

# RIGHTS-BASED KNOWLEDGE CREATION IN SEXUAL AND REPRODUCTIVE HEALTH

AN INTRODUCTORY GUIDE

*Written by B. Subha Sri*



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Sexual and Reproductive Health Matters (SRHM) is an organisation that promotes sexual and reproductive health and rights globally.

This guide has been produced as resource material for the mentoring programme on rights-based knowledge creation in sexual and reproductive health, conducted by the South Asia Hub of SRHM. It is meant to provide an introduction for researchers, practitioners and activists on how to use a human rights-based approach to knowledge creation in the area of sexual and reproductive health.

## Acknowledgements

**Written by B. Subha Sri**

Several people have contributed at different stages of developing this guide.

Sapna Mishra (Assistant Professor, School of Development, Azim Premji University, India) assisted with the literature review that forms the basis of the examples and resources provided in this guide.

Earlier drafts received input from mentors in the South Asia mentoring programme including Sivakami M (Professor, School of Health Sciences, Tata Institute of Social Sciences, India), Dipika Jain (Director, Centre for Justice, Law and Society (CJLS), Jindal Global Law School, NCR Delhi, India), Mahesh Puri (Co-Director Center for Research on Environment Health & Population Activities (CREHPA), Nepal), and Kausar S Khan (Advisor Community Engagement, Interactive Research & Development, Visiting faculty Aga Khan University, Pakistan).

From SRHM, TK Sundari Ravindran (Senior Editor) and Eszter Kismódi (Chief Executive) helped conceptualize this guide, and reviewed and provided extensive comments on earlier drafts. In addition, Emma Pitchforth (Executive Editor) provided editorial input, Sanjeeta Gawri reviewed drafts and assisted with the operational development of the guide, Pathika Martin (Monitoring Editor) copyedited the document, and Alexane Bremshey (Communications Manager) designed the publication.

This guide also draws from published work in this area from several authors and thanks are due to them and to the communities that formed a part of these studies.

To cite this guide: B. Subha Sri. Rights-based knowledge creation in sexual and reproductive health: an introductory guide. Sexual and Reproductive Health Matters. 2022. [http://www.srhm.org/rights-based-knowledge-creation\\_srhm2022/](http://www.srhm.org/rights-based-knowledge-creation_srhm2022/)

# INTRODUCTION TO THE HUMAN RIGHTS-BASED APPROACH

Human rights-based approaches to the creation of knowledge[1] involve application of human rights principles to both the content and process of knowledge creation. Human rights-based approaches have special significance for the sexual and reproductive health and rights (SRHR) of all people, in particular for women and girls, people living with disability, lesbian, gay, bisexual, trans, queer or Intersex (LGBTQI) populations, refugees, migrants and other marginalised populations. Violation of human rights is pervasive at different levels in matters related to sexuality and reproduction – from state policies that are blind to human rights, to social norms and practices that violate the human rights of marginalised communities. Applying a human rights lens to knowledge creation enables all, and especially marginalised populations, with capacities and resources to claim their SRHR in a way that empowers them, while simultaneously providing the opportunity to hold duty-bearers accountable to fulfil their human rights obligations.

A human rights-based approach to sexual and reproductive health (SRH) is based on the principles laid out in various international and regional human rights treaties and consensus documents, as well as in national constitutions and laws. These include the rights to life, security, to be free from inhumane and degrading treatment, non-discrimination, autonomy, health, privacy, confidentiality, freedom of assembly and participation. These rights are indivisible and interdependent. It means that SRH research designs and evaluations always need to incorporate these human rights principles, while the processes of research and other types of knowledge creation need to be inclusive, participatory and accountable to the needs of the communities involved in the research.



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[1] We use the term “knowledge creation” here to denote not only the production of academic knowledge through formal academic research, but also a wider set of different forms of knowledge produced through experiential learning from implementation of programmes, legal and policy analyses, and community-led knowledge production through documentation of experiences, community-based initiatives, violation of rights, and abuses.

**Human rights are indivisible and interdependent.** For example, lack of quality emergency obstetric care services or denial of abortion often lead to maternal deaths and morbidity, which in turn constitutes a violation of the right to health, life or security. In certain circumstances, this can amount to torture or cruel, inhuman or degrading treatment when the lack of quality services is paired with, for example, obstetric or other type of violence.

In addition to the human rights standards elaborated by international, regional and national human rights bodies, consensus documents and public health standards provided by the World Health Organization, other international public health entities, and regional or national public health authorities, provide specific guidance for an integrated health and rights approach for SRH.

Based on these health and human rights standards, in this guide, we discuss the following human rights and human rights-based principles as underpinning rights-based knowledge creation:

1. The right to non-discrimination and equality
2. The right to the highest attainable standard of health including availability, accessibility, acceptability, and quality of services
3. The right to autonomy and self-determination, including informed decision-making
4. The right to privacy and confidentiality
5. Accountability, including transparency
6. The right to participation

Each of these principles is explained below.

### THE RIGHT TO NON-DISCRIMINATION AND EQUALITY



All individuals and groups should be able to enjoy equal access to the same range, quality and standard of SRH facilities, information, goods and services, and to exercise their rights to SRH without experiencing any discrimination based on race, colour, ethnicity, caste, language, religion, national origin, age, sex, sexual orientation, gender identity, health status, disability, social and economic and other status. Laws, policies, programmes and services, as well as research, should factor in and address various barriers to the enjoyment of SRHR, especially as they are relevant to vulnerable and marginalised populations.

**Non-discrimination and equality require not only legal and formal equality but also substantive equality.** Substantive equality requires that the distinct SRH needs of particular groups, as well as any barriers that particular groups may face, be addressed and given tailored attention. For example, persons with disabilities should be able to enjoy not only the same range and quality of SRH services but also those services which they would need specifically because of their disabilities.

Use of an **intersectionality lens to non-discrimination would** help to understand how the multiple axes of inequity operate together and often exacerbate each other. For example, a poor dalit woman not only faces the independent effects of poverty, caste and gender, but these determinants act together to create effects that are much more than the sum of their individual effects. Special consideration of intersectionality is needed especially when studying marginalised populations.

## THE RIGHT TO NON-DISCRIMINATION AND EQUALITY

The right to the highest attainable standard of sexual and reproductive health extends beyond sexual and reproductive health care to the underlying determinants of sexual and reproductive health.

The right to the highest attainable standard of health encompasses four key domains.

- 1. Availability:** Adequate health care infrastructure (e.g. hospitals, community health facilities, trained healthcare professionals); goods (e.g. drugs, equipment, supplies); human resources (healthcare providers and support staff); basic amenities such as safe drinking water and sanitation; information and services on SRH must be available in sufficient quantity within a state, and distributed equitably across geographical areas and communities.
- 2. Accessibility:** All health care must be accessible to all without discrimination. No one shall be denied preventive, promotive or curative health care including contraceptive services and allied SRH services that they need. Accessibility has three overlapping dimensions:
  - *Physical accessibility* - This would include consideration of geographical distances, terrain, time taken to reach a facility. This would also include the time at which services are available.
  - *Economic accessibility or affordability* - Essential goods and services, for example, must be provided at no cost or based on the principle of equality to ensure that individuals (and families) are not disproportionately burdened with health expenses to protect their SRH.
  - *Access to information* – Information related to SRH and SRH care must be available to all in a manner that is easily accessible and understood.

**3. Acceptability:** Sexual and reproductive health information and services must be respectful of human rights and medical ethics, the dignity and culture of individuals, minorities, peoples and communities, and sensitive to gender, age, disability, sexual diversity. However, acceptability, or lack of it, to a particular dominant group cannot be used to justify the refusal to provide tailored facilities, goods, information and services to specific marginalised groups. For example, SRH services cannot be denied to LGBTQI populations or single unmarried women because it is against prevailing political ideology.

Lack of cultural acceptability cannot be used to justify refusal to provide services to specific groups, e.g. LGBTQI populations.

**4. Quality:** Facilities, goods, information and services related to SRH must be of good quality, meaning that they are evidence-based and scientifically and medically appropriate and up-to-date. This requires trained and skilled healthcare personnel and scientifically approved and appropriate drugs and equipment. The failure or refusal to incorporate technological advances and innovations in the provision of SRH services, such as medication for abortion, assisted reproductive technologies and advances in the treatment of HIV and AIDS, jeopardises the quality of care. In addition, healthcare facilities should be characterised by positive attitudes on the part of providers, informed decision-making on the part of the client and provided in a timely and safe manner, and to the client's satisfaction.

The right to the highest attainable standard of health, including SRH, includes not only the absence of disease and infirmity and the right to the provision of preventive, curative and palliative health care. The right to health also includes the right to access the underlying determinants of health. This would imply examining the role of access to safe and potable water and adequate sanitation in ensuring menstrual hygiene, adequate food and nutrition in protecting the right to maternal health, and access to comprehensive SRH and rights-related education and information as a facilitator of effective protection from all forms of violence.

## THE RIGHT TO AUTONOMY AND SELF-DETERMINATION

The right to autonomy and self-determination is a fundamental human right expressed in various international treaties, national constitutions and human rights and health care laws. The human rights principle of autonomy is expressed through free, full and informed decision-making. Respect and protection of autonomy and self-determination includes giving each person the opportunity to make autonomous sexual and reproductive choices, to choose or refuse SRH services and protect their physical and mental integrity from violence and forced interventions, such as forced sterilisation, Female Genital Mutilation or involuntary intersex surgery.

**Full and informed decision-making**[2] is an expression of autonomy, upheld by medical ethics and international human rights law. In order to make an informed decision about their SRH, comprehensive information, counselling and support should be accessible to all, including to people with disabilities, indigenous peoples, ethnic minorities, people living with HIV, and transgender and intersex people. Censoring, withholding or intentionally misrepresenting SRH information can put health and basic human rights in jeopardy.

The right to autonomy also entails the right to access information regarding one's health and includes **access to medical records**. All persons are entitled to know what information has been collected about their own health. Where individuals cannot access their medical records, this may make it hard for them to get information about their health status or to receive a second opinion or follow-up care, and can block their access to justice.

### THE RIGHT TO PRIVACY AND CONFIDENTIALITY

The **right to privacy** means that individuals should not be subject to interference with their privacy, and they should enjoy legal protection in this respect. Sexual and reproductive health involves many sensitive issues that are not widely discussed within families or communities, and health workers are often entrusted with very personal information by their patients. **Confidentiality**, which implies the duty of providers to keep secret or private the medical information they receive from patients and to protect an individual's privacy, has an important role to play in SRH. If people feel that confidentiality and privacy are not guaranteed in the healthcare environment, they may decide not to seek services, thus jeopardising their own health and potentially that of others. This is often the case for vulnerable groups such as adolescents. Healthcare providers have an obligation to keep medical information confidential, both written records and verbal communications. Such information may only be disclosed with the consent of the client. Privacy is also key to protecting the sexual and reproductive rights of groups who are stigmatised on the basis of their sexuality, sexual identity or sexual practices, such as LGBTQI people, as well as sex workers.

While researching SRH, upholding a research participant's privacy and confidentiality is a key element of research ethics. Informed consent processes must be adhered to completely in letter and spirit so the participants' autonomy is upheld. Approval of the research protocol by an institutional review board that considers the ethical aspects of the study is a useful and necessary process to ensure the study adheres to ethical principles of research. Once approved, adherence to the recommendations of the ethics committee in spirit and practice is also important.

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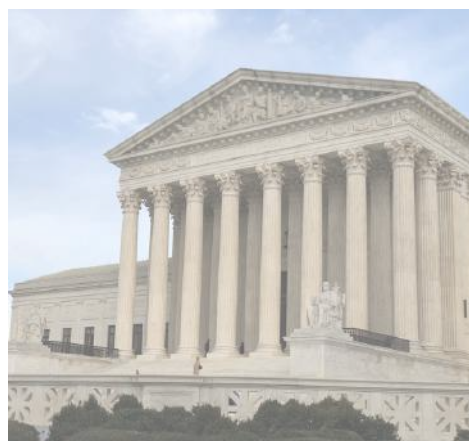
[2] Informed decision-making is also a component of health services that respect medical ethics and are acceptable, and is a characteristic of good quality of care. These aspects of informed decision-making are discussed later in this section.



### THE RIGHT TO ACCOUNTABILITY AND TRANSPARENCY

Accountability guides States in putting their legal, policy and programmatic frameworks and practices in line with international human rights standards. It includes that States need to ensure effective accountability mechanisms, including monitoring and evaluation, and availability of effective processes for remedy and redress, and to ensure participation of a wide range of stakeholders in the development and implementation of laws, policies, programmes and services. Governments and public agencies must be held accountable and answerable for their acts or omissions in relation to their duties related to protecting the right to health care, including the right to SRH services like contraceptive information and services and access to safe and legal abortion, through enforceable standards, regulations, and independent compliance-monitoring bodies. Governments are also accountable for regulating the actions of private entities such as private healthcare providers, insurance companies and pharmaceuticals so that their actions do not violate citizens' right to health.

Accountability is achieved through a variety of processes and institutions, which vary from country to country and may involve both national and international mechanisms and multiple forms of review and oversight, including administrative, social, political and legal forms. Examples of these processes and institutions include courts, national human rights institutions, professional disciplinary proceedings, international and regional human rights bodies' State reporting processes, and individual complaint mechanisms.



Accountability also includes the establishment of accountability and **remedial mechanisms**. All victims of human rights violations have a right to an effective remedy and to reparation. Remedies take a variety of forms including: restitution (e.g. re-establishing a situation as it was before a violation took place); rehabilitation (e.g. medical or psychological care or social or legal services for survivors of violence); compensation (e.g. payment for any financially assessable damage in case of maternal mortality or torture of intersex or transgender people); satisfaction (e.g. acknowledgement of a breach, an apology); and guarantees of non-repetition (e.g. legislation, organisational improvements). Depending on the situation, full reparation for a violation may require a combination of these measures. In all cases, remedies should be accessible, affordable, timely and effective, which will require adequate funding, capacity and mandates.

Remedial mechanisms can take a variety of forms and can require a combination of measures. For example, in the case of forced sterilisation of minority populations, reestablishment of accessible informed contraceptive services, financial compensation of victims, and formal apology to the minority community may be an appropriate package of remedial services.

## THE RIGHT TO PARTICIPATION



People should be seen as active agents who are entitled to participate in decisions that affect their SRH. Individuals and communities must be able to play an active, free and meaningful part in the design and implementation of SRH laws, policies, health systems, programmes, services. Laws, policies and programmes are therefore required to create structures and mechanisms that will allow and enable such participation by all stakeholders, especially traditionally excluded and marginalised populations. Participation not only respects autonomy and dignity but leads to improved health and health-related outcomes.

# APPLYING A HUMAN RIGHTS-BASED APPROACH TO KNOWLEDGE CREATION

Applying a human rights-based approach to the process of knowledge creation can be done with regard to what the research is being done on, how it is done, and how the knowledge that is created is used and by whom. This therefore entails the following.

- Undertaking research or implementing an initiative that is directly connected to the realisation of human rights, for example, research on informed consent in family planning services, investigating the manifestations of discrimination against certain population groups, for example, women living with disability, those living in humanitarian settings or belonging to ethnic minorities.
- Applying the human rights principles - non-discrimination, participation, accountability and transparency – in the design and processes of knowledge creation, for example, directly involving marginalised communities in each step of the research process in a meaningful way, while adhering to principles of consent and confidentiality during the research.
- Empowering marginalised groups, e.g. women, girls, women living with HIV/AIDS, women with disability, transpersons, with knowledge generated from the research process to enable them to address their situation and claim their rights individually and collectively.
- Using the outcomes of the research process and the findings from the research in developing capacities of and providing resources for those who have power and formal obligations to protect, respect and fulfil human rights obligations, for example, governments at national and local levels, parliamentarians, policy makers, professional organisations, judiciary.



A human rights-based approach could thus be applied to

- The issue or the expected results of the research itself (content or goal),
- How the research is done (process), and/or
- The use to which the research is put (outcome)

Given below in Box 1 are some examples of how a human rights-based approach could be applied.

### BOX 1 - APPLYING RIGHTS-BASED PRINCIPLES TO KNOWLEDGE CREATION – SOME EXAMPLES

- The research is relevant to the needs of women and girls, transgender and other gender-diverse people, and other marginalised communities living in poverty and conditions of oppression based on race, ethnicity, gender, and/or religion. This would uphold the right to equality and non-discrimination.
- The research empowers women and girls and other marginalised communities to address their problems and realise their human rights, that can contribute to equality.
- The research follows guidelines that will guarantee no harm will come on account of the study to the research participants or any individual involved in the research (that is, connected to the bioethics principle of no harm), and respect and protect the human rights of intended beneficiaries.
- The research process adheres to human rights principles and ethical standards - for example, related to consent, confidentiality, and participation.
- The research findings are communicated transparently and intended to be used for enhancement of human rights.
- The research brings out recommendations that could lead to policy changes that promote enjoyment of human rights, such as non-discrimination, autonomy, choice and the protection of bodily integrity - for example, elimination of forced sterilisation, routine surgery on intersex children, compulsory surgery requirement for transgender people for legal identity change.
- The research provides knowledge and information to all, with a special focus on marginalised communities, who can use it to demand accountability from their governments.
- Communities constituting the sample population in the study are able to participate meaningfully in the research process.

Human rights principles are closely allied to the principles of bioethics. Adherence to the principles of bioethics is an essential component of a human rights-based knowledge creation (see Box 2 for the principles of bio-ethics).

## BOX 2 - THE PRINCIPLES OF BIOETHICS IN MEDICAL AND PUBLIC HEALTH RESEARCH

Medical and public health research is guided by the following principles of bioethics:

1. Beneficence - requires that potential benefits to individuals and to society be maximised
2. Non-maleficence - requires that harmful acts be avoided
3. Autonomy - focuses on the right of self-determination
4. Justice - a just and fair distribution of benefits to all

While the field of bioethics is based on a philosophical analysis of what is morally right, these bioethics principles overlap with the human rights-based principles. For example, the principle of autonomy in bioethics requires that a person have autonomy of thought, intention, and action when making decisions regarding their own health and overlaps closely with the right to self-determination. This is the key principle underlying the need for informed consent by a person before they participate in any research activity. This is very similar to the principle of autonomy within the human rights framework.

Similarly, the principle of justice describes the moral obligation to act fairly and is linked to equity. It resonates closely with the right to non-discrimination and the principle of participation by communities in decisions that affect their lives.

There are standard and internationally accepted bioethics guidelines for research. These provide clear guidance on how the rights to privacy, confidentiality, informed decision-making, and autonomy should be upheld during any research that involves human beings as participants in the research. National level regulatory bodies for research publish standard guidelines governing research in each country – for example, the Indian Council of Medical Research in India has published the National Ethical Guidelines for Biomedical and Health Research involving Human Participants. These guidelines clearly lay out the requirements for protecting the right to privacy, confidentiality, informed decision-making, and autonomy of the participants.

Internationally, the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: **Convention on Human Rights and Biomedicine**, also known as the Oviedo Convention, **is a legally binding instrument** on the protection of human rights in the biomedical field, including in relation to research.

## APPLYING A HUMAN RIGHTS-BASED APPROACH TO KNOWLEDGE CREATION

In the following sections, we detail further the application of human rights-based principles to different stages of the knowledge creation cycle. These sections are organised as follows.

- Deciding the research topic
- Framing research questions
- Methodology of research
- Analysis of results
- Sharing of knowledge created

At the end of this guide, we give a list of further resources that one can refer to in order to explore these topics further.

# DECIDING THE RESEARCH TOPIC

A human rights approach could be applied to deciding on a research topic in a few different ways as given in Box 3. Examples for each are provided below.

## BOX 3 - HUMAN RIGHTS-BASED APPROACH TO DECIDING THE RESEARCH TOPIC – SOME SUGGESTIONS

- Study of SRH laws and policies to determine if they adhere to international, regional and national human rights principles and/or commitments
- Evaluation of or research on SRH programmes such as contraception, safe abortion, maternal health to determine if they adhere to human rights principles both in their conceptualisation and implementation – e.g. non-discrimination, accountability, participation as related to these issues
- Evaluate SRH services from a lens of the human rights principles – e.g. availability, accessibility, quality, privacy, confidentiality

One way to apply a human rights-based approach to selection of a topic to research on is to analyse the legal and policy frameworks or programmes on the ground to determine their adherence to international, regional and national human rights commitments.

- Migrants from non-EU countries to the EU are known to have worse access to SRH services like antenatal care, cervical cancer screening, gynaecological care, and have higher infant and newborn mortality rates than citizens of the EU. The EU acknowledges that health is a human right in its various policies and documents. Despite this, however, on the ground, migrants' right to health does not seem to be protected. A group of researchers explored the SRH of migrants in the EU and focused their research on this group as it is a vulnerable community often left out of services. They thus applied the principle of right to non-discrimination or equity in their selection of research topic. They also studied whether different EU countries have incorporated the UN human rights instruments related to migrants in their laws or policies related to health and health care.[3]

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[3] Keygnaert I, Guieu A, Ooms G, et al. Sexual and reproductive health of migrants: Does the EU care? Health Policy 2014;114(2-3):215-25.

## DECIDING THE RESEARCH TOPIC

Another possible way to apply a human rights-based approach to selecting a research topic is to study the principles of human rights – non-discrimination, accountability, participation etc. as related to a particular subject matter related to SRH.

- This could include studying access to services or the benefits of particular interventions of specific marginalised communities, thus affirming the principle of non-discrimination or equity. For example, researchers in Gujarat in India studied the experiences of disabled women with regards to access to SRH and SRHR.[4] This study explored the experiences of a vulnerable community. It also went one step further in applying an intersectional lens to the issue and looked at different axes of marginalisation, e.g. caste and poverty, as they intersect with disability.
- A systematic review was done by a group of researchers to examine the literature on healthy sexuality among older women living with HIV (WLHIV). This review focused on studies on a group that was doubly vulnerable – because of its HIV status and because of age, thus applying the principle of non-discrimination and equity.[5]
- Similarly, several studies explore the experiences of different vulnerable communities – youth, LGBTQI – with regard to their access to SRH services. They look at availability of services for this community, the quality of these services, whether they are provided in a manner that is acceptable to the clients of these services, upholding the right to autonomy, privacy, confidentiality.
- Several studies and initiatives look at accountability in the area of SRH/SRHR in different programmes – for e.g. SAHAYOG, an organisation in Uttar Pradesh in India, has been implementing an initiative that works on poor and marginalised women’s access to maternal health care in the state and demands accountability from the state for it. [6] SAHAYOG had facilitated the formation of a women’s collective that advocates for better maternal health care, gathers evidence on availability and quality of maternal health services and demands accountability from the state and duty-bearers for better access to services in the public sector.



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[4] Dean L, Tolhurst R, Khanna R, et al. ‘You’re disabled, why did you have sex in the first place?’ An intersectional analysis of experiences of disabled women with regard to their sexual and reproductive health and rights in Gujarat State, India. *Global Health Action* 2017;10:sup2, 1290316.

[5] Narasimhan M, Payne C, Caldas S, et al. Ageing and healthy sexuality among women living with HIV. *Reproductive Health Matters* 2016;24(48):43-51.

[6] Dasgupta J. Ten years of negotiating rights around maternal health in Uttar Pradesh, India. *BMC Int Health Hum Rights*. 2011 Dec 16;11 Suppl 3(Suppl 3):S4. doi: 10.1186/1472-698X-11-S3-S4. Epub 2011 Dec 16. PMID: 22376057; PMCID: PMC3287460.



# FRAMING RESEARCH QUESTIONS

Once a research topic has been selected, the next step is to frame the research questions that one wants answers to from the study. This could be done in different ways as shown in Box 4.

## BOX 4 - HUMAN RIGHTS-BASED APPROACH TO FRAMING RESEARCH QUESTIONS – SOME SUGGESTED WAYS

- Framing SRH services such as contraception and abortion from the perspective of right to availability, accessibility, acceptability, and quality of health services, right to autonomy and privacy, right to informed consent, and examining if these rights are upheld.
- Examining an SRHR issue from the perspective of whether the different human rights principles like privacy, confidentiality, autonomy are being upheld or violated in different programmes or services provided, especially for marginalised populations such as women living with HIV, women with disability, adolescent girls.
- Examining if there are any violations to human rights in the implementation of a programme or in a service, such as demanding third party authorisation for seeking contraceptive services for women, introducing lengthy waiting periods for the provision of abortion services, requiring unnecessary medical examination for the provision of health services for the survivors of sexual violence.

A review of the literature reveals some important examples of how a human rights lens could be built in at this stage even in studies that look at mainstream biomedical topics or in the analysis of large-scale survey data.

## FRAMING RESEARCH QUESTIONS

- Post-partum haemorrhage, i.e., excessive bleeding after childbirth, is the leading cause of maternal deaths in the world. The use of medicines like oxytocin or misoprostol immediately after the baby is born to help the uterus contract, has been proven to reduce the risk of excessive bleeding. A programme in Mozambique in Africa distributed the drug misoprostol to pregnant women to use at the time of childbirth at home to prevent post-partum haemorrhage. A group of researchers evaluated this programme.[7] While the intervention being studied is a mainstream biomedical intervention, the researchers framed the issue as an intervention that could affirm the right to maternal health and asked whether different aspects of human rights principles were upheld by the intervention.
  - They framed access to misoprostol as the right to access life-saving medicines to prevent maternal death and morbidity. They studied whether this was being fulfilled or if, in fact, there were violations of this right in the implementation of the programme.
  - They examined whether women had adequate access to correct information regarding this life-saving drug and framed this from the lens of women's right to information.
  - They documented that women were pressured by health staff to reach facilities for childbirth even if it was very difficult to do so because of distances and lack of transportation. Women who delivered at home were discriminated against, and access to services like newborn-immunisation was denied to them. This was a violation of women's right to autonomy and self-determination.
  - They also documented power hierarchies between healthcare providers, traditional birth attendants and pregnant women (some health staff limited the distribution of misoprostol to pregnant women due to their personal belief that it could cause abortion – this violated women's access to a life-saving medicine).

Research questions from a rights perspective when evaluating the misoprostol for PPH intervention.

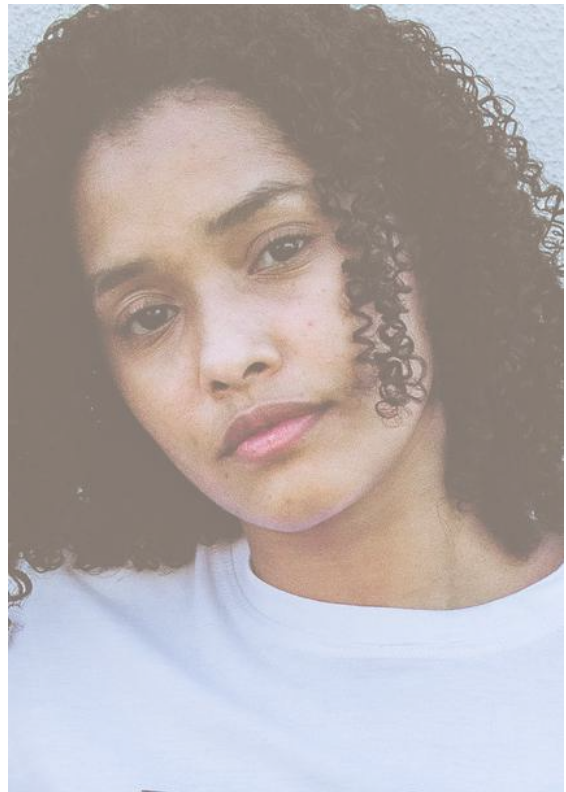
- Is women's right to access the life-saving medicine misoprostol uniformly fulfilled for all women in the study areas?
- Is women's right to information regarding the lifesaving medicine misoprostol fulfilled?
- Are women able to exercise their right to self-determination to decide where to have their births?

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[7] Hobday K, Zwi AB, Homer C, et al. Misoprostol for the prevention of post-partum haemorrhage in Mozambique: an analysis of the interface between human rights, maternal health and development. BMC International Health and Human Rights 2020;20:1-3.

## FRAMING RESEARCH QUESTIONS

- In 2016, Brazil faced an outbreak of Zika, a viral infection that is transmitted by the *Aedes aegypti* mosquito. While the Zika infection is usually mild, it can be particularly dangerous for pregnant women as it can cause a condition called microcephaly in the foetus, where the foetal brain is affected. The federal government in Brazil took a “security” approach and focused on vector control, postponing pregnancies, and mosquito repellent. On the contrary, UNFPA supported an intervention that adopted a human rights-based response to the epidemic. Researchers from Brazil documented this initiative and compared it to the response of the government to the Zika epidemic, using a human rights lens to frame the research question.[8]



### Research questions from a rights perspective in the study in Zika interventions

- Does the government response to Zika adhere to human rights principles like access to SRH services, autonomy and self-determination?
- Does the UNFPA response to Zika adhere to human rights principles like access to SRH services, autonomy and self-determination?

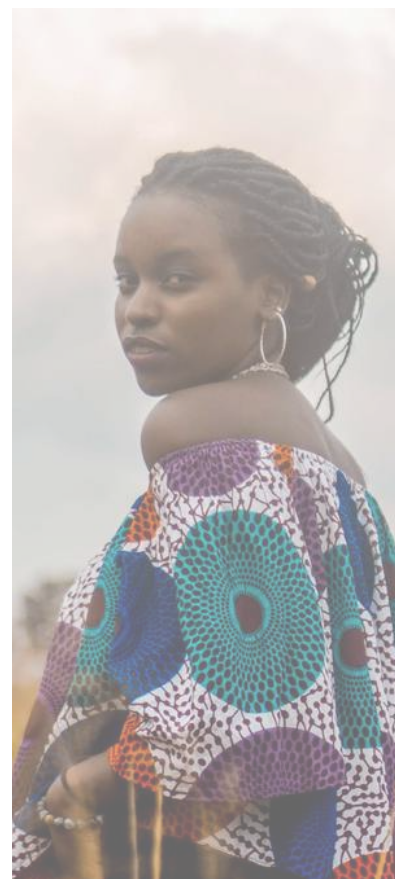
- They examined whether the government’s response to Zika adheres to human rights principles like access to SRH services, autonomy and self-determination, or in fact violates them. The government termed the issue of Zika and mosquitoes in military terms as “the war against the mosquito” and there was also involvement of military personnel on the ground to enforce these strategies. Women were seen as passive beings who had to “keep their house clean and not get pregnant”. There was no recognition of the barriers that women faced in practising safe sex, accessing contraception or safe abortion services. Asking women to delay pregnancy without understanding and respecting their choices was seen by the researchers as a violation of the principle of autonomy and self-determination.

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[8] Ventura D, Rached D, Martins J, et al. A rights-based approach to public health emergencies: The case of the ‘More Rights, Less Zika’ campaign in Brazil, *Global Public Health* 2021;16(10):1576-1589.

## FRAMING RESEARCH QUESTIONS

- The researchers also documented the alternative intervention by UNFPA that uses a human rights and SRHR approach to the same issue, and showcased it as a positive example of how human rights-affirming approaches could be used to address a mainstream problem like an outbreak/epidemic. This involved communicating the concept of reproductive rights – that a woman has a choice on when she should get pregnant, regardless of a health emergency context – widely to various group of people. The intervention simultaneously reached out to vulnerable communities where the consequences of Zika on pregnancy were found to be higher and also to partners and family members of women of reproductive age in order to increase support available for them in their choices.
- Cervical cancer can be prevented through regular screening programmes where cervical lesions are detected and treated at the pre-cancerous stage, preventing their progression to cancer. Many countries have national level screening programmes, but these often leave out women from marginalised communities. Indeed, the burden of cervical cancer incidence and mortality is much higher in under-screened women. Perehudoff et al. studied national level cervical cancer screening programmes[9] in selected countries. They framed cervical cancer screening as an essential SRH service and therefore an SRH right. To understand if this right (access to cervical cancer screening) is available to all without discrimination and in the principle of equity, they examined who is left out of national level cervical cancer screening programmes and framed this as a violation of the right to non-discrimination. They also examined factors that influence poor screening among the marginalised including availability, accessibility and information accessibility.



Research questions from a rights perspective when evaluating national screening programmes for cervical cancer

- Is the right to access cervical cancer screening available to all without any discrimination?
- What are the factors that affect poor screening rates among different marginalised communities?

[9] Perehudoff K, Vermandere H, Williams A, et al. Universal cervical cancer control through a right to health lens: refocusing national policy and programmes on underserved women. BMC International Health and Human Rights 2020;20(1):1-9.

## FRAMING RESEARCH QUESTIONS

- Attitudes to abortion in a community can influence access to abortion. Widely prevalent negative attitudes to abortion can increase stigma related to abortion and can impede access to services, thus leading to unsafe abortion. A study from South Africa examines data from a large-scale national survey, the South African Social Attitudes Survey (SASAS) 2013, and specifically focuses on two questions in the survey that focused on abortion attitudes.[10] It frames the research question from a human rights lens where access to safe abortion is seen as a human right and “to the extent that negative abortion attitudes are tied to the limited availability of safe abortion and resulting health consequences, abortion attitudes are a human rights issue”. It also places these abortion-related indicators in the broader context of women’s rights to comprehensive health care, personal dignity and non-discrimination by gender or other social categorisation. The study also uses an intersectional lens in analysing the data – it postulates that social hierarchies and each of their intersections compounds the stigma. An example is given of a poor woman facing discrimination in receiving services and how this is influenced by both her poverty and the stigma related to the fact that she is seeking an abortion. This study is a good example of how framing research questions through a human rights lens can bring about a nuanced analysis of even large-scale quantitative data.

### Research questions from a rights perspective on community attitudes to abortion

- What is the prevalence in South Africa of negative abortion attitudes that affect right to access safe abortion services?
- How do negative abortion attitudes differ by different variables like geography, race, socio economic status that determine unsafe abortion risk in South Africa?

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[10] Mosley EA, King EJ, Schulz AJ, et al. Abortion attitudes among South Africans: findings from the 2013 social attitudes survey. *Culture, Health & Sexuality* 2017; 19(8): 918-933. DOI: 10.1080/13691058.2016.1272715

# METHODOLOGY OF RESEARCH



Over the last several decades, public health research including in SRH has placed a great deal of emphasis on positivist approaches to methodology. A positivist view would be that only facts collected through objective observation can be considered valid and the role of the researcher has to be neutral and restricted to collecting the data and interpreting them. Positivist approaches usually rely on quantitative data collection, use of various statistical methods to analyse them, and consider that the findings are generalisable.

Positivist approaches, however, do not capture the lived experiences of people and do not take into account the contexts of people's lives. This is especially important in the area of SRH where people's gendered experiences and their intersections with determinants like caste, ethnicity, poverty and with the health system play a great role in health outcomes and consequences. In order to address these gaps, there have been attempts to use interpretivist approaches to research methodology as an alternative to positivist ones. Interpretivist approaches collect information in everyday settings, are subjective, rooted in local contexts, and provide deep and valid information that can be generalised to similar settings and populations. This involves the use of qualitative methodologies like in-depth interviews, observations, group discussions. More recently, mixed methods – which use a mix of both approaches and methodologies - are gaining popularity.

However, neither of these approaches are necessarily rights-based. In this section, we present some examples of research which have attempted to incorporate human rights into their research methodologies even when they use different research approaches as detailed in the above paragraph.

Rights-based principles can be incorporated into research methodology in different ways. Some of the ways we discuss in this section include:

- Ensuring the right to participation
- Including different ways of knowledge creation (epistemologies)
- Using feminist and human rights principles in research methodology
- Challenging traditional research methodologies through alternative approaches such as lay epidemiology

### ENSURING THE RIGHT TO PARTICIPATION

One of the most common ways in which human rights principles have been incorporated into research methodologies has been through ensuring the right to participation of research participants. Researchers are often seen as a separate group that research on a particular topic or community. Often, such distancing from the research participants is seen as essential to maintaining neutrality and eliminating bias in research. Efforts have been made to break this dichotomy between the researcher and the researched and ensure meaningful participation of those whose issues are being researched in all stages of the research process, thus upholding their right to participation. This entails a shifting of power from the researcher to the research participant – so that participants have a say on the research agenda, the research process, and the outcomes of the research. Research participants are involved not only in data collection, but also in the analysis and interpretation of the findings. Box 5 presents some possible ways to ensure a meaningful right to participation in research.



#### BOX 5 - ENSURING A MEANINGFUL RIGHT TO PARTICIPATION IN RESEARCH – SOME POSSIBLE WAYS

- Develop meaningful community engagement by developing and fostering relationships
- Select field investigators from the community being studied
- Develop research plan, research questions and research tools jointly with them
- Define concepts according to the community's perspectives, along with them
- Develop the conceptual framework - i.e., outcome variables, independent variables, and their inter-relationships – based on consultations with the community
- Engage community members in collection of data
- Develop the analysis plan along with community members with inclusion of their philosophies, ways of thinking and belief systems
- Consult community members in interpretation of findings and development of recommendations
- Ensure reflexivity of the researcher, entailing constant examination of one's own beliefs, assumptions, and judgements and how these may have influenced the research

## METHODOLOGY OF RESEARCH

There are several examples of SRHR research where the right to participation has been ensured in the research methodology. Some of these studies are also good examples of how the right to participation can be ensured in a substantive meaningful way during the research process.

- A number of studies on adolescent SRH have ensured the participation of young people in different aspects of the research. A study from Bangladesh that researched adolescent sexuality took a participatory research approach[11] – young people were trained to conduct the qualitative research that explored adolescents’ sex culture, access to information and services. The research plan and interview questions were developed together with them as co-researchers. Young researchers collected the data. They then presented the preliminary findings to a wide group of stakeholders, got their perspectives to triangulate their findings, and then jointly discussed and developed recommendations.

Going beyond the field of SRHR, there have been several other areas of research where the right to participation has been explored in depth for it to be operationalised meaningfully. Some examples from the fields of research involving indigenous people, alternative paradigms of epidemiology, occupational health, and environmental research are presented below as illustrative examples of how the right to participation has been operationalised in these areas.

## INCLUDING DIFFERENT WAYS OF KNOWLEDGE CREATION



There have been several efforts in the area of indigenous peoples’ research at deeply interrogating and exploring ways to ensure meaningful participation of indigenous communities in research that concerns them, as opposed to external “outsider” researchers conducting research on them. These efforts have included questioning the assumption that western paradigms of science are the gold standard; and introducing indigenous philosophies and ways of thinking, creating knowledge, and framing issues into the research methodology. This has also included taking into account historical contexts including the effects of colonialism on indigenous people’s health and its determinants.

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[11] van Reeuwijk M, Nahar P. The importance of a positive approach to sexuality in sexual health programmes for unmarried adolescents in Bangladesh. *Reproductive Health Matters* 2013;21(41):69-77.



Epidemiology is the study and analysis of the distribution, patterns and determinants of health and disease conditions in defined populations. There have been several epidemiological studies of indigenous people and their health. However, these studies have often essentialised Indigenous people (that is, treated all members of a social group as the same) to categories or variables without taking into account historical and other contexts that could be determinants of their health, for example, the effects of colonialism on health, education, and poverty. Such traditional epidemiology has been challenged, and alternative paradigms proposed[12] (see box 6).

### **Epidemiological research on/with/by indigenous people - an alternative research paradigm that honours indigenous cultural ways of knowledge creation[12]**

- Includes an ontology (what is considered truth/reality) that explores the subjectivity within epidemiology and the influence of the positionality of the researcher.
  - Follows an epistemology (way of knowledge creation) that understands that knowledge can be generated through many ways that include, but are not limited to, statistical analyses.
  - Follows an axiology (values) that research aims to affect social change and improve the lives of the communities participating in the research.
  - Follows a methodology that is participatory and empowers community partners to meaningfully contribute to statistical research.
- 
- An example of such use of alternative paradigms of knowledge creation is from Canada. In Canada, large scale data show that Inuit (Indigenous people) youth have poorer SRH outcomes than other youth in Canada. Studies have documented the effects on SRH outcomes of poverty, changing family structures, ongoing colonialism, and lack of culturally sensitive care for indigenous people. However, there was a need to understand young Inuit people's experiences of SRHR and SRH care to bring in their voices into the foreground.
    - A study on Inuit youth experiences of access to sexual and reproductive health and rights in a province in Canada aimed to generate youth-focused evidence on experiences of SRHR relating to access to care.[13] The study thus focused on ensuring participation of youth themselves and bringing their voices into the research. It also addressed the right to non-discrimination and equality by highlighting gaps in care for a vulnerable community like that of the Inuit.

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[12] Jaworsky D. An allied research paradigm for epidemiology research with Indigenous peoples. *Archives of Public Health* 2019;77(1):1-2.

[13] Corosky GJ, Blystad A. Staying healthy "under the sheets": Inuit youth experiences of access to sexual and reproductive health and rights in Arviat, Nunavut, Canada. *International Journal of Circumpolar Health* 2016;75(1):31812.

## METHODOLOGY OF RESEARCH

- The study however went one step further in exploring ways in which the research would be culturally acceptable and would not impose Western paradigms of knowledge creation on an indigenous community. It used the principles of Piliriqatigiinniq Partnership Community Health Research Model (PRM) as a way of decolonising research. The PRM model is built on Inuit “relational epistemology”: “a foundation for knowing ... based on the formulation of relationships among members of the community of knowers”. The PRM is made up of four pillars derived from Inuit cultural knowledge: Inuuqatigiitsiarniq (“being respectful of all people”), Unikkaaqtigiinniq (“story-telling”), Pittiarniq (“being kind and good”), and Iqqaumaqatigiinniq (“all things coming into one”).
- This was operationalised by the researchers as practical guidelines for collaborating with Inuit communities. The guidelines for research collaboration with indigenous communities included: reflexivity of the researcher, meaningful community engagement, developing and fostering relationships, sharing and finding meaning and understanding in stories, and doing good as defined by Inuit conceptions of goodness. Thus, participation was also ensured in epistemology or the way of creating knowledge.
- In addition, findings were continuously checked with community members during the analysis phase, and their feedback was incorporated into the report. It can thus be seen that this study explored ensuring participation in multiple ways – by involving the youth of the community in research on their needs, by bringing in Inuit cultural principles into its philosophy of knowledge creation, by operationalising them in the methodology and methods of the study, and finally in the analysis phase.

### BOX 6 - BEING RESPECTFUL AND INCLUSIVE OF ALTERNATIVE WAYS OF KNOWLEDGE CREATION – SOME SUGGESTIONS

- Be reflexive at all times – examine your beliefs, judgements, prejudices, and how these affect the research
- State your positionality openly and transparently in all interactions with the community and in any publications/reports generated from the research – what is your relationship with the community being researched, and how does this influence your research both in its content and processes
- Be aware of the power dynamics between the researchers and the community being researched, and explore ways to reduce power inequities – for example, in the ways you address the community, behave with them, by ensuring their meaningful participation in the research
- Examine the language being used – do not use terms that reflect power and hegemony, for example, “these lower caste people”.
- Be respectful of the community’s lived experiences and perspectives and their interpretations and meanings of these as sources of knowledge. For example, what is the community’s perception of discrimination in a healthcare setting.

## FEMINIST AND HUMAN RIGHTS PRINCIPLES IN RESEARCH

Applying feminist principles that are closely linked to human rights, in particular women's rights, to research design is one way through which traditional research methodologies have been reconfigured. Feminist epidemiology is one such example.

An alternative paradigm for epidemiology that is explicitly informed by a feminist perspective has been explored by researchers such as Inhorn and Whittle.[14] They critique traditional epidemiology, which forms the foundational basis of public health research, as being too focused on the individual, ignoring determinants of disease like religion, ethnicity, poverty that determine a person's agency and choices regarding their health, and ignoring larger political economies that influence health. Inhorn and Whittle provide suggestions for an alternative form of epidemiology that incorporates a feminist framework. Such a feminist epidemiological framework would recognise that women are not a universal category that is homogenous, but rather occupy diverse spaces and identities; would actively engage women in the process of knowledge generation; would recognise that women are both reproductive and non-reproductive human beings; would explore how gender oppression shapes women's health; and would also connect women's oppression to other larger political forces both globally and nationally. They also call for researchers to make a personal commitment to examine how they themselves and their institutions may be engaged in hierarchical relationships of power and dominance and to address the hierarchical power relations by creating new structures and relationships.

### **Lessons for SRHR research from feminist and lay epidemiological approaches**

- Do not treat women (or any gender) as a universal homogenous category. Recognise the diversities between them.
- Ensure active and meaningful participation of the community being researched in the process of knowledge generation. This includes in developing concepts and conceptual frameworks, in designing and actual collection of data, in analysis and interpretation of findings, and in providing meaning to the findings and deciding how to use them. (Refer to box on ensuring participation).
- Recognise that all persons, especially women and girls, have both reproductive and non-reproductive aspects to their lives. Do not reduce women to just reproductive beings.
- Examine and recognise the role of gender oppression in shaping health outcomes of women, girls, and gender diverse persons.

*...continued on next page*

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[14] Inhorn MC, Whittle KL. Feminism meets the "new" epidemiologies: toward an appraisal of antifeminist biases in epidemiological research on women's health. *Social Science & Medicine* 2001;53(5):553-67.

- Examine and recognise the larger social, political economy-related factors that influence health. These could be at global, national, or local levels, and include institutions and structures like global policies on funding, national laws and policies, religious doctrines, social institutions like marriage, race, caste and heteronormativity-related oppression.
- Be aware and reflexive of the researcher's own hierarchical relationships with the community and how this may result in power differentials. Constantly strive to address these.

- One example of how feminist principles have been applied in a research study is the ongoing study by CommonHealth in India on documenting reproductive health histories of women through a life stories method. The study engages with different groups of women from diverse marginalised communities – dalit, adivasi, women engaged in sex work – and elicits their narratives or stories through detailed conversations with them about their lives overall, with a focus on SRH. What the method seeks to do is to document women's own stories as data, and apply a gender and rights lens to analyse and interpret the data. It seeks to make meaning from the collation of experiences of diverse groups of women, especially women from marginalised backgrounds who have not had the opportunity to have their voices heard, and to have their experiences inform the body of knowledge on the SRH of women in India. In addition, it also seeks to locate these experiences within the larger context of their lives by analysing the policy and programme context of SRH and larger political economy-related factors.

## LAY EPIDEMIOLOGY

Lay epidemiology is another field that has worked on meaningful participation of the communities involved in the research. Lay epidemiology has been defined as "the process by which lay persons gather statistics and other information and direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease".<sup>[15]</sup> Lay epidemiology includes two elements to identify "what constitutes an illness or disease"; first, the lay person's belief about an illness and second, how this is influenced by the values or beliefs that people link to health and health risks in life. In lay epidemiology, the affected communities have a say in the problem being studied, but more importantly have a say in the way their day-to-day suffering is recorded and communicated. Two studies are detailed below that have used lay epidemiology in very interesting ways.

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[15] Rangamani S, Obalesha KB, Gaitonde R. Health issues of sanitation workers in a town in Karnataka: Findings from a lay health-monitoring study. *The National Medical Journal of India* 2015;28(2):70-3

## METHODOLOGY OF RESEARCH

- In India, sanitary work that includes all forms of collecting waste, cleaning sewage pits and drains, sweeping roads and collecting and disposing of human and animal excreta and animal corpses, is done mostly by persons belonging to the Dalit community. While there are laws explicitly prohibiting manual scavenging, it continues in many places. There are often media reports of sanitary workers dying while cleaning sewers without safety equipment and there is no data on the mortality and morbidity and the health effects of their occupation. A study on health issues faced by this marginalised community of sanitary workers in India used a participatory methodology to document the nature of health problems and the treatment-seeking practices of sanitation workers in Chitradurga, Karnataka.[15] A local community-based organisation's team was trained to identify and record health issues of workers using a health monitoring tool. The study resulted in documenting the different health issues faced by sanitary workers, but in addition, it was able to look at these issues from the perspectives of the community members themselves and frame them accordingly. For example, while widespread alcoholism was documented amongst male community members, alcohol was framed by the community members as a therapeutic modality for work-related problems rather than as a health issue.
- Another paper documented the case study of SIPCOT Area Community Environmental Monitors (SACEM) in the villages around Cuddalore in Tamil Nadu, India.[16] This community has been engaged in a struggle against the polluting activities of various factories in the industrial estate of SIPCOT (State Industries Promotion Corporation of Tamil Nadu) in their area, and in opposing expanding developments elsewhere in the state by mobilising science in the interests of pollution-impacted communities. The community was trained in lay epidemiology using innovative methods like odour mapping and air sampling of industrial gases in their area with a cheap, accessible technique using a bucket. This helped the community collect the data themselves regarding pollution in their area, analyse it, and use it for further action with pollution-related regulatory authorities. Thus, these communities became actual generators of scientific knowledge.



These challenges to traditional ways of knowledge creation, while not explicitly termed by the authors as rights-based, incorporate rights-based principles of non-discrimination and equality, participation, acceptability, and accountability in their framing. Principles from these studies could be applied when studying issues of SRHR.

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[16] Narayan S, Scandrett E. Science in community environmental struggles: lessons from community environmental monitors, Cuddalore, Tamil Nadu. *Community Development Journal* 2014;49(4):557-72.

### EXAMPLES OF INNOVATIVE METHODS TO INCORPORATE RIGHTS-BASED METHODOLOGIES

In addition to methodological approaches, there are also examples of how researchers have used innovative methods to promote the right to participation: the use of photography by community members, the use of mobile phones to facilitate community-based data collection, the use of pictorial tools, are all such examples.

- VideoVolunteers, a group based in India, trains community members to use a camera and to document through videos real life case stories related to many themes. As part of this initiative, community members have documented poor quality of maternal healthcare services, lack of consent in provision of contraceptive services, lack of abortion services and many such issues related to violation of sexual and reproductive rights. These videos are then widely disseminated to the community as well as in the public domain to facilitate demand generation and advocacy for better services. It is important, however, to ensure the informed consent of those being videographed when using such methods; this should include information on what is being filmed, for what purpose, with whom it will be shared, and what it will be used for. It is also important to ensure that those being videographed do not come to any harm because of it – for example, through breaks in confidentiality related to sensitive subjects like use of abortion services, or belonging to the LGBTQI community.
- Ushahidi is a digital platform that facilitates bottom-up flow of information and allows ordinary citizens to report and document different significant events using a mobile phone app. One example of its use is in India where the platform was used to allow community members to document informal payments for maternal health care in public hospitals. This allows community members to participate in data collection while the data is simultaneously displayed publicly, thus fulfilling both the right to participation and right to transparency.

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[16] Narayan S, Scandrett E. Science in community environmental struggles: lessons from community environmental monitors, Cuddalore, Tamil Nadu. *Community Development Journal* 2014;49(4):557-72.

# ANALYSIS OF RESULTS

A human rights-based approach can be brought in at the stage of analysis of research findings in different ways.

- An explicit way to bring a human rights lens to the analysis framework could be analysing the data based on adherence of laws, policies, and programmes to human rights principles – examining whether government obligations to respect, protect and fulfil human rights as laid out in various international and regional treaties, national constitutions and human rights laws have been met

It is useful for researchers to plan the analysis of their data and the frameworks they intend to use for it even before data collection. This would ensure that all the information that is necessary for the analysis has been collected appropriately. For example, if one plans to do an intersectional analysis, the data collection tools would have to be designed to capture the different axes of inequity as appropriate to the particular issue and community being studied.

- Another way would be to examine power and marginalisation as a key determinant in the enjoyment of SRHR. Exertion of power and, as a corollary, lack of power or powerlessness, are key pathways to marginalisation and inequity. This approach would examine whether the right to non-discrimination and equality has been met in the enjoyment of different human rights related to SRH – e.g. right to privacy, informed consent – through examining how different axes of power act and contribute to health outcomes and consequences.
- A third way would be to bring an intersectional lens to the analysis – examining how different axes of inequity like race, gender, caste, poverty operate together and exacerbate each other's influences.

We present some examples of each of these approaches to human rights-based analysis.

## HUMAN RIGHTS PRINCIPLES AS PART OF ANALYTICAL FRAMEWORK

One of the ways in which studies have analysed results from a human rights perspective is to bring an explicit human rights lens to the analysis framework using governments' international commitments to various human rights conventions and instruments.

## ANALYSIS OF RESULTS

- Over the years, there have been several scientific advances in preventing parent-to-child transmission of HIV. This has also led to an increased emphasis on testing of pregnant women for HIV. National policies for HIV testing have evolved alongside, and concerns have been expressed about whether these uphold the pregnant woman's autonomous decision-making regarding getting tested, or end up being coercive. This is especially true given the power differentials between healthcare providers who recommend the testing and pregnant women who may feel powerless to express their opinion and decline testing. King et al carried out a policy analysis of national policies for HIV testing of pregnant women using a human rights-based approach.[17] They used a standardised framework that focused on government obligations to respect, protect and fulfil the human rights of pregnant women. They used clear definitions to assess the governments' obligation to respect, protect and fulfil human rights in the area of HIV testing. This included, for example, examining that testing policies do not violate the right of a person to decline an HIV test (consent) and confidentiality; whether states protect women from potential adverse consequences, including violence, as a result of HIV testing or an HIV diagnosis; whether there is provision of adequate counselling services on access to treatment and care for women who are diagnosed with HIV. This framework was then applied to national policies, holding the states accountable to ensure that their national HIV testing laws and policies uphold these human rights obligations.
- Another study that explicitly built in the human rights framework in its analysis is the Dead Women Talking initiative from India.[18] Maternal mortality ratios (MMR) are globally accepted as an indicator of a country's maternal health status. However, aggregate MMR figures do not reveal who the women dying are or what the causes and contributors to maternal deaths in a particular country or geographical area are. The Dead Women Talking initiative was planned with the understanding that maternal deaths affected women from marginalised communities disproportionately and that accountability of health systems was a key issue when looking at maternal deaths. The initiative designed and used a specially developed social autopsy tool to document maternal deaths in specific geographical areas of ten different states in India. The social autopsy tool specifically looked at social determinants and health systems contributors to the maternal deaths from a human rights perspective. Women's access to various SRH services and the underlying determinants needed to enjoy good reproductive health were all framed as basic human rights and the data examined whether these rights had been protected and fulfilled or in fact violated. For example, discrimination based on caste or tribal status was framed as a violation of right to non-discrimination and equality, lack of access to food security and livelihoods as a violation of right to life and health. Community-based organisations in different parts of the country documented maternal deaths using this social autopsy tool and identified causes and contributors to these deaths. An SSSR framework for analysis - this framework looked at Science related or Technical Factors, Health System Factors, Social Factors, and Human

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[17] King EJ, Maman S, Wyckoff SC, et al. HIV testing for pregnant women: a rights-based analysis of national policies. *Global Public Health* 2013;8(3):326-41.

[18] Sri BS, Khanna R. Dead Women Talking. A civil society report on maternal death in India. 2014 Jul.



## ANALYSIS OF RESULTS

Rights - was used for each maternal death. Participants in the Dead Women Talking initiative were trained in using the SSSR framework for analysis. They analysed each death across these four domains. For each domain, gaps that were found to cause or contribute to the death were listed. Actions to address each gap were then listed as recommendations. A compilation of these recommendations across all deaths in a particular geographical area was done periodically to come up with actionable recommendations for both the health system and the community in that area. This study is a good example of rights-based knowledge creation – upholding the right to participation in its different phases, and including right to health and right to life in its analytical framework.

- A similar study by Jat et al from India looks at maternal mortality from a human rights framework.[19] The study documents maternal deaths from the state of Madhya Pradesh in India and integrates a human rights lens along with the Three Delays framework to analyse 22 maternal deaths documented using social autopsy. It also uses an AAAQ (Availability, Accessibility, Acceptability and Quality) framework as part of right to health in its analysis.

## EXAMINING POWER AND MARGINALISATION

Power relations between individuals, between genders, between communities, between users and the health system, all influence a person's enjoyment of rights, especially of those from marginalised communities. Thus, examining power as a key determinant would be an important aspect to analysing the realisation of SRHR. A review of literature reveals that studies have adopted a human rights approach by interrogating power and marginalisation in their analysis, even though they may not explicitly term it human rights-based analysis. Two examples are given below where the researchers have studied how power influences the SRHR issue being researched.



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[19] Jat TR, Deo PR, Goicolea I, et al. Socio-cultural and service delivery dimensions of maternal mortality in rural central India: a qualitative exploration using a human rights lens. *Global Health Action* 2015;8(1):24976.

## ANALYSIS OF RESULTS

- The testing and counselling process for HIV was initially designed as a voluntary process where clients can choose to get tested and request for the same. However, in the mid-2000s, this was changed globally to a routine testing process with an opt-out option. A study from Uganda on the HIV Prevention of Mother to Child Transmission (PMTCT) programme[20] looks at the microdynamics of power between the healthcare workers and women, underlying dominant discourses amongst healthcare workers, and how these affect women's rights of consent and opt out. The study documents the case study of one antenatal clinic, using participant and non-participant observation of the counselling and testing processes. It also explores different healthcare workers' perspectives on the PMTCT counselling process. While the study does not explicitly use a human rights discourse, it clearly addresses whether the right to informed decision making and autonomy is being upheld in practice.
- Another study that explores disrespect and abuse during childbirth also uses power as a key domain of analysis.[21] The authors state that human rights-based approaches are sometimes tokenistic when applied on the ground. They often remain as legal requirements that are communicated to healthcare workers in capacity building sessions, without a true understanding of how these are to be operationalised. In order to truly transform the relationship between women and healthcare providers, human rights-based approaches (HRBAs) will need to go beyond articulation, dissemination and even legal enforcement of formal norms of respectful maternity care. They also state that HRBAs must also develop a deeper, more nuanced understanding of how power operates in health systems under particular social, cultural and political conditions, if they are to effectively challenge settled patterns of behaviour and health systems structures that marginalise and abuse. They therefore study how power – especially “invisible” power – works in health systems through a mixed methods study of two hospitals in one province of Tanzania. Using this, they highlight the dissonance between the human rights discourse and how power operates in real life in the labour room setting and how this influences the perspectives and practice of healthcare providers on the ground. For example, they highlight how everyday practices like slapping women during childbirth normalise deviations from existing policies that are based on respect and dignity, how healthcare workers occupy spaces in health facilities for their personalised use such as making tea, and thus make patients feel unwelcome. They describe these as colonial and post-colonial influences on bureaucratic and professional cultures and as examples of pathways through which power operates. They thus bring to the fore the gaps that need to be addressed for a more meaningful implementation and practice of human rights.

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[20] Vernooij E, Hardon A. 'What mother wouldn't want to save her baby?' HIV testing and counselling practices in a rural Ugandan antenatal clinic. *Culture, Health & Sexuality* 2013;15(sup4):S553-66.

[21] Freedman LP, Kujawski SA, Mbuyita S, et al. Eye of the beholder? Observation versus self-report in the measurement of disrespect and abuse during facility-based childbirth, *Reproductive Health Matters* 2018;26(53):107-122

### INTERSECTIONALITY

Intersectionality is another lens through which power and marginalisation have been studied. As Kimberlé Crenshaw, who coined the term "intersectionality", states:

"It's basically a lens, a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other. We tend to talk about race inequality as separate from inequality based on gender, class, sexuality, or immigrant status. What's often missing is how some people are subject to all of these, and the experience is not just the sum of its parts".[22]

Intersectional analysis is an effective tool for examining how power and power relations are maintained and reproduced. Intersectionality analysis does not simply add categories (gender, class, race, sexuality) to one another. Intersectional analysis moves away from essentialising any category (treating all members of a social group as the same). Intersectional analysis recognises the multidimensional and relational nature between categories, and places lived experiences and overlapping systems of discrimination and subordination at the centre of analysis. Using an intersectional lens during analysis is one way in which researchers have identified hierarchies of power and marginalisation among their research participants. Intersectionality analysis may also be counted as a human rights-based approach in that it addresses the right to equality and non-discrimination by taking into account how power flows between different groups and how this impacts marginalisation. Some of the studies described earlier have used an intersectional lens in their analysis, including the study on abortion stigma from South Africa, and the study on disability and SRH from Gujarat, India.

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[22] Katy Steinmetz, "She Coined the Term 'Intersectionality' Over 30 Years Ago. Here's What It Means to Her Today," TIME, February 20 2020. <https://time.com/5786710/kimberle-crenshaw-intersectionality/>

# SHARING OF THE KNOWLEDGE CREATED

## BOX 7 - HUMAN RIGHTS-BASED APPROACHES TO SHARING RESEARCH KNOWLEDGE

- Ensure that the knowledge created reaches lawmakers, policy-makers, and programme implementers through easily readable user-friendly material.
- Ensure that the research findings are shared with the community that was researched. Use material that is accessible to the community concerned – local language, pictorial forms.
- Treat the community as an active participant in the sharing process, not a passive receiver of information. Make efforts to actively engage with the community. Recognise diversities in the community and tailor different forms of sharing knowledge accordingly.

Once the research is complete, sharing of the knowledge created can be done using a human rights-based approach. Researchers should ensure that the knowledge created should reach those who are involved in making laws, policies and programmes related to the research area. This should be done through user-friendly material like policy briefs, short research reports, or writing in popular media.



In addition, researchers have an obligation to be accountable to the community from which information was collected and to share the findings of the research with them. This would include upholding the right to participation, and the right to accountability and transparency.

But for such sharing with local communities to be meaningful, the findings must be shared in a manner that is accessible to the community. This includes using the local language and pictorial forms to communicate the message. There are several examples of how this has been done in different studies.

## SHARING OF THE KNOWLEDGE CREATED

- The community monitoring of health services in India has been carried out in several states in the country as part of an accountability initiative under the National Health Mission. As part of this, community-based structures have been created – community members who are part of these spaces are trained and, with the help of local community-based organisations, monitor the availability of health services at different levels of the health system. The results are then collated using a traffic signal approach – different colour codes of green, yellow, and red are given to the services based on whether they meet standards that have been set, partially meet such standards, or do not meet them at all. This colour-coded format of the results is then widely disseminated in community meetings and used as a starting point for discussions on further actions.
- In the Dead Women Talking initiative, analysis of maternal deaths that took place in a community was shared in community-led spaces like the Gram Sabha (part of the local governance structure) or in women’s group meetings. This was then used to initiate discussions on possible community level actions to prevent such deaths in the future. Similarly, another initiative in Koppal, Karnataka which documented maternal deaths used street plays as a medium to communicate with the community the analysis of the factors contributing to the death.
- In a paper on a rights-informed approach to engaging participants in research findings, George et al report on a study from Kerala.[23] They describe how dissemination of results to the community studied often becomes a tokenistic exercise where community members are seen as passive recipients of the research findings. As opposed to this, they describe a process where they made efforts to engage the research participants as active agents during the dissemination process of their research. This involved taking steps to reduce power hierarchies between the researchers and the community during this process and also tailoring outputs to the needs of the different participants.

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[23] George MS, Gaitonde R, et al. Engaging Research Participants with Results: A Rights Informed Approach. (Pre-publication 2022)

# LIST OF RESOURCES

*Sexual and Reproductive Health Matters* (SRHM) routinely publishes articles that adopt a rights-based approach to research in one or more ways described in this guide. The following are some recent issues of SRHM, which include several such articles:

- Exporting harm: impact of the expanded Global Gag Rule on sexual and reproductive health and rights: *Sexual and Reproductive Health Matters* July 2020.
- ICPD25: Accelerating accountability for sexual and reproductive health and rights: *Sexual and Reproductive Health Matters* November 2019.
- The elimination of stigma and discrimination in sexual and reproductive health care. *Sexual and Reproductive Health Matters* August 2019.
- Sexual and reproductive rights for all? Exploring inequities within countries. *Reproductive Health Matters* December 2018.
- Disrespect and abuse in maternal care: Addressing the challenges. *Reproductive Health Matters* October 2018.

We list below some of the resources used in this guide.

1. Mosley EA, King EJ, Schulz AJ, et al. Abortion attitudes among South Africans: findings from the 2013 social attitudes survey. *Culture, Health & Sexuality* 2017; 19(8): 918-933.

- Research question – Frames access to abortion as a human right. Negative attitudes to abortion may increase stigma and affect access. Studies abortion attitudes in SA and also looks at different sociodemographic factors affecting attitudes to abortion.
- Method – Uses data from a large scale national survey.
- Analysis – Intersectional lens on how different axes of marginalisation, eg. Poverty and abortion stigma may intersect to affect abortion attitudes and resultant discrimination. Both the axes are framed as human rights issues, with a resultant human rights violation.

2. Hobday K, Zwi AB, Homer C, et al. Misoprostol for the prevention of post-partum haemorrhage in Mozambique: an analysis of the interface between human rights, maternal health and development. *BMC International Health and Human Rights* 2020;20:1-3.

- Programme evaluation of a government programme distributing misoprostol to women undergoing homebirths to prevent PPH
- Methodology – Document review and qualitative methods
- Analysis uses a human rights lens – frames the issue as one of right to access to maternal health care, right to information, right to essential medicines. Looks at barriers to access identified in the programme from a human rights lens. For e.g.

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- Lack of information on misoprostol seen as violation of right to information
- Enforcing facility-based births and discriminatory attitudes against women who are unable to reach facilities – seen as violation of right to participate in design and implementation of a programme
- Selective distribution of misoprostol by HCPs with fear of misuse for abortion – framed as violation of right to access essential medicines

3. Jat TR, Deo PR, Goicolea I, et al. Socio-cultural and service delivery dimensions of maternal mortality in rural central India: a qualitative exploration using a human rights lens. *Global Health Action* 2015; 8(1):24-976.

- Integrates a human rights lens along with 3 delays framework to analyse 22 maternal deaths documented using social autopsy. Uses a AAAQ framework as part of Right to health

4. van Reeuwijk M, Nahar P. The importance of a positive approach to sexuality in sexual health programmes for unmarried adolescents in Bangladesh. *Reproductive Health Matters* 2013; 21(41):69-77.

- Qualitative research study about adolescents' sex culture, access to information and services
- Participatory research approach – Young people were trained to conduct the research. Research plan and interview questions developed together with them as co-researchers
- Young researchers then presented the preliminary findings to a wide group of stakeholders, got their perspectives to triangulate and jointly discussed and developed recommendations

5. Paiva V, Garcia J, Rios LF, et al. Religious communities and HIV prevention: an intervention study using a human rights-based approach. *Global Public Health* 2010;5(3):280-294.

- Looks at the perspectives of religious youth and religious authorities in Brazil on HIV prevention discourses of the national programme
- The national programme uses a framework of human rights and vulnerability - The concept of vulnerability, as developed through the Brazilian AIDS response, designates a set of individual and socio-cultural aspects related to the greater susceptibility of individuals and communities to a disease or disability and, in an inseparable way, the lesser availability of policies and resources for their protection
- This concept seeks to understand the political and social bases of risk behaviour and the ethical-political implications of risk reduction policies, and goes beyond the tendency to hold individuals exclusively responsible for their behavioural changes, responsible for supposedly having not 'adhered' to safer practices. This concept further considers the violation and neglect of human rights, especially sexual rights and the right to health, as indexes of social, programmatic and inter-subjective scenarios that build vulnerability to HIV infection and AIDS
- This specific research looks at the acceptability component of human rights discourse – and how participation can promote acceptability

## LIST OF RESOURCES

6. Keygnaert I, Guieu A, Ooms G, et al. Sexual and reproductive health of migrants: Does the EU care? *Health Policy* 2014;114(2-3):215-225.

- Policy analysis of EU country policies on SRH of non EU migrants – Analysis from frame of right to health

7. Ventura D, Rached D, Martins J, et al. A rights-based approach to public health emergencies: The case of the 'More Rights, Less Zika' campaign in Brazil. *Global Public Health* 2021;16(10):1576-1589.

- Based on a campaign by UNFPA in Brazil during the Zika epidemic that tried to bring in an alternative paradigm based on SRHR frameworks to the government's securitisation response to the pandemic
- Documents both how the mainstream response is a violation of human rights and how an alternative rights-based response is possible

8. Dean L, Tolhurst R, Khanna R, et al. (2017) 'You're disabled, why did you have sex in the first place?' An intersectional analysis of experiences of disabled women with regard to their sexual and reproductive health and rights in Gujarat State, India. *Global Health Action* 2017; 10(sup2):1290316.

- Documented disabled women's experiences around SRH
- Framed the issue from both a rights (SRHR) and intersectional perspective

9. Corosky GJ, Blystad A. Staying healthy "under the sheets": Inuit youth experiences of access to sexual and reproductive health and rights in Arviat, Nunavut, Canada. *International Journal of Circumpolar Health* 2016;75(1):31812.

- Aims to generate youth-focused evidence on experiences of SRHR relating to access to care
- Uses the principles of Piliriqatigiinniq Partnership Community Health Research Model (PRM) as a way of decolonising research
- The model is built on Inuit "relational epistemology:" "a foundation for knowing . . . based on the formulation of relationships among members of the community of knowers". The PRM is made up of four pillars derived from Inuit cultural knowledge: Inuuqatigiitsiarniq ("being respectful of all people"), Unikkaaqatigiinniq ("story-telling"), Pittiarniq ("being kind and good"), and Iqqaumaqatigiinniq ("all things coming into one")
- Operationalised as practical guidelines for researchers collaborating with Inuit communities to include (inter alia): reflexivity of the researcher, meaningful community engagement, developing and fostering relationships, sharing and finding meaning and understanding in stories, and doing good as defined by Inuit conceptions of goodness
- Findings were continuously checked with community members during the analysis phase, and their feedback was incorporated into the report



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10. Perehudoff K, Vermandere H, Williams A, et al. Universal cervical cancer control through a right to health lens: refocusing national policy and programmes on underserved women. *BMC International Health and Human Rights* 2020;20(1):1-9.

- Frames cervical cancer screening as an essential SRH service and an SRH right
- Looks at who is left out of national level cervical cancer screening programmes as part of its discussion and frames this as a violation of HR
- Looks at factors that influence poor screening among the marginalised including availability, accessibility and information accessibility based on country examples

11. Muzyamba C, Broaddus E, Campbell C. "You cannot eat rights": a qualitative study of views by Zambian HIV-vulnerable women, youth and MSM on human rights as public health tools. *BMC International Health and Human Rights* 2015;15(1):1-6.

- Examined the local Zambian understandings of human rights approaches to HIV-prevention among three highly HIV-vulnerable groups: women, youth, and men-who-have-sex-with-men (MSM).
- NGO workers report how human rights approaches are donor driven and do not match local Zambian realities
- Interviews with local communities report how human rights approaches do not take into account material conditions driving HIV - eg poverty, lack of education and livelihoods
- Calls for a more holistic and locally acceptable interpretation of human rights in order for it to be culturally acceptable and not seen as a western neo colonial imposition. Calls for more participation in the conceptualisation of human rights programmes

12. Narasimhan M, Payne C, Caldas S, et al. Ageing and healthy sexuality among women living with HIV. *Reproductive Health Matters* 2016;24(48):43-51.

- Systematic review looking at studies on sexuality and older WLHIV
- Specifically looks at a group that is often ignored even within the marginalised WLHIV community – older women, and looks beyond issues like reproduction and PMTCT at sexual health
- Very little literature available – identifies ageist and other barriers to sexual health of older WLHIV

13. King EJ, Maman S, Wyckoff SC, et al. HIV testing for pregnant women: a rights-based analysis of national policies. *Global Public Health* 2013;8(3):326-341.

- Policy analysis using a human rights-based approach of national policies for HIV testing of pregnant women
- Uses a standardised framework that focused on government obligations to respect, protect and fulfil - included the cornerstones of HIV testing and counselling designed to uphold human rights and also key criteria to assess governments' commitment to protect pregnant women's health and well-being.

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14.Vernooij E, Hardon A. 'What mother wouldn't want to save her baby?' HIV testing and counselling practices in a rural Ugandan antenatal clinic. *Culture, Health & Sexuality* 2013; 15(sup4):S553-66.

- Looks at PMTCT programme in Uganda – case study of one antenatal clinic – using participant and non-participant observation and also interviews with HCWs
- Explores different HCWs' perspectives on PMTCT counselling process
- Does not explicitly use a human rights discourse – but looks at the micro dynamics of power and also underlying dominant discourses amongst HCWs – and how these affect women's rights of consent and opt out

15.Freedman LP, Kujawski SA, Mbuyita S, et al. Eye of the beholder? Observation versus self-report in the measurement of disrespect and abuse during facility-based childbirth, *Reproductive Health Matters* 2018;26(53):107-122.

- Framing – to truly transform the relationship between women and providers, human rights-based approaches (HRBAs) will need to go beyond articulation, dissemination and even legal enforcement of formal norms of respectful maternity care. HRBAs must also develop a deeper, more nuanced understanding of how power operates in health systems under particular social, cultural and political conditions, if they are to effectively challenge settled patterns of behaviour and health systems structures that marginalise and abuse.
- How power – especially "invisible" power – works in health systems
- Definition of D&A – included both experiential and normative building blocks. Also went beyond the individual provider actions to structural and systemic issues that create disrespectful conditions
- A six month long participatory process involving community members, community leaders, and health system actors in Tanga to locally adapt and disseminate a client rights charter that articulated a local consensus about the standards of respectful care for facility-based childbirth
- For all D&A items, the observers reported more D&A than the women themselves
- Women's low self-report of D&A shows that their powerlessness to prevent or challenge D&A, perhaps even their expectation and acceptance that they will be subjected to D&A, are internalised; and that providers' high propensity to commit these acts despite knowledge that they are being observed shows that D&A is normalised
- The typical HRBA asserts that health systems are by and for the people. It elaborates entitlements based on human rights law and encourages users to demand fulfilment as a matter of right. But the global health literature rarely acknowledges how profoundly different this conception of the health facility is from the actual, hierarchical way that facilities have historically functioned. Moreover, there is only minimal attention to understanding the psychosocial processes that shape people's stance when they encounter abusive or humiliating exercises of power in their interactions with social institutions including health systems.

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- HRBA must be grounded in actual practical norms that can be identified empirically and its message must be vernacularised into a discourse that can connect effectively to the fears, hopes and aspirations of both women and providers. Perhaps most profoundly, an HRBA must nurture what Scott-Villiers and Oosterom identify as another form of invisible power: the “resisting imagination,” the power to imagine the world differently

16. Wikström E, Eriksson E & Lindroth M. Sexual and reproductive health and rights (SRHR) education with homeless people in Sweden. *Sex Education* 2018; 18:6, 611-625.

- Based on the assumption that all people, regardless of the social situations, have the right to highest attainable sexual health
- Homeless people in supportive housing were offered sexual health information and the opportunity to talk about and reflect on sexual health, rights and norms in group sessions - Snacka Sex educational programme
- Preparatory phase took inputs on needs and conceptualisation from both housing facility staff and service users

17. Fish J, Bewley S. Using human rights-based approaches to conceptualise lesbian and bisexual women’s health inequalities. *Health & Social Care in the Community* 2010;18(4):355-362.

- Framing – Uses Yogyakarta principles - concepts embodied in the Yogyakarta Principles, it is proposed that the right to health includes access to health information, participation, equity, equality and non-discrimination
- Examines how LB women’s health can be considered as a health inequality
- While the right to a private life is enshrined in human rights legislation, the right to a public life is not. Because their identities are seen to properly belong in the private sphere, the basis on which LB women present themselves publicly, in healthcare, schools or other public services, is contested. Equity in health and health care is concerned with facilitating public LB women’s identities.
- Online survey in UK – purposive sampling through different channels
- Methodological limitations – heteronormativity of traditional sampling strategies – Random sampling frames of LB women not available

18. Bhana D. Childhood sexuality and rights in the context of HIV/AIDS. *Culture, Health & Sexuality* 2007;9(3):309-324.

- Explores what HIV and AIDS mean to seven- and eight year-old children in South Africa and how sexual and gender dynamics are embedded within these meanings.
- Views young children as sexual and gendered agents with the ability to exercise their rights. In contrast to research that addresses children as relatively passive desexualised beings, focusing on their dependence on adults, their innocence and their need for protection, this paper examines how HIV and AIDS are constructed and negotiated by young people. It views children not simply in terms of their need for sexual rights but as potentially active participants in the negotiation of their rights.

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19. Freeman T, Baum F, Mackean T, et al. Case study of a decolonising Aboriginal community controlled comprehensive primary health care response to alcohol-related harm. *Australian and New Zealand Journal of Public Health* 2019;43(6):532-537.

- Provides a case study of the responses to alcohol of an Aboriginal Community Controlled Health Service (The Service), and investigates the implementation of comprehensive primary health care and how it challenges the logic of colonial approaches
- Colonisation is a root cause, or underpinning social determinant of health for Indigenous peoples, providing the social and political context that drives inequities in the intermediate and proximal determinants of health such as education, health and other systems, employment, housing, interpersonal and institutional racism, discrimination and alcohol use
- The research used participatory action methods where participating services were partners in the research. Its aim was to understand how the principles of comprehensive PHC were implemented on the ground by these services
- Government policies look at alcohol as a law and order problem of public drunkenness instead of as a health and wellbeing issue.
- Intervention uses methods that include addressing social determinants of alcohol related harm and providing treatment services and strategies to minimise alcohol related harm
- Aims to respect and include Aboriginal knowledge and be culturally relevant and safe. This requires respecting Aboriginal ways of knowing, being and doing, alongside Western medicine – an approach termed the “two-way model”.
- Explicit about supporting people to regain control over their lives, a core determinant of health.
- United Nations Declaration on the Rights of Indigenous Peoples, which emphasises Indigenous peoples’ rights to “participate in decision-making”, “maintain and develop their own [I]ndigenous decision-making institutions”, “traditional medicines and to maintain their health practices”, and have “access, without any discrimination, to all social and health services”

20. Hyett S, Marjerrison S, Gabel C. Improving health research among Indigenous Peoples in Canada. *Canadian Medical Association Journal* 2018;190(20): E616-E621.

- Gives examples of methodologies and methods that are indigenous and culturally appropriate

21. Jaworsky D. An allied research paradigm for epidemiology research with Indigenous peoples. *Archives of Public Health* 2019;77(1):1-2.

- Challenges traditional epidemiology that essentialise Indigenous people to categories or variables without taking into account historical and other contexts

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- Describes an allied research paradigm – follows an ontology that explores the subjectivity within epidemiology and the influence of the positionality of the researcher. It follows an epistemology that understands that knowledge can be generated through many ways including, but not limited to statistical analyses. It follows an axiology that research aims to affect social change and improve the lives of the communities participating in the research. It follows a methodology that is participatory and empowers community partners to meaningfully contribute to statistical research. This allied research paradigm, which makes no claims to universality, describes several important principles: reconciliation, relationships, perspective, positionality, self-determination and accountability

22. Inhorn MC, Whittle KL. Feminism meets the “new” epidemiologies: toward an appraisal of antifeminist biases in epidemiological research on women's health. *Social Science & Medicine* 2001;53(5):553-567.

- Explores an alternative paradigm for epidemiology, one which is explicitly informed by a feminist perspective.
- Suggestions for an emancipatory epidemiology that incorporates an alternative feminist framework –

23. Rangamani S, Obalesha KB, Gaitonde R. Health issues of sanitation workers in a town in Karnataka: Findings from a lay health-monitoring study. *The National Medical Journal of India* 2015;28(2):70-73

- Participatory methodology to document the nature of health problems and the treatment-seeking practices of sanitation workers in Chitradurga, Karnataka.
- Lay epidemiology has been defined as “the process by which lay persons gather statistics and other information and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease”. Lay epidemiology includes two elements to identify “what constitutes an illness or disease”; first, the lay person’s belief about an illness and second, how this is influenced by the values or beliefs that people link to health and health risks in life.
- The affected communities have a say in the problem being studied, but more importantly have a say in the way their day-to-day suffering is recorded and communicated.
- A local community-based organisation’s team was trained to identify and record health issues of workers using a health monitoring tool
- Framing of alcohol as a therapeutic modality for work related problems rather than as a problem

21. Jaworsky D. An allied research paradigm for epidemiology research with Indigenous peoples. *Archives of Public Health* 2019;77(1):1-2.

- Challenges traditional epidemiology that essentialise Indigenous people to categories or variables without taking into account historical and other contexts

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24.Narayan S, Scandrett E. Science in community environmental struggles: lessons from community environmental monitors, Cuddalore, Tamil Nadu. *Community Development Journal* 2014;49(4):557-572.

- Seldom are communities in struggle considered as generators of scientific knowledge. Even more rarely considered are the material interests embedded in scientific knowledge that result from the economic location of the generators of knowledge. This paper draws on the experience of a community in Tamil Nadu, South India, that has been mobilising against the polluting impacts of industrial development. The SIPCOT Area Community Environmental Monitors have been generating scientific knowledge by building on indigenous knowledge through the systematisation of observation.
- Case study of SIPCOT Area Community Environmental Monitors (SACEM) in the villages around Cuddalore in Tamil Nadu, India. This community has been engaged in a struggle against the polluting activities of various factories in the industrial estate of SIPCOT (State Industries Promotion Corporation of Tamil Nadu), and in opposing expanding developments elsewhere in the state by mobilising science in the interests of pollution-impacted communities.
- Odour mapping and air sampling using a cheap, accessible technique using a bucket

25.George MS, Gaitonde R, Davey R, Mohanty I, Upton P. Engaging research participants with results: A rights-informed approach (Pre-publication)