Navigating Ethics in the Design of Health Benefits

Evidence-Informed Practices to Promote Equitable and Ethical Progress on the Path to UHC

Carleigh Krubiner, PhD
ckrubiner@cgdev.org

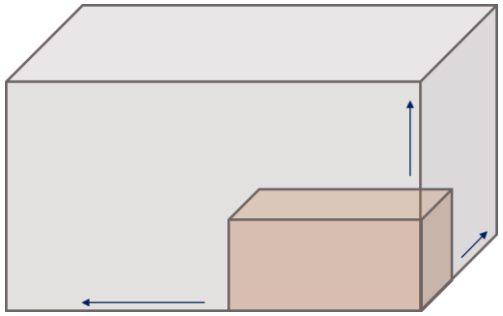
Ethics: Common Misconceptions

Myths	Reality
• Ethics analysis is not evidence-based	• You *cannot* do good ethics without good evidence
• Ethics is only about oversight/ process	• Ethics can also help define decision criteria/principles
• Ethics can be used to justify covering anything – always about adding more	• Ethics is as much about what *not* to cover – what is not justifiable to include
• Ethics/Equity are at odds with Efficiency	• Many of the most cost-effective investments also equity promoting!

How ethics can aid priority-setting

With limited resources, tough choices must be made about what gets covered:

- Which health services and goods?
- For which population groups?
- With what kinds of cost-sharing arrangements?

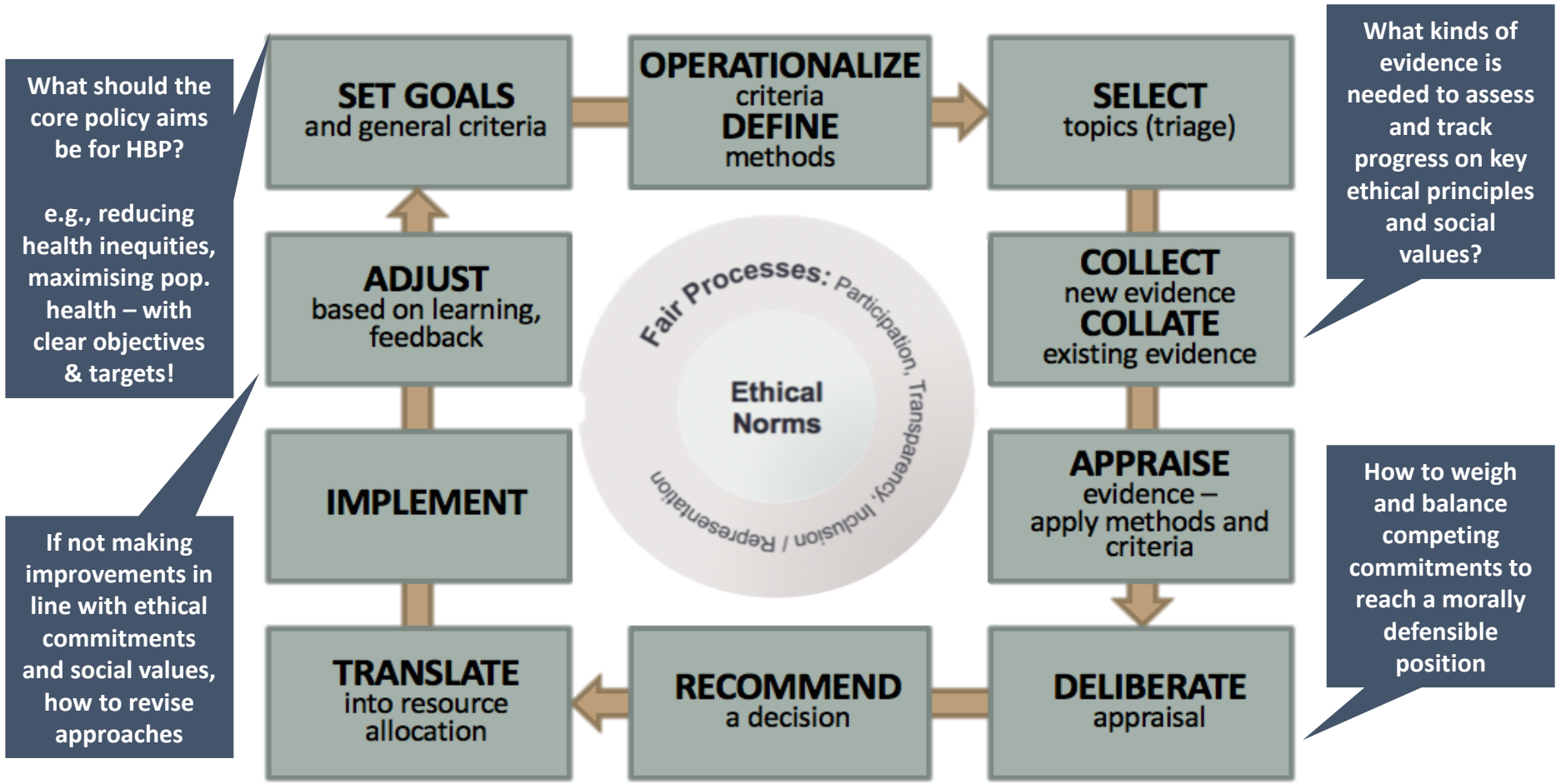


These choices are inherently value-laden with morally relevant consequences

Ethics analysis allows policymakers to examine policy options, processes and outcomes through a different lens – evaluating them against principles, norms and values. Can ensure priority-setting decisions that:

- cohere with public health goals and societal values
- are publicly justifiable and morally defensible
- protect against serious moral harms and contribution to gross inequities

Explicit Ethics Across HBP Policy Cycle



Pitfalls of Ignoring Ethics & Equity

- **Failure to realise critical goals of UHC schemes**
- **Charges of unethical practice and unfair policies**
- **Undermining public trust in the health system**
- **Challenges in the courts**

Economic&PoliticalWEEKLY

Role of Government in Funded Health Insurance Schemes

Vol. 53, Issue No. 25, 23 Jun, 2018

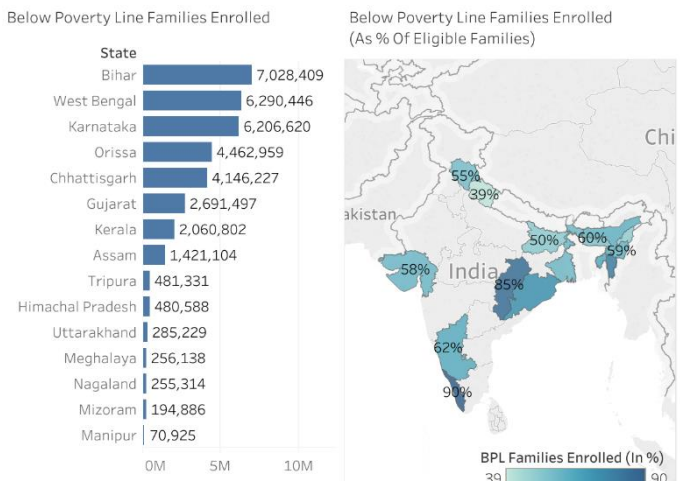
Commentary | *Tejal Barai-Jaitly, Soumitra Ghosh*

"[T]hese schemes do not take into account the fact that there are existing social exclusionary processes that exacerbate the situation for the vulnerable and marginalized… Migrants, tribals, and deserted or widowed women were found less likely to be covered by insurance schemes."

Business Standard

Why Rashtriya Swasthya Bima Yojana has failed India's poor

Coverage Of Rashtriya Swasthya Bima Yojana, By State

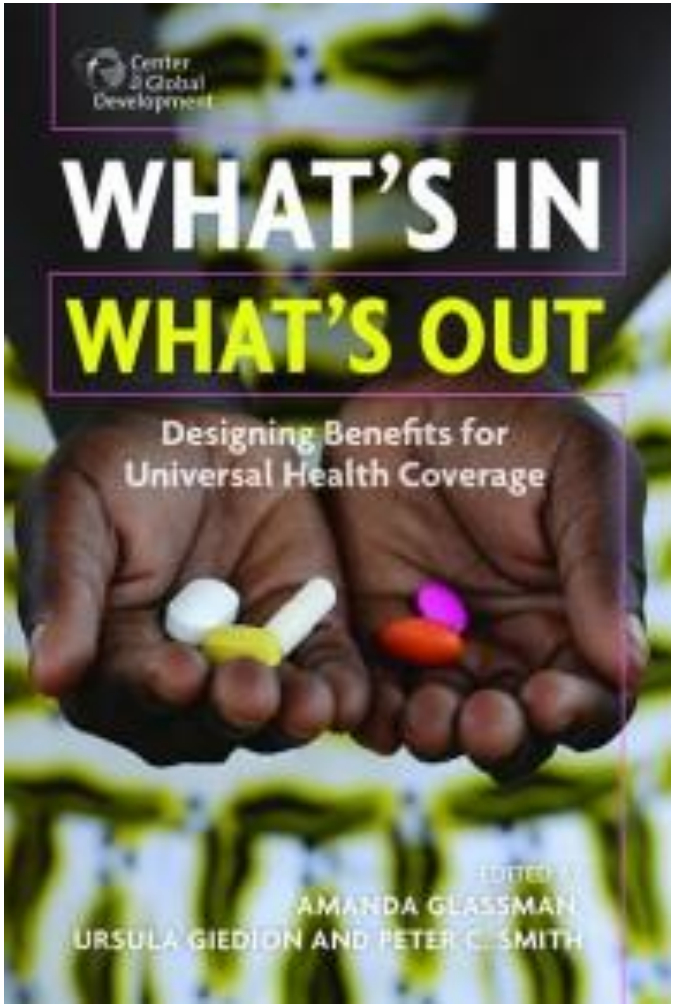


Source: RSBY (March 2017)

iDSI

Center for Global Development

Ethical Principles to Inform HBP Decision-Making



Equity

Efficiency

Individual Benefits and Harms

Respect and Dignity of Patients/Citizens

Respect for Clinician Judgment

Evidence-Informed Action and New Health Systems Knowledge

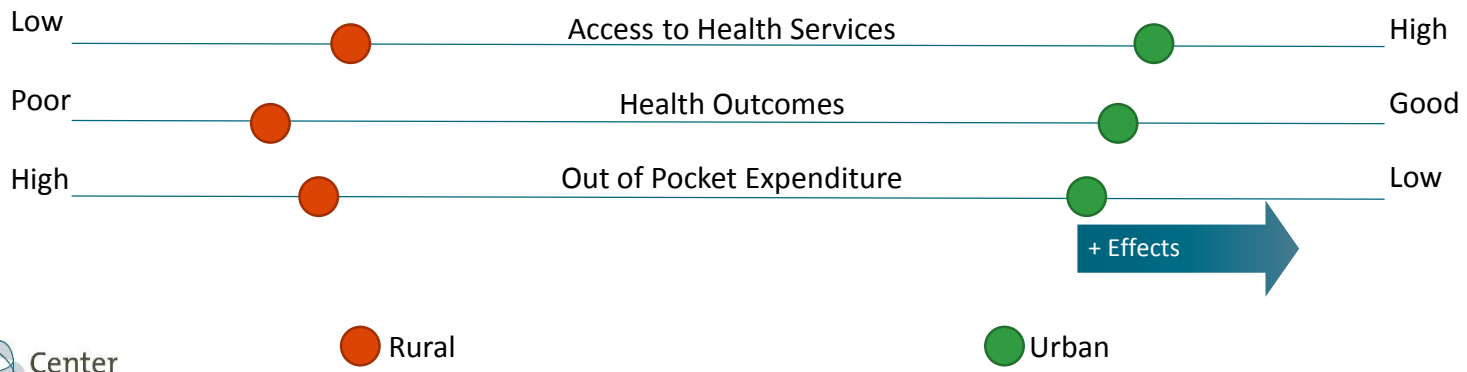
Procedural Fairness for Decision-Making

EQUITY

Relates to fairness and distributive justice

- Allocating resources unequally to address inequalities (*vertical equity*)
- Treating like cases like/non-discrimination (*horizontal equity)*

Positive obligations: address and make improvements on current disparities (unfair and avoidable inequalities in health)



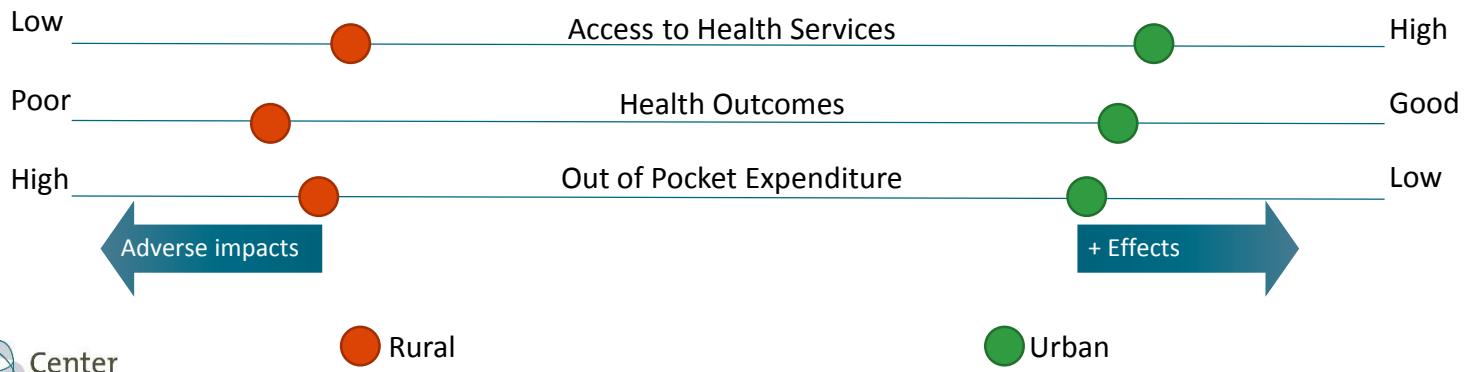
EQUITY

Relates to fairness and distributive justice

- Allocating resources unequally to address inequalities (*vertical equity*)
- Treating like cases like/non-discrimination (*horizontal equity)*

Positive obligations: address and make improvements for current disparities (unfair and avoidable inequalities in health)

Negative obligations: avoid exacerbating existing inequities or introducing new ways in which people experience unfair differences in health



EQUITY: Which inequities?

Many types of commitments and policy goals related to equity – important to clearly articulate specific commitments and targets to inform decision-making, collect evidence, track progress, make adjustments

Commitments to Equity	Explanations
Equity in Financial Protection and Cost-Sharing	Ensuring that the burdens of out-of-pocket payments and plan contributions are fairly distributed across the population, so that no one experiences an undue financial burden in accessing services
Equity in Access to Care	Ensuring that all beneficiaries experience both coverage and availability of health services
Equity in Quality of Health Care	Ensuring that all beneficiaries have access to high quality services and respectful treatment regardless of personal circumstances (geography, socio-economic status, gender, ethnicity, age, etc.)
Equity in Outcomes	Ensuring comparable improvements in health status (morbidity, mortality, burden and severity of disease) among different groups within the population

EQUITY: Which subgroups to focus on?

Each type of inequity (in access, outcomes, financial burden, etc.) can be more pronounced by specific subgroups of the population

Which groups/dimensions require special consideration in the design of the HBP? Consider what needs to be assessed by:

- Gender
- Ethnicity
- Age
- Geographic location
- Socioeconomic status
- Religion
- Other (based on context)

EFFICIENCY

Not just an economics concern! It is a moral obligation!

Using limited resources efficiently to achieve greater population health gains is a core component of all public health ethics frameworks

- Rooted in utilitarian and consequentialist theories of distributive justice

Investment in high-cost, low-value services will result in morally relevant *opportunity costs* = more suffering and more lives lost as a result of paying for expensive interventions that have little associated benefit

- Opportunity costs of inefficient allocations often fall disproportionately on the most disadvantaged (particularly when coverage of these interventions are driven by those who have greater wealth and/or political influence) – widening disparities

Many of the most cost-effective interventions are ones that benefit the most disadvantaged, and many interventions that are essential for the most disadvantaged are cost-effective

Failure to steward resources efficiently can also threaten progress on all objectives of the HBP – leading to sustainability issues and erosion of public trust

But CEA can't "Do it All"

Examples of Equity Criteria Not Well-Captured in CEA (Norheim et al. 2014)

Group 1: disease and intervention criteria	
Severity	Have you considered whether the intervention has special value because of the severity of the health condition (present and future health gap) that the intervention targets?
Realization of potential	Have you considered whether the intervention has more value than the effect size alone suggests on the grounds that it does the best possible for a patient group for whom restoration to full health is not possible?
Past health loss	Have you considered whether the intervention has special value because it targets a group that has suffered significant past health loss (e.g. chronic disability)?
Group 2: criteria related to characteristics of social groups	
Criteria	Question
Socioeconomic status	Have you considered whether the intervention has special value because it can reduce disparities in health associated with unfair inequalities in wealth, income or level of education?
Area of living	Have you considered whether the intervention has special value because it can reduce disparities in health associated with area of living?
Gender	Have you considered whether the intervention will reduce disparities in health associated with gender?
Race, ethnicity, religion and sexual orientation	Have you considered whether the intervention may disproportionally affect groups characterized by race, ethnicity, religion, and sexual orientation?
Group 3: criteria related to protection against the financial and social effects of ill health	
Economic productivity	Have you considered whether the intervention has special value because it enhances welfare to the individual and society by protecting the target population's productivity?
Care for others	Have you considered whether the intervention has special value because it enhances welfare by protecting the target population's ability to take care of others?
Catastrophic health expenditures	Have you considered whether the intervention has special value because it reduces catastrophic health expenditures for the target population?

INDIVIDUAL BENEFITS & HARMS

Although population health is the key focus of UHC schemes, must remember that individuals are going to be impacted by priority-setting decisions

- Real consequences (+/-) of adopting, denying, and delisting

When coverage decisions have negative impacts, how severe are they?

What can be done to minimize individual harms among those affected?

- Offer a different cost-effective option to provide some benefit
- Palliation to minimize suffering when tx not available
- Apply changes in coverage only to newly diagnosed

What, if any, provisions can be made to address the concerns of those with more specialized needs?

- e.g., if genetic predispositions to side-effects, gender-related differences in response – may want to consider specific targeting or eligibility criteria

➢ *looking solely at the aggregate can lead to prioritizing small benefits to the many over large benefits to the few – "the aggregation problem"*

INDIVIDUAL BENEFITS & HARMS

An Example from Thailand: HLA-B*1502 Gene Screening & Epilepsy/Neuropathic Pain

Carbamazepine: 1st line therapy – while generally safe and cost-effective, has severe, life-threatening complications or risk of permanent disabilities for <1% patients

Alternative therapies would be extremely costly if given to the entire patient population

Personalized medicine and advances in screening can help detect those most likely to have complications

With HLA-B*1502 screening can identify those that should go straight to second line options – reducing complications by 88%

Adapted from: Rattanavipapong W, Koopitakkajorn T, Praditsitthikorn N, Mahasirimongkol S, Teerawattananon Y. Economic evaluation of HLA-B* 15: 02 screening for carbamazepine-induced severe adverse drug reactions in Thailand. Epilepsia. 2013 Sep 1;54(9):1628-38.

INDIVIDUAL BENEFITS & HARMS

Engagement as a critical tool for understanding patient needs, preferences, what would be most beneficial, what harms are most important to mitigate

Understanding "Patient-Centered Outcomes" and Preferences

- Disability community: preferences for greater investments in assistive devices over novel/experimental approaches to restore function; paraplegics more concerned with restored sexual function than walking
- Kidney disease patients: 61% with ESRD expressed regret about starting dialysis – preferences for pain management, social supports, and end-of-life counseling *(Davison SN, 2010)*

Understanding patient perspectives can avoid costly, inefficient investments that not only have opportunity costs for other investments, but also better meet the expressed needs of patients receiving services

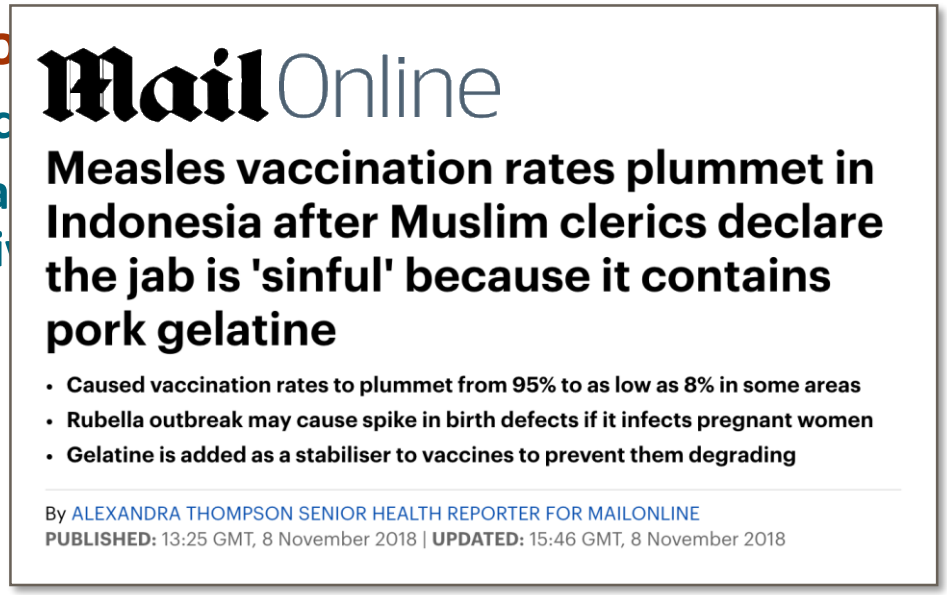
RESPECT & DIGNITY

Respect for persons and their autonomous choices

- **Many care decisions affect important aspects of peoples lives, and they want to have a say or have options**
  - *Family planning options based on pregnancy intention (LTC vs. short-term)*
  - *Choice between 2 medications that may have different kinds of side-effects – with important implications on lifestyle and functioning*
- **Other coverage decisions don't affect self-determination interests**

Sensitivity to Cultural or Religio

- **Attention to language and prac**
- **Whether certain medicines ma religions because they are deri**



Mail Online

Measles vaccination rates plummet in Indonesia after Muslim clerics declare the jab is 'sinful' because it contains pork gelatine

- Caused vaccination rates to plummet from 95% to as low as 8% in some areas
- Rubella outbreak may cause spike in birth defects if it infects pregnant women
- Gelatine is added as a stabiliser to vaccines to prevent them degrading

By ALEXANDRA THOMPSON SENIOR HEALTH REPORTER FOR MAILONLINE
PUBLISHED: 13:25 GMT, 8 November 2018 | **UPDATED:** 15:46 GMT, 8 November 2018

RESPECT & DIGNITY

Avoiding and Reducing Social Stigma

- Targeting interventions to certain population groups could stigmatise them – worth considering alongside efficiency
- Some interventions can have side-effects that may make people subject to stigma (e.g., skin discoloration with clofazimine MDR-TB tx)
- Some interventions can be offered in ways that reduce the potential for stigma (often linked to privacy-related concerns) – particularly when condition itself is stigmatised

Privacy and Confidentiality

- Offering services in a way that protects people from having private known/seen by others; Keeping data about people's information safe from unwanted disclosures

Preserving human dignity

- Helping people retain their sense of self and self-respect across all ages and stages of life

RESPECT & DIGNITY

Some Additional Examples of Services

- Coverage of incontinence-related products to preserve dignity
- At-home HIV testing kits that may reduce exposures to stigma that may result from visiting a clinic
- “Youth corners” to provide sexual and reproductive health services to adolescents to help ensure their privacy within facility settings

RESPECT FOR CLINICIAL JUDGMENT

Providers in are often in the best position to promote the best interests of individual patients, and they have role-specific obligations to do so

They are also critical to a well-functioning health system

Engaging providers and respecting their role in meeting health objectives and delivering services should be a key consideration in decision-making

But this does not mean giving practitioners discretion over every domain of health care decision-making

RESPECT FOR CLINICIAL JUDGMENT

Some priority-setting decisions impact providers' ability to carry out their obligations to patients more than others

Some physicians are also not up-to-date on the latest evidence and best practice – "the bench to bedside lag"

Also a matter of politics and pragmatics:

- *If physicians do not feel adequately respected or free to practice on their own terms through the public system, they may challenge the plan and its legitimacy, or seek opportunities in the private sector that offer greater liberty in how they care for their patients.*

What can be done to engage providers in the decision making process, to build legitimacy and buy-in for decisions?

EVIDENCE-INFORMED PRACTICE

Evidence on disease burden and *distributions* of ill health

Evidence on interventions

- Including cost-effectiveness, comparative effectiveness, and data on patient-centered outcomes
- Evidence on externalities – other non-health benefits for patients and benefits to other persons not directly receiving services
- Evidence on social values in the particular context

> *…securing just health care requires a constantly updated body of evidence about the effectiveness and value of health care interventions…*
>
> *~ Faden et al. (2013)*

iDSI Center for Global Development

Navigating Tensions and Trade-Offs

In many cases, there will be obvious “good buys for health” that are not only cost-effective but also favourable across many ethics commitments

There will also be cases where it is clear there is not a good ethical justification for coverage, like high-cost, low value services that tend to improve health only among the most advantaged members of the population

But, for a number of cases, there may be conflicts that arise across different types of ethics commitments

- One equity dimension vs another equity dimension
- Equity vs Efficiency/Affordability
- Evidence-informed practice & respect for clinician judgment

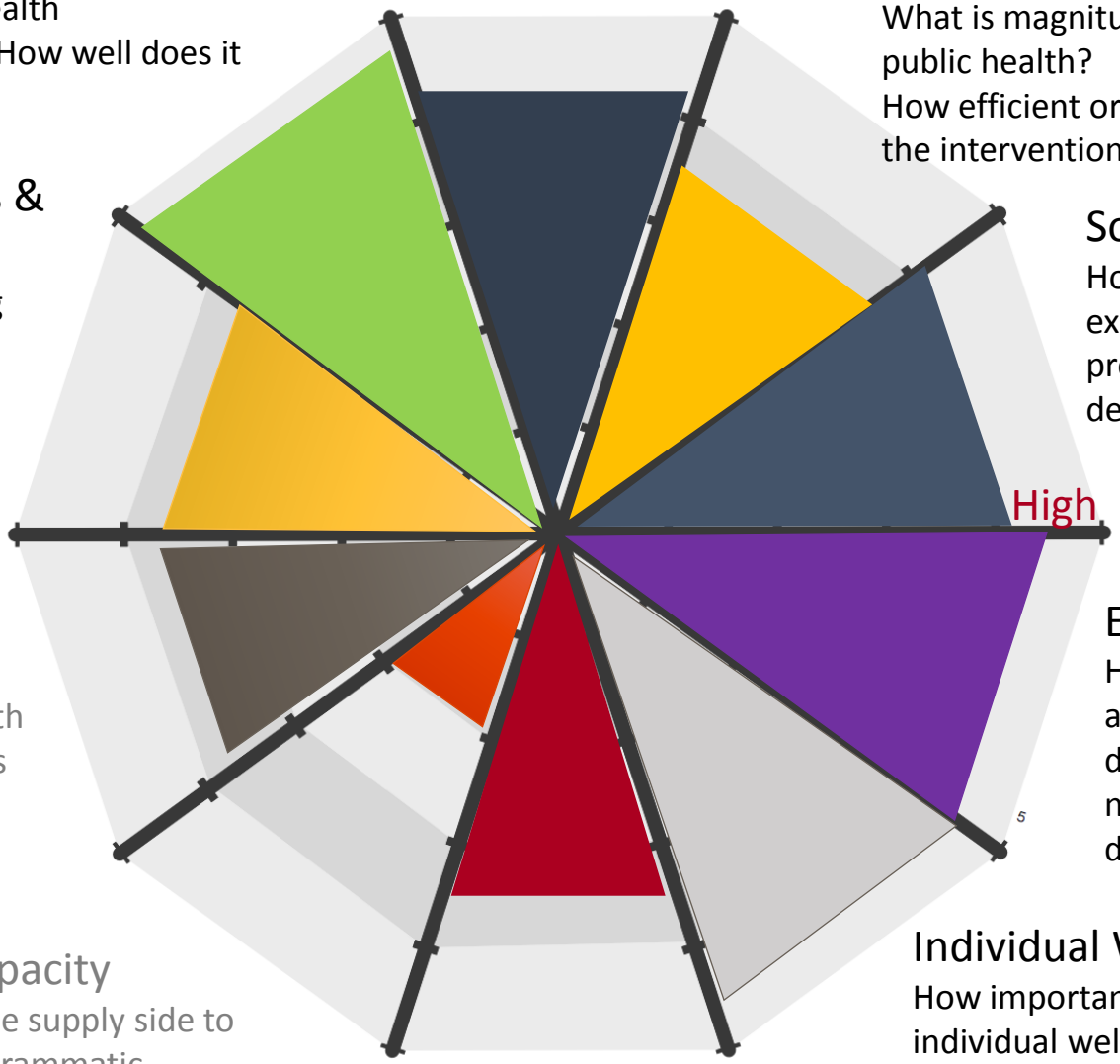
Capturing Multiple Considerations and Visualizing Tradeoffs

Financial Protection
How well does this reduce catastrophic health expenditures? How well does it reduce OOP?

Respecting Clinicians
How well does this align with meaningful provider choice?

Efficiency & Population Health Impact
What is magnitude of impact on public health?
How efficient or cost-effective is the intervention?

Respecting Patients & Preserving Dignity
How much does covering this service contribute to meaningful self-determination interests, reducing stigma, and enhancing dignity?



Social Value
How does this rank on expressed public preferences? Is demand high?

Affordability
How well does this fit with budgetary considerations and constraints?

Equity
How well does this address health disparities and the needs of the disadvantaged?

Supply Side Capacity
How prepared is the supply side to deliver on the programmatic feature of the package?

Political Feasibility
How likely to have support from important political actors?

Individual Wellbeing
How important is this service to the individual wellbeing of those who need it? How severe are the consequences of not providing the service?

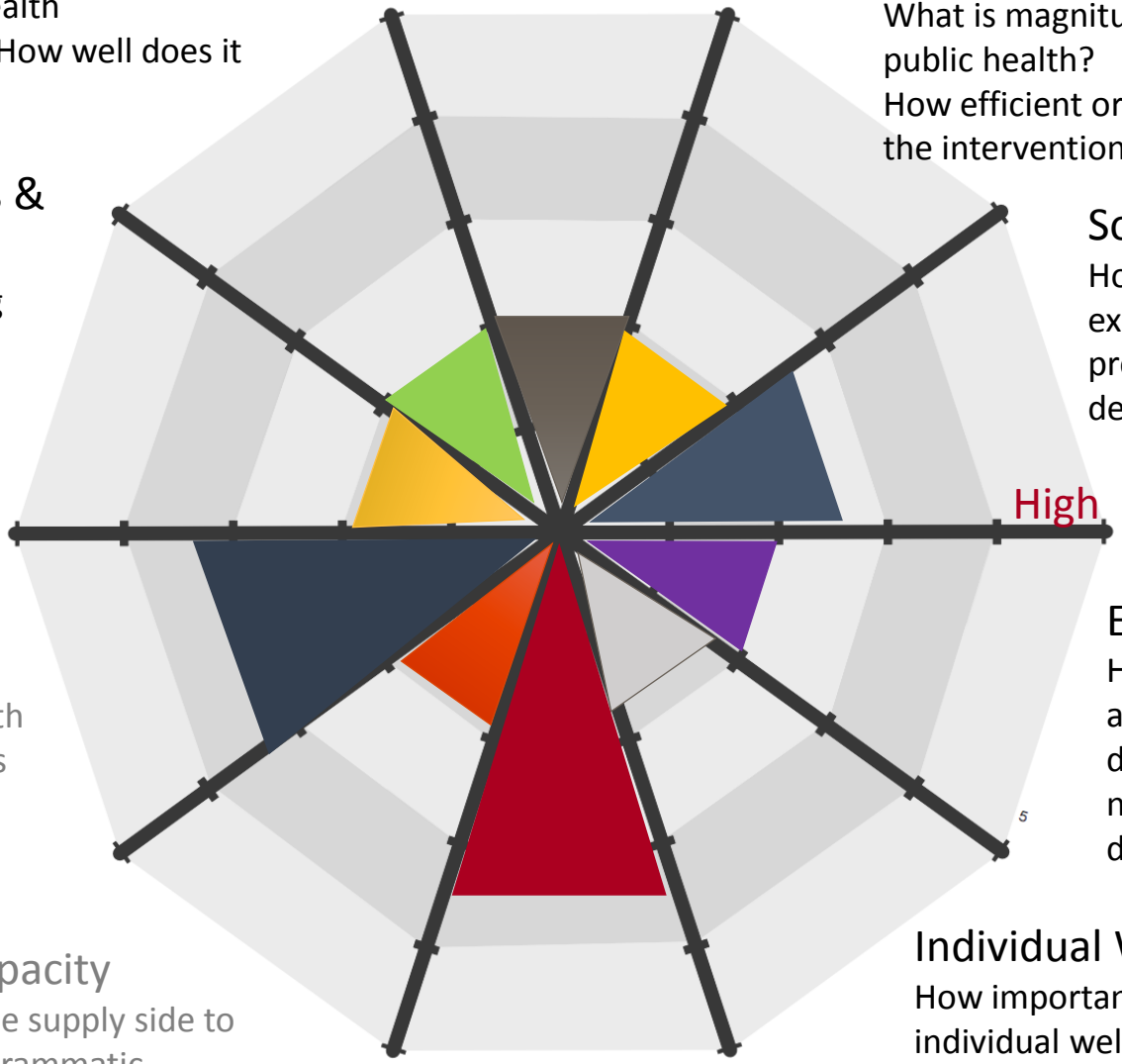
Capturing Multiple Considerations and Visualizing Tradeoffs

Financial Protection
How well does this reduce catastrophic health expenditures? How well does it reduce OOP?

Respecting Clinicians
How well does this align with meaningful provider choice?

Efficiency & Population Health Impact
What is magnitude of impact on public health?
How efficient or cost-effective is the intervention?

Respecting Patients & Preserving Dignity
How much does covering this service contribute to meaningful self-determination interests, reducing stigma, and enhancing dignity?



Social Value
How does this rank on expressed public preferences? Is demand high?

Affordability
How well does this fit with budgetary considerations and constraints?

Equity
How well does this address health disparities and the needs of the disadvantaged?

Supply Side Capacity
How prepared is the supply side to deliver on the programmatic feature of the package?

Political Feasibility
How likely to have support from important political actors?

Individual Wellbeing
How important is this service to the individual wellbeing of those who need it? How severe are the consequences of not providing the service?

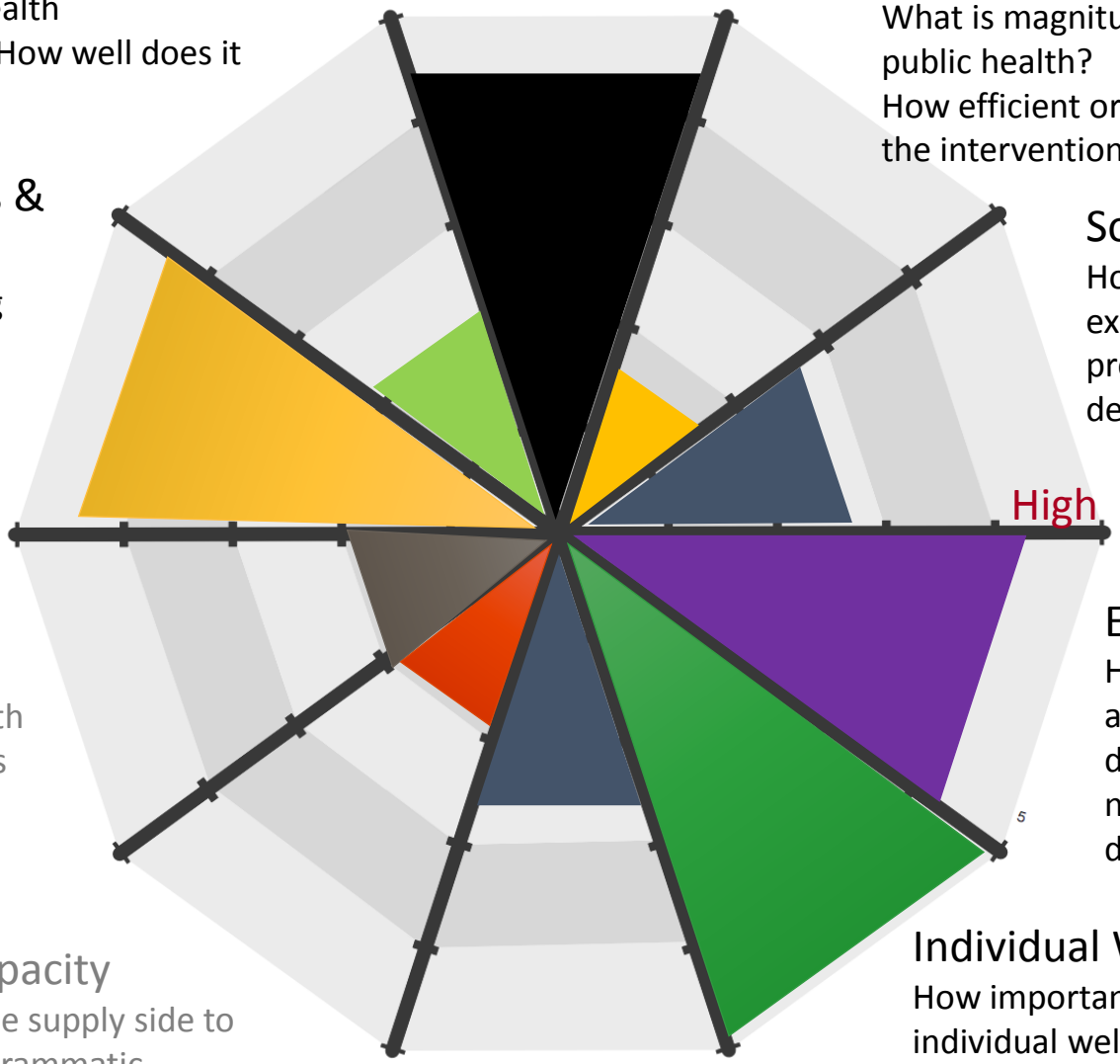
Capturing Multiple Considerations and Visualizing Tradeoffs

Financial Protection
How well does this reduce catastrophic health expenditures? How well does it reduce OOP?

Respecting Clinicians
How well does this align with meaningful provider choice?

Efficiency & Population Health Impact
What is magnitude of impact on public health?
How efficient or cost-effective is the intervention?

Respecting Patients & Preserving Dignity
How much does covering this service contribute to meaningful self-determination interests, reducing stigma, and enhancing dignity?



Social Value
How does this rank on expressed public preferences? Is demand high?

Affordability
How well does this fit with budgetary considerations and constraints?

Equity
How well does this address health disparities and the needs of the disadvantaged?

Supply Side Capacity
How prepared is the supply side to deliver on the programmatic feature of the package?

Political Feasibility
How likely to have support from important political actors?

Individual Wellbeing
How important is this service to the individual wellbeing of those who need it? How severe are the consequences of not providing the service?

Navigating Tensions and Trade-Offs

Are there other interventions for this condition that do better across the range of ethics considerations?

Are there ways to address the ways in which the intervention is ethically problematic?

On balance, based on the range of pros/cons, is the coverage decision justifiable?

Often, avoiding tough tradeoffs will not be possible. The important thing is to be able to justify the decisions taken, providing morally sound arguments for tradeoffs, and minimizing negative impacts wherever possible

Fair Processes and Procedures

Given that reasonable people will disagree about which tradeoffs ought to be made, a commitment to fair processes can help navigate these tradeoffs and result in fairer and more legitimate decisions

This includes:

- participatory processes with relevant stakeholders
- transparency about the decisions being made and the rationales for adopting them
- accountability mechanisms to ensure the plan delivers on its promises,
- opportunities for stakeholders to participate in and influence revisions to the plan

Mini Case: Maternal Care

Questions for Breakout Groups

Center for Global Development

What aspects presented in this case (or in your own State contexts) are ethically problematic?

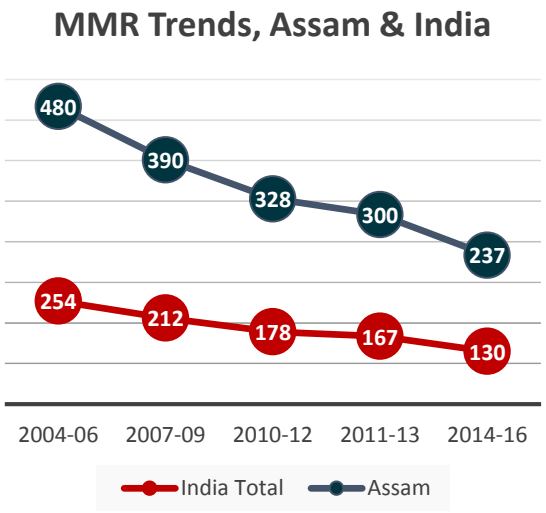
What changes can/should be made to the design and implementation of the health benefits plan to help address these issues?

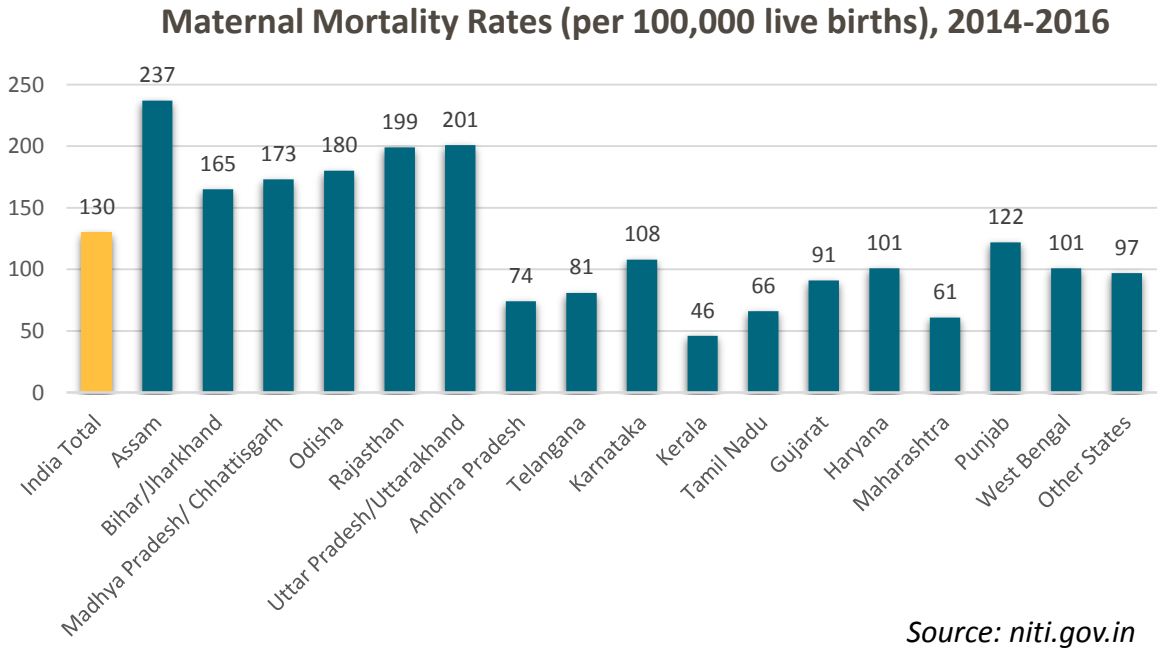
What kinds of evidence can/should be used to monitor and track progress on issues related to ethics in maternal care?

***each group will focus on *one* category of ethics consideration**

Maternal Mortality: Facts of the Case

Despite improvements in maternal mortality rates, many states in India still have still some of the highest rates of maternal death in the world





Source: niti.gov.in

iDSI Center for Global Development

Maternal Mortality: Facts of the Case

Although inequities in ANC and facility deliveries have reduced, differences in access and utilization persist

- By geographic location
- By income status
- By maternal education
- By group membership

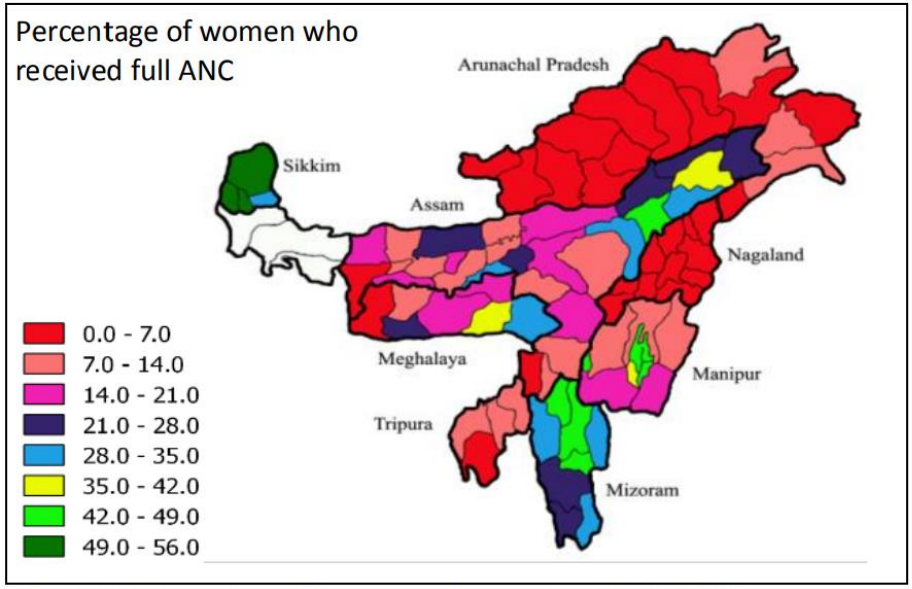


Fig 3.1: Percentage of women who received full ANC by districts

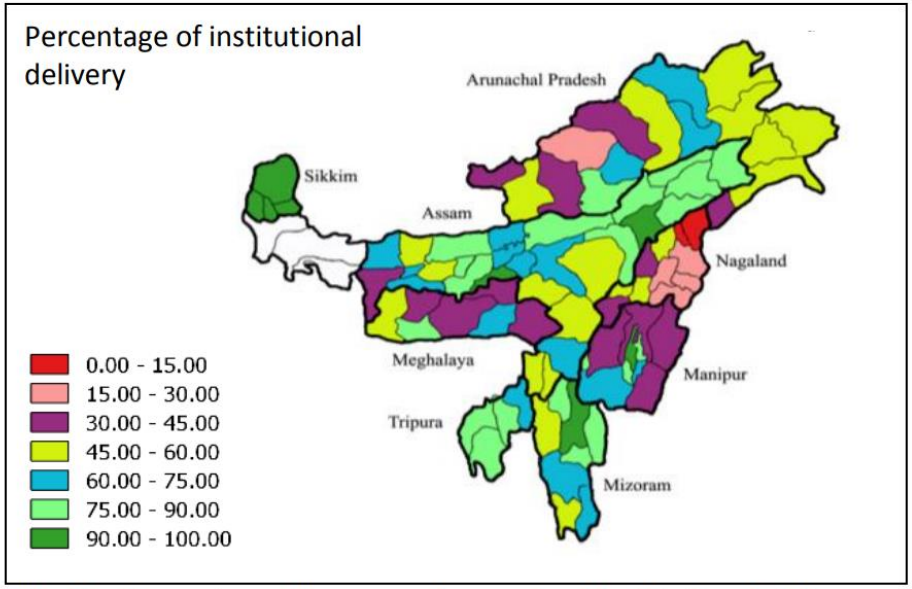


Fig 4.1: Percentage of women who received institutional delivery by districts

Source: Singh et al, 2017

Maternal Mortality: Facts of the Case

Too little, too late

- inadequate access to and uptake of evidence-based, beneficial interventions in the antenatal, intrapartum, and post-partum periods

Too much, too soon

- overuse of non-evidence-based interventions that, in some cases, may be harmful

Inadequate respect of women during labour and delivery

- Issues related to dignity and respect in the context of childbirth as well as quality of care provided

Uneven distribution of the harms/benefits of maternal care as currently provided

Source: niti.gov.in

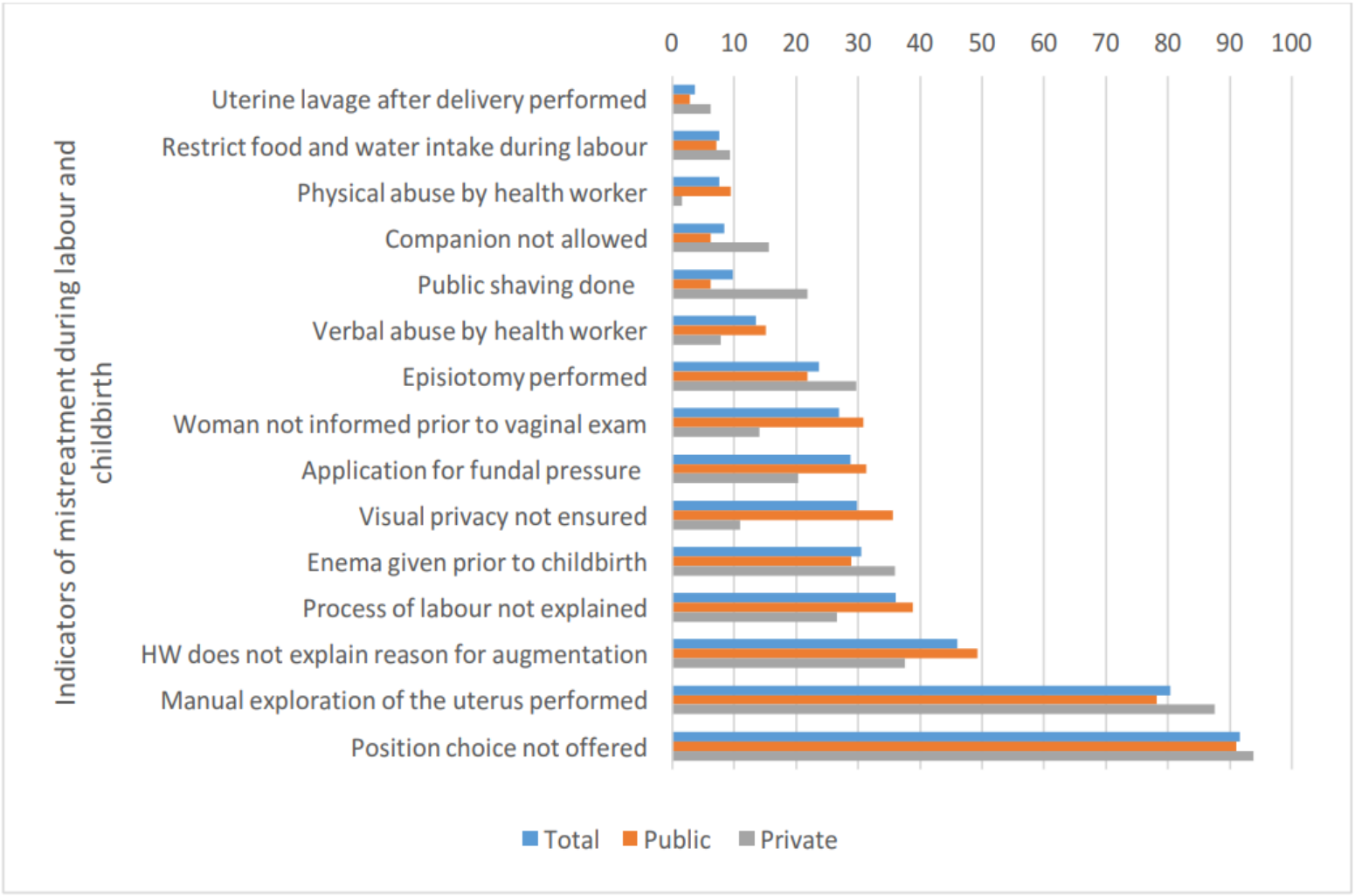
Maternal Mortality: Facts of the Case

A complex, multifaceted issue - some specific factors to consider

- High rates of anaemia; failure to identify early enough to provide iron supplementation and avert adverse maternal & newborn outcomes
- Uneven availability of blood transfusions for PPH
- Labour induction/augmentation too early or without indication
- High rates of episiotomy
- Shaving; enema
- Lack of information provided to women about procedures nor consent for episiotomy
- Reports of not using anesthesia as indicated during procedures
- Reports of mistreatment and abuse in context of childbirth

Source: niti.gov.in

Maternal Mortality: Facts of the Case



Questions for Breakout Groups

Center for Global Development

What aspects presented in this case (or in your own State contexts) are ethically problematic?

What changes can/should be made to the design and implementation of the health benefits plan to help address these issues?

What kinds of evidence can/should be used to monitor and track progress on issues related to ethics in maternal care?

***each group will focus on *one* category of ethics consideration**