CONTEXT												
Case study / Indicators	**Social Science Research in a Humanitarian Emergency Context**	**International Genomics Research Involving the San People**	**Sex Workers in HIV/AIDS Research**	**Cervical Cancer Screening in India**	**Ebola Vaccine Trials**	**Hepatitis B Study with Gender Inequities**	**Healthy Volunteers in Clinical Studies**	**International Collaborative Genetic Research Project in China**	**Human Food Trial of a Transgenic Fruit**	**ICT and Mobile Data for Health Research**	**Seeking Retrospective Approval for a Study in Liberia**	**Compensation for Serious Adverse Events in Clinical Trials**
Vulnerable Participants re frameworks	**Research by humanitarian assistance NGO**	**✓**	**✓**	**✓**	**✓**	**Indirect involvement of female partners**	**✓**	**✓**	**✓**	**✓**	**Ebola survivors / family**	**X**
Risk of inducement for individuals to participate	**Provision of food**	**Comprehension compromised**	**Healthcare otherwise inaccessible**	**Healthcare otherwise inaccessible**	**Political announcements Health and financial benefits**	**Indirect involvement of female partners**	**✓**	**✓**	**✓**	**Lack of clear consent**	**✓**	**X**
Local / country resistance	**Conflict over revealing FGM findings**	**After the fact**	**X**	**X**	**✓**	**Governance blocked trial**	**X**	**X**	**✓**	**X**	**After the fact**	**X**
Stable / safe socio-political situation	**Refugee camp**	**Historic genocide; marginalisation**	**Illegal sex workers**	**Extreme rural poverty**	**✓**	**✓**	**✓**	**✓**	**✓**	**Variable**	**Ebola epidemic**	**✓**
Active individual risks identified	**FGM. Stigmatized displaced community**	**Breaches of privacy and pejorative use**	**Breaches of anonymity in stigmatized group**	**Risk from no treatment trial arm**	**Planned recruitment of children**	**Indirect involvement of female partners**	**Multiple trial registration**	**X**	**To female participants**	**Potential**	**Extreme distress**	**Victim of SAE**
Conflict over ownership of samples/data	**Conflict over revealing unexpected findings**	**✓**	**X**	**X**	**Actively unclear**	**Follow-up of indirect participants**	**X**	**✓**	**X**	**Potential**	**X**	**X**

FRAMEWORK												
Case study / Indicators	**Social Science Research in a Humanitarian Emergency Context**	**International Genomics Research Involving the San People**	**Sex Workers in HIV/AIDS Research**	**Cervical Cancer Screening in India**	**Ebola Vaccine Trials**	**Hepatitis B Study with Gender Inequities**	**Healthy Volunteers in Clinical Studies**	**International Collaborative Genetic Research Project in China**	**Human Food Trial of a Transgenic Fruit**	**ICT and Mobile Data for Health Research**	**Seeking Retrospective Approval for a Study in Liberia**	**Compensation for Serious Adverse Events in Clinical Trials**
International laws / regulations apply	Also Human Rights	Also Indigenous Research Protocols	✓	✓	✓	✓	✓	✓	✓	Governance unclear	✓	✓
Specific national laws apply	FGM illegal	X	Sex work illegal	X	Local age of consent was relevant	Related to immunization calendar	X	X	X	Governance unclear	Emergency research regulations	X
Functioning (ethical) governance regime	National REC approval failed to identify risks	4 x REC approvals failed to identify risks	High-functioning governance regime	Non-drug trial lacked oversight; now corrected	Initial national REC approval disguises lack of credible governance	Governance regime blocked trial		Appropriate ethical approval not obtained	✓	Governance unclear	Overwhelmed by Ebola emergency	Issues around governance of compensation for harm
Individual consent to access and use samples/data	Complexity over quality of consent	Complexity over quality of consent	✓	✓	Misleading	Follow-up of indirect participants	✓	Many participants did not consent	Unclear	Lack of clear consent	Appropriate ethical approval not obtained	✓
Individual consent to export samples/data	Disagreement re revealing human rights abuses	Lack of clarity about intentions	Unclear	Unclear	X	X	✓	Many participants did not consent	X	Unclear	Appropriate ethical approval not obtained	✓
Political / regulatory intervention	X	X	X	Non-drug trial lacked oversight; now corrected	✓	Governance regime blocked trial	X	Sample export restricted later	X	X	Denial of retrospective ethical approval blocked	Compensation paid direct by company not insurers

Table excludes exploratory case study, "Safety and Security Risks of CRISPR / Cas 9", and animal research case study, "The use of non-human primates in research".

Appendix R

TRUST Timeline of Stakeholder Engagement October 2015 – September 2018



The TRUST project timeline October 2015 – September 2018

Appendix S

Table S.1. *(3) Ethics Dumping Case Studies: Selected Gender indicators for comparison 2020*

Identified as mild gender issue Identified as moderate gender issue Identified as strong gender issue Not identified as a gender issue	**(3) Ethics Dumping Case Studies: Selected Gender indicators for comparison: (Cook, J., 2020).**		
SITUATION			
Final theme in Ethics Dumping	**Vulnerable Participants**	**New & Emerging Technology**	**Clinical Trials**
Case Study	**Cervical Cancer Screening in India**	**Human Food Trial of a Transgenic Fruit**	**Hepatitis B Study with Gender Inequities** **(excluded from Cook (2020) as trial not approved)*
Time period	Since 1998	2014	2014
Country	India	USA	Russia
100% female participants	✓	✓	✓
Human samples/data	Biological samples/data	Biological samples/data	Biological samples/data
Export of human samples/data	✓	X	✓
Clinical trials	✓	✓	✓
New & Emerging Technology	X	✓	X
External (international HIC) research funding & design	Multiple international science / philanthropic funders (including BMGF)	HIC philanthropic funder (BMGF)	External sponsor (unidentified)
Research discipline	Biomedical science (Cancer)	Biomedical science (Nutrition)	Biomedical science (vaccine)
LMIC host research partners	✓	X	✓
Involvement of community/participants in research design	X	X	X
Research enacted	✓	✓	Governance regime blocked trial

CONTEXT			
	Cx Cancer	**Transgenic fruit**	**Hepatitis B**
Vulnerable participants re frameworks	✓	✓	Governance regime blocked trial
Risk of inducement/coercion for individuals to participate compromising consent	Otherwise inaccessible healthcare	$900 paid to participants	Indirect involvement of female partners
Local/country resistance to planned activities	X	Increasingly less prominent	Governance regime blocked trial
Stable/safe socio-political situation	Extreme rural poverty; women always poorer	X	✓
Active individual risks identified	Risk from no treatment trial arm	To female participants	Indirect involvement of female partners
Conflict over nature of ownership of samples/data	X	X	Follow-up of indirect participants without consent
FRAMEWORK			
	Cx Cancer	**Transgenic fruit**	**Hepatitis B**
Specific national laws apply	X	X	✓
Functioning (ethical) governance regime	Non-drug trial lacked oversight - now corrected	Failed to address gender dimension	Governance regime blocked trial
Individual consent to access and use samples/data	Illiteracy rates worse for women	$900 paid to participants	Follow-up of indirect participants without consent
Individual consent to export samples/data	Unclear. Illiteracy rates worse for women	X	X
Political / regulatory intervention	Non-drug trial lacked oversight. Now corrected.	X	Governance regime blocked trial

Appendix T

Table T.1.

*2021: Reflection on comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) compared to curated analysis (Cook Lucas & Castillo, 2013): Traditional Knowledge Cases: San-*Hoodia */ Kani (Jeevani) / Nigeria – Niprisan*

Traditional Knowledge Cases: San-Hoodia / Kani - Jeevani / Nigeria - Niprisan. 2021: Reflection on comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) compared to curated analysis (Cook Lucas & Castillo, 2013)			Identified as mild gender issue Identified as moderate gender issue Identified as strong gender issue
Original data from Appendix O: *Comparison of indicators selected for gender analysis 2009 / 2013* was binary coded 'identified / not as gender issue'. Here I code this - mild - moderate - strong gender issue and reflect on this	**(Alvarez Castillo & Cook Lucas, 2009)**	**(Cook Lucas & Castillo, 2013)**	**2021: Reflections on gender dimensions**
SITUATION	**2009**	**2013**	**REFLECTIONS 2021**
Country	✓	✓	**I would also analyse LMIC setting against GCC and ethics dumping risks, as a gender issue.**
Indigenous Peoples (IP)	**Strong emphasis**	**Strong emphasis**	**2021: GCC would also apply**
Pharma products from plant TK	**Emerging acknowledgement of gender-based knowledge**	**Developed acknowledgement of gender-based knowledge**	**Stronger acknowledgement of gender-based knowledge systems**
External (international) research funding & design	**X**	**Discussed emerging funder expectations.**	**I would now expect/assume funder frameworks to require gender considerations of various research aspects and would analyse against these**
Local / national host research partners	**X**	**X**	**GCC expectation for this now applies**
IPs / TK holders involved in research design	✓	✓	**2021: not to do this would be contra the GCC**
IPs / TK holders involved in research project	✓	✓	**2021: not to do this would be contra the GCC**
Research enacted	**X**	**X**	**I would now analyse a halted study for gender issues**

CONTEXT	2009	2013	REFLECTIONS 2021
Local resistance to planned activities	Only data from one case - collapsed into framework themes	Emphasis on empowering women to say 'no' independently	I consider this a significant area for analysis as it may obscure gender dimensions (Cook, 2020) or reveal dimensions unseen by the researcher (me)
Organised resistance within country to planned activities	Only data from one case - collapsed into framework themes	Emphasis on empowering women to say 'no' independently	I consider this a significant area for analysis as it may obscure gender dimensions (Cook, 2020) or reveal dimensions unseen by the researcher (me)
International support for resistance to planned activities	Gender dimension notably missing, hence analysis here	E.g., NGO action not addressed here	I consider this a significant area for analysis as it may obscure gender dimensions (Cook, 2020) or reveal dimensions unseen by the researcher (me)
Conflict between concepts/governance of community/territories (land)	✓	A more nuanced approach to IP cultures was included based on new data	I would see this as a gender issue and look at differentials
Stable / safe political situation	✓	✓	I would directly address gender aspects of this - does situation affect women differently? What is women's situation?
Conflict over nature of knowledge / IPR	Noted that Nigerian women with TK interest were excluded but this was not explored	A more nuanced approach to IP cultures was included based on new data	I would see this as a gender issue and look at differentials

FRAMEWORK	2009	2013	REFLECTIONS 2021
R&D intention to abide by CBD-style benefit sharing principles	X	X	N/A - Not to do so would be contra national / international laws under CBD
National CBD policy framework in place	X	X	X
Functioning implementation of relevant existing policies	Situated critique applied	Strong focus	✓
Adequate processes and structures for negotiating CBD-style benefit sharing	Regarding women's representation/participation in decision-making. Did not include data on differential gender opinions (Vermeylen, 2009b)	A strong focus on this - Nagoya Protocol applied	2021: Nagoya Protocol and GCC would also apply
Identification of TK holders	Regarding women's representation/participation in decision-making	Nagoya Protocol applied	2021: GCC would also apply
Consent from TK holders to access biodiversity	Regarding women's representation/participation in decision-making	Additional emphasis on empowering women to say 'no' independently. Nagoya Protocol applied.	2021: GCC would also apply
Benefit sharing agreement reached	Regarding women's participation in management, distribution and use of benefits	Synthesis of 2009 indicators re better targeting funds	2021: GCC would also apply
Structure for payment of benefits	Regarding women's control of and access to the benefits (given exclusion from previous stages)	Synthesis of 2009 indicators - Nagoya Protocol applied	2021: GCC would also apply
Adequate governance structure for distribution of benefits	Regarding women's participation in management, distribution and use of benefits	Synthesis of 2009 indicators - Nagoya Protocol applied	2021: GCC would also apply
Benefits paid	Regarding women's control of and access to the benefits	This was further critiqued here	2021: GCC would also apply

Appendix U

Table U.1.

2021: Reflection on comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) compared to curated analysis (Cook Lucas & Castillo, 2013): Human Samples Cases: Iceland / Kenya

Human Samples Cases: Iceland / Kenya. 2021 Reflection on comparison of indicators selected for gender analysis (Alvarez Castillo & Cook Lucas, 2009) compared to curated analysis (Cook Lucas & Castillo, 2013)			Identified as mild gender issue Identified as moderate gender issue Identified as strong gender issue
Original data from Appendix O: Comparison of indicators selected for gender analysis 2009 / 2013 was binary coded 'identified / not as gender issue'. Here I code this - mild - moderate - strong gender issue and reflect on this	**(Alvarez Castillo & Cook Lucas, 2009)**	**(Cook Lucas & Castillo, 2013): Gender dimensions considered in broader analysis**	**2021: Reflections on gender dimensions**
SITUATION	**2009**	**2013**	**REFLECTIONS 2021**
Country	✓	✓	**I would also analyse LMIC setting against GCC and ethics dumping risks, as a gender issue.**
Indigenous Peoples (IP) / Traditional Knowledge (TK)	**Strong emphasis**	**This is developed with new data**	**2021: GCC would also apply**
Human samples / data	**X**	**Not explicitly presented as gender issue**	**I would now look at this carefully as gender issue**
External (international) research funding & design	**n/a**	**2013 I discussed emerging funder expectations.**	**I would now expect/assume funder frameworks to require gender considerations of various research aspects and would analyse against these**
Local / national host research partners	**X**	**X**	**This would relate to GCC so would be addressed - gender impact might relate more to researchers**
Clinical trials	**n/a**	**Not explicitly presented as gender issue**	**In 2021 I consider this an area for gender analysis**
Export of human samples / data	**n/a**	**X**	**I am currently considering ways to genderise this issue in an accessible way using ecofeminist understandings.**
Research enacted	**X**	**X**	**I would now analyse a halted study for gender issues - see Ethics Dumping case (Kubar 2018)**

CONTEXT	2009	2013	REFLECTIONS 2021
Vulnerable Participants re frameworks	Addressed in general terms	Directly addressed re gendered dimensions	2021: I consider any single gender cohort to be a gender issue and am developing this
Organised resistance within country to planned activities	Strong resistance in Iceland indicated potential gender dimension	Strong resistance in Iceland indicated potential gender dimension	I consider this a significant area for analysis as it may obscure gender dimensions (Cook, 2020) or reveal dimensions unseen by the researcher (me)
International support for resistance to planned activities	Very few discussions considered gender analysis in Majengo, probably due to single gender cohort.	Not explicitly presented as gender issue	I consider this a significant area for analysis as it may obscure gender dimensions (Cook, 2020) or reveal dimensions unseen by the researcher (me)
Risk of inducement for individuals to participate compromising consent	Not addressed directly	Gendered aspects addressed e.g. individual v community consent	I would emphasize gendered nature of vulnerabilities
Stable / safe political situation	I first introduced the idea that it was a gender issue when cohort is all female	✓	I would directly address gender aspects of this - does situation affect women differently? What is women's situation?
Conflict over nature of knowledge / IPR	Not addressed directly as gender issue	Not addressed directly as gender issue	I am currently considering ways to genderise this issue in an accessible way using ecofeminist understandings.

FRAMEWORK	2009	2013	REFLECTIONS 2021
Benefit sharing intentions	n/a	Addressed contextually, e.g. exclusion of women in Nigerian case	I now consider this to be a potential gender issue in every case
International laws / regulations apply	Directly addressed	Relevance of international framework developed strongly	Relevance of international frameworks of increasing importance along with awareness of developments which may have differential impacts.
Functioning implementation of relevant existing policies	Directly addressed	Directly addressed and expanded	This is a crucial area for analysis of e.g., ethics dumping or exploitative research
Potential alternative benefits in accordance with governance regimes	Not addressed directly	Synthesis of 2009 indicators re better targeting funds	The potential for this is ever-expanding
Individual consent to access and use samples/data	Not addressed directly	✓	2021: GCC would also apply
Benefit sharing agreement reached with governance structure and payment schedule	Regarding women's representation/participation in decision-making, management, distribution and use of benefits	Extended discussion of participation and representation in decision-making in multi-level contexts	2021: GCC would also apply
CBD-style benefit sharing appealed to	n/a	n/a	This is an area I would like to explore because of the ecofeminist intersections
Dramatic parliamentary / legal intervention	Women's representation in parliament addressed	Women's representation in parliament addressed	If this occurred I would look at gender angle around e.g., issues raised, who by etc. as well as women's representation in parliament
Benefits paid	n/a no benefits paid	n/a no benefits paid	2021: GCC would also apply

Full Academic Publications List – Julie Cook[1]

(December 2021)

Edited Books (peer reviewed)

Schroeder, D., **Cook, J**., Hirsch, F., Fenet, S., & Muthuswamy, V. (Eds.). (2018). *Ethics dumping: Case studies from North-South research collaborations*. SpringerOpen: at http://www.springer.com/in/book/9783319647302

Schroeder, D., & **Cook Lucas, J**. (Eds.). (2013). *Benefit sharing in theory and practice: From biodiversity to human genetics.* Springer.

Book Chapters (peer reviewed)

Cook, J., Chatfield, K., & Schroeder, D. (2018). Promoting equity and preventing exploitation in international research: The aims, work and output of the TRUST project. In Z. Koporc (Ed.)*, Ethics and integrity in health and life sciences research* (pp. 11-31). Emerald.

Schroeder, D., **Cook, J**., Hirsch, F., Fenet, S., & Muthuswamy, V. (2018). Ethics dumping: Introduction. In D. Schroeder, **J. Cook**., F. Hirsch, S. Fenet, & V. Muthuswamy (Eds.), *Ethics dumping: Case studies from North-South research collaborations* (pp. 1-8). SpringerOpen: at http://www.springer.com/in/book/9783319647302

Cook, J. (2016). (Translated by Noteris, E.). La colonisation de l'écoféminisme par la philosophie. In E. Hache (Ed.), *Reclaim - Recueil de textes écoféministes* (pp. 285-318). Cambourakis.

Schroeder, D., & **Cook Lucas, J**. (2013). Benefit sharing: From biodiversity to human genetics – an introduction. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 1-7)*.* Springer.

Cook Lucas, J., Schroeder, D., Chennells, R., Chaturvedi, S., & Feinholz, D. (2013). Sharing traditional knowledge: Who benefits? Cases from India, Nigeria, Mexico and South Africa. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 65-93)*.* Springer.

Cook Lucas, J., Schroeder, D., Arnason, G., Andanda, P., Kimani, J., Fournier, V., & Krishnamurthy, M. (2013). Donating human samples: Who benefits? Cases from Iceland, Kenya

[1] Between 2000 and 2015 I published as Julie Cook Lucas.

and Indonesia. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 95-127). Springer.

Cook Lucas, J. & Castillo, F. (2013). Fair for women? A gender analysis of benefit sharing. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 129-151). Springer.

Schroeder, D. & **Cook Lucas, J**. (2013). Towards best practice for benefit sharing involving access to human biological resources: Conclusions and recommendations. In D. Schroeder & **J. Cook Lucas** (Eds.), *Benefit sharing in theory and practice: From biodiversity to human genetics* (pp. 217-229). Springer.

Feinholz Klip, D., Garcia Barrios, L., & **Cook Lucas, J**. (2009). The limitations of good intent: Problems of representation and informed consent in the Maya ICBG project in Chiapas, Mexico. In R. Wynberg, D. Schroeder & R. Chennells (Eds.)*, Indigenous peoples, consent and benefit sharing: Lessons from the San-Hoodia case* (pp. 315-331). Springer.

Journal Articles (peer reviewed)

Chatfield, K., Schroeder, D., Guantai, A., Bhatt, K., Bukusi, E., Adhiambo Odhiambo, J., **Cook, J**., & Kimani, J. (2021). Preventing ethics dumping: The challenges for Kenyan research ethics committees. *Research Ethics, 17*(1), 23-44. Published online May 24, 2020. Open access at https://journals.sagepub.com/doi/full/10.1177/1747016120925064

Miller, C., **Cook, J**., Gibson, J., Watkins, C. L., & Jones, S. (2020). Clinical academic research internships for nurses, midwives and allied health professionals: A qualitative evaluation. *Nurse Researcher*. Online publication, 2020, September, 3. https://journals.rcni.com/nurse-researcher/evidence-and-practice/clinical-academic-research-internships-for-nurses-midwives-and-allied-health-professionals-a-qualitative-evaluation-nr.2020.e1724/full

Cook, J. (2020). Avoiding gender exploitation and ethics dumping in research with women. *Cambridge Quarterly of Healthcare Ethics, 29*(3), 470-479.
DOI: https://doi.org/10.1017/S0963180120000213

Moran, V.H., Thomson, G., **Cook, J**., Storey, H., Beeson, L., MacArthur, M., & Wilson, M. (2019). Qualitative exploration of women's experiences of intramuscular pethidine or remifentanil patient-controlled analgesia for labour pain. *BMJ Open 2019(9):e032203.* DOI:10.1136/ bmjopen-2019-032203

Jones, S.P., Miller, C., Gibson, J.M.E., **Cook, J**., Price, C., & Watkins, C.L. (2018). The impact of education and training interventions for nurses and other health care staff involved in the delivery of stroke care: An integrative review. *Nurse Education Today*, *61*, 249-257.
DOI: 10.1016/j.nedt.2017.11.024

Lightbody, C.E., Clegg, A., Patel, K., **Cook Lucas, J**., Storey, H., Hackett, M.L., & Watkins, C.L. (2017). Systematic review and meta-analysis of psychosocial risk factors for stroke. *Seminars in Neurology*, *37*(03). 294-306. DOI: 10.1055/s-0037-1603758

Alvarez Castillo, F., & **Cook Lucas, J**. (2009). Fairness and gender in benefit sharing: Learning from the Kani, San, Nigerian, Kenyan and Icelandic cases for moving forward. *UP Manila Journal*, Special Issue, 140-173.

Alvarez-Castillo, F., **Cook Lucas, J**., & Cordillera Castillo, R. (2009). Gender and vulnerable populations in benefit sharing: an exploration of conceptual and contextual points. *Cambridge Quarterly of Health Care Ethics, 18*(2), 130-37. DOI: 10.1017/S0963180109090227

Cook, J. (1998). The philosophical colonization of ecofeminism. *Environmental Ethics*, *20*(3), 227-246. DOI: 10.5840/enviroethics199820316

Cook, J. (1991). Toxic shock syndrome: Toxic shock syndrome, though rare, can kill. *Primary Health Care*. 1 (6). 22-23. DOI: 10.7748/phc.1.6.22.s21

Editorials

Schroeder, D., & **Cook, J**. (Eds.). (2019). Looking for justice from the health industry [Special section]. *Cambridge Quarterly of Health Care Ethics*. 28 (1). 121-123. DOI: 10.1017/S0963180118000452

Funded Project Reports

Thomson, G., **Cook, J.,** Jassat, R., Crossland, N., Balaam, M. C., Palmer, S., & Gerrard, S. (2021). *ENABLE: Exploring the perinatal needs and care of BAME women in Lancashire and South Cumbria*. Report for NHS Local Maternity Services; not publicly available.

Wilson, N., **Cook, J**., & Thetford, C. (2019). *Evaluation of an integrated palliative service providing specialist care for heart failure patients with a life limiting illness*. Report for St Catherine's Hospice; not publicly available.

Chatfield, K., Coles, D., Chennells, R., Schroeder, D., & **Cook, J**. *Complaints procedures for collaborative research in resource-poor settings*. http://www.globalcodeofconduct.org/learning-materials/

Chatfield, K., Biernacki, O., Schroeder, D., Cavallaro, F., **Cook, J**., N'Diaye, D., Bompart, F., Chennells, R., Toohey, J., Wynberg, R., van Niekirk, J., & Ait Aissa, M. (2018). *Research with, not about, communities: Ethical guidance towards empowerment in collaborative research*. http://trust-project.eu/new-publication-research-with-not-about-communities/

Schroeder, D., **Cook Lucas, J**., Fenet, S., & Hirsch F. (Eds.). (2016). *Ethics dumping: Paradigmatic case studies*. http://trust-project.eu/deliverables-andtools/

Benjamin, C., Boudioni, M., Ward, H., Marston, E., Lindenmeyer, A., Bangee, M., **Cook Lucas, J**., Leavey, R., Caulfield, M., Fowler, T., Lucassen, A., Rennie, F., Riley, L., Parker, M., Parry, V., Thomas, E., Patch, C., Cranage, A., & Dinh, L. (2016). *Project report - NHS Genomic Medicine Centres: Process and participant materials used in the 100,000 Genomes project.* Genomics England.

Cook Lucas, J. (2012). Civil society, Non-Governmental Organizations and participatory TA. In *Ethics State of the Art, EU Debate*. www.uclan.ac./gest

Andanda, P., & **Cook Lucas, J**. (2007). *Majengo HIV/AIDS research case*. www.uclan.ac.uk/genbenefit

Code

Global code of conduct for research in resource-poor settings. (2018). Schroeder, D., Adhiambo, J., Altare, C., Alvarez-Castillo, F., Andanda, P., Bompart, F., Cavallaro, F.I., Chatfield, K., Chennells, R., Coles, D., **Cook, J**., Dammann, J., Azra Dean, A., Feinholz, D., Fenet, S., Hirsch, F., Ijsselmuiden, C., Kamat, S., Kasiba, R., Kiai, J., Kimani, J., Kritikos, K., Kubar, O., Kumar, N.K., Ladikas, M., Leisinger, K.M., Louw, C., Luc, G., Mahongo, M., Makanga, M., Morton, D., Munuo, N., Muthuswamy, V., Mwaura, P., N'diaye, D., van Niekerk, J., Njoki, C., Postulart, H., Rath, J., Shiwarra, Z., Schmitt, K.M., Shuchman, M., Singh, M., Sirugo, G., Snyders, L., Steenkamp, A., Swart, H., Tavlaki, E., Thatte, U., Toohey, J., Tukai, A., Waithera, J., Wathuta, J., Woodgate, P., Wynberg, R., & Zhao, Y. http://www.globalcodeofconduct.org/

Posters

Jarvis, K., Branscombe, N., **Cook, J**., Haworth, J., Thetford, C., Rose, A., & Stockley, R. (2021). An early implementation study of digital technology: Virtual Engagement Rehabilitation Assistant (VERA). *UK Stroke Research Forum, December 2021.*

Wilson, N., **Cook, J**., Thetford, C., Bacon, A., & Fletcher, A. (2020, 18 February). Evaluation of an integrated palliative service for heart failure patients with a life limiting illness. Sustainable development Goal 3. Presented at *Health Research with Real Impact*, Faculty of Health & Wellbeing 6th International Conference, University of Central Lancashire. First Prize poster presentation.

Wilson, N., **Cook, J**., Thetford, C., Bacon, A., & Fletcher, A. (2020, 13 January). Evaluation of an integrated palliative service for heart failure patients with a life limiting illness. *Research @ UCLan*, University of Central Lancashire.

Bacon, A., Fletcher, A., Wilson, N., **Cook**, J., Thetford, C. (2019, November 20-22). Integrated palliative heart failure service, St Catherine's Hospice, Preston. Presented at *Dying for change; Evolution and revolution in palliative care,* Hospice UK Conference, Liverpool.

Jones, S., Miller, C., **Cook Lucas, J**., Gibson, J., Leathley, M., Price, C., & Watkins, C. (2014). The impact of educational interventions for health professionals on stroke patient care: an integrative review. *International Journal of Stroke*, *9*(Suppl 4), 21.

Commissioned Book Reviews

Cook Lucas, J. (2010). Review: Salleh, A. (Ed.). (2009). Eco-sufficiency and global justice: Women write political ecology. *Environmental Values*, *19*(1), 136-139.

Cook Lucas, J. (2009). Review: Kheel, M. (2007). Nature ethics: An ecofeminist perspective. *Environmental Values*, *18*(2), 247-2499.

Cook Lucas, J. (2004). Review: Gates, B. T. (Ed.). (2002). In nature's name: An anthology of women's writing and illustration, 1780-1930. *Environmental Values, 13*(3), 412-414**.**

Cook, J. (2000). Review: Cuomo, C. J. (1998). Feminism and ecological communities: an ethic of flourishing. *Environmental Values, 9*(3), 398-399.

Cook, J. (1994). Review: Mellor, M. (1992). Breaking the boundaries: Towards a feminist green socialism. *Environmental Values, 3*(3), 278-279.

Cook, J. (1990). Review: Adams, C. J. (1990). The sexual politics of meat. *The Vegan*, 6(3), 24.