

**Designing and Evaluating
Action Research:
analysis through an ethical lens**

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Action research in public health

- Comparative research on the conditions and effects of various forms of social action
- Dual commitment
 - to study a system to generate knowledge
 - to collaborate with members of the system in changing it in what is together regarded as a desirable direction

Are the commitments conflicting?

The dual commitments: what they entail?

- ***to study a system to generate knowledge***
 - Effectiveness, efficacy, processes of community based interventions
 - Using experimental methods to compare outcomes in intervention v/s control groups
- ***to collaborate with members of the system in changing it in what is together regarded as a desirable direction***
 - Social, behavioural, biomedical interventions identified to address needs
 - ‘Action’ from knowledge – programmes & policies for the ‘public’

Case Study
***The Reduction of Low Birth
Weight Project***

The Context of Jharkhand

Formed in 2000, predominantly tribal, rich in natural resources, hilly terrain with scattered settlements

- **Maternal and Child Health Indicators: a dismal scenario**

Undernutrition among children (0-5 years) (underweight)	54.6%
Low birth weight	41.7%
Undernutrition among women (15-49 years) (BMI <18.5)	42.6% *
Anaemia among women (15-49 years)	70.6%
Anaemia among pregnant women	68.4% *

- **Health Infrastructure: significant shortfalls**

Health sub-centre (HSC)	38%
Primary health centres (PHC)	64%
Community health centres (CHC)	82%

The Project – an introduction

- **Aim**

To study the effectiveness of lifecycle-based community level interventions in reducing the incidence of low birth weight and improving maternal, child and adolescent health in an area where mandated public health & related services are ensured.

- **Project Period - 2003 – 2008**

- **Project Intervention Area**

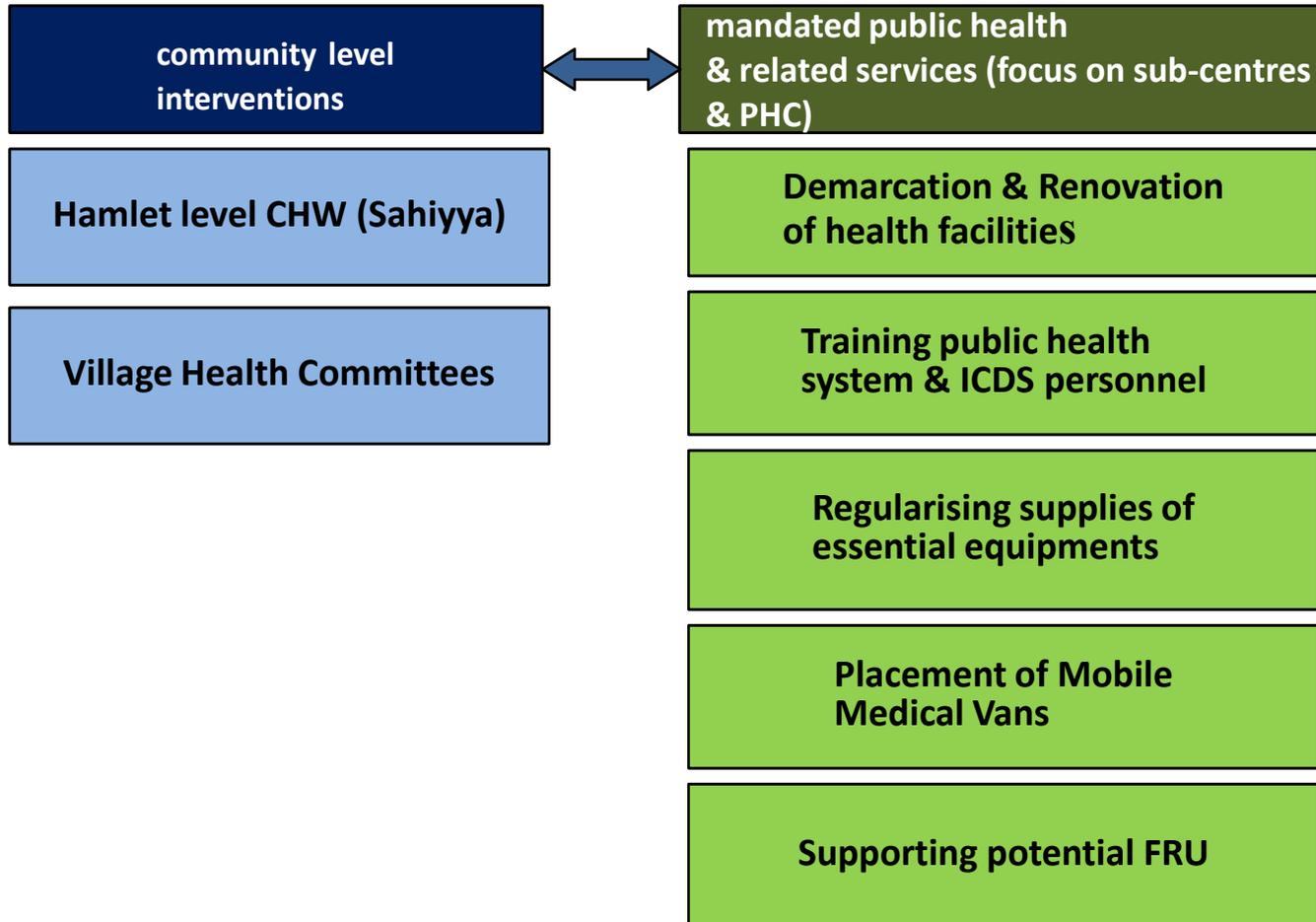
Angara & Sili blocks, Ranchi district,
Jharkhand (200,000 population approx)

- **Project Partners**

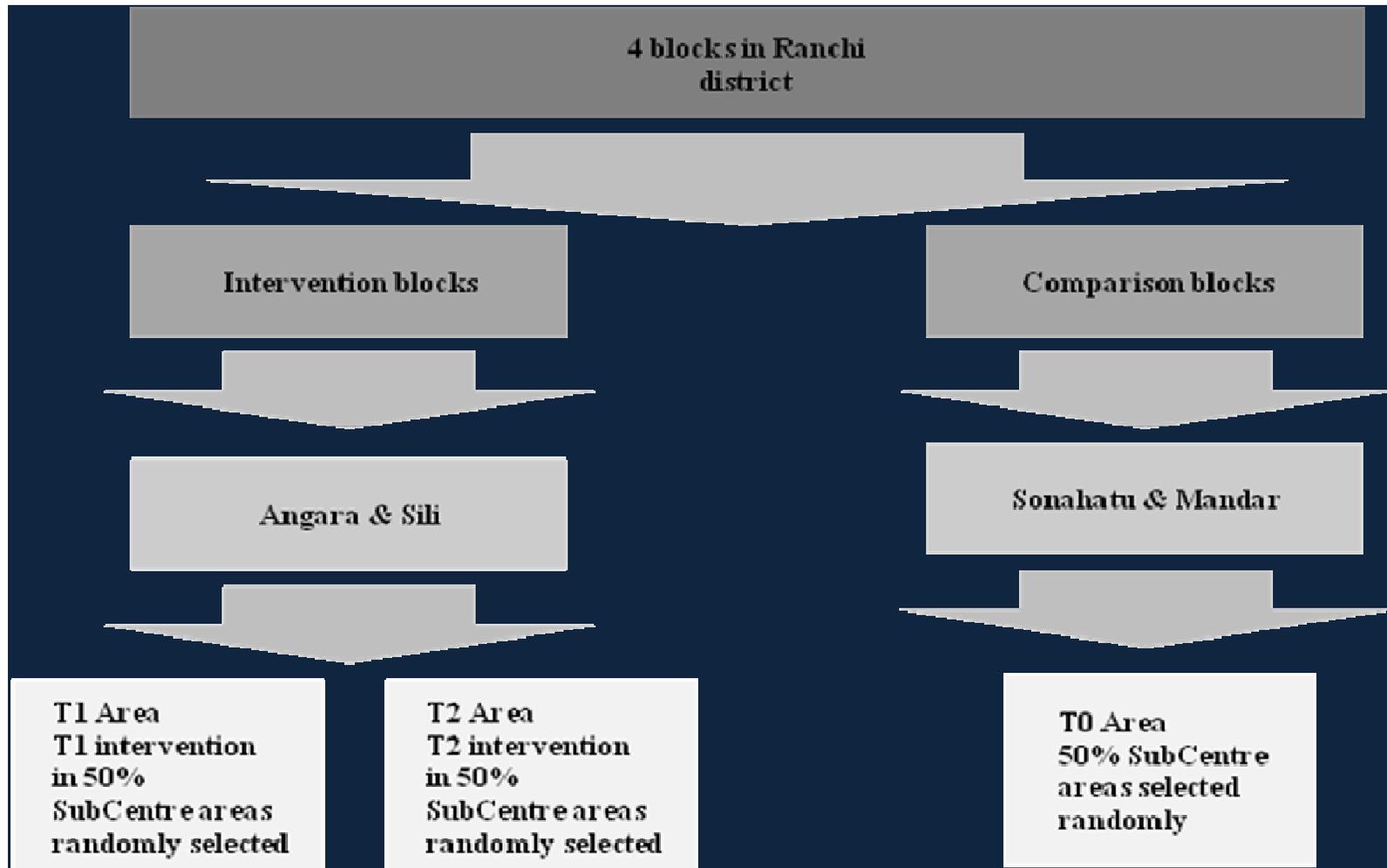
- Krishi Gram Vikas Kendra
- Child in Need in Institute
- ICICI Centre for Child Health & Nutrition
- Government of Jharkhand



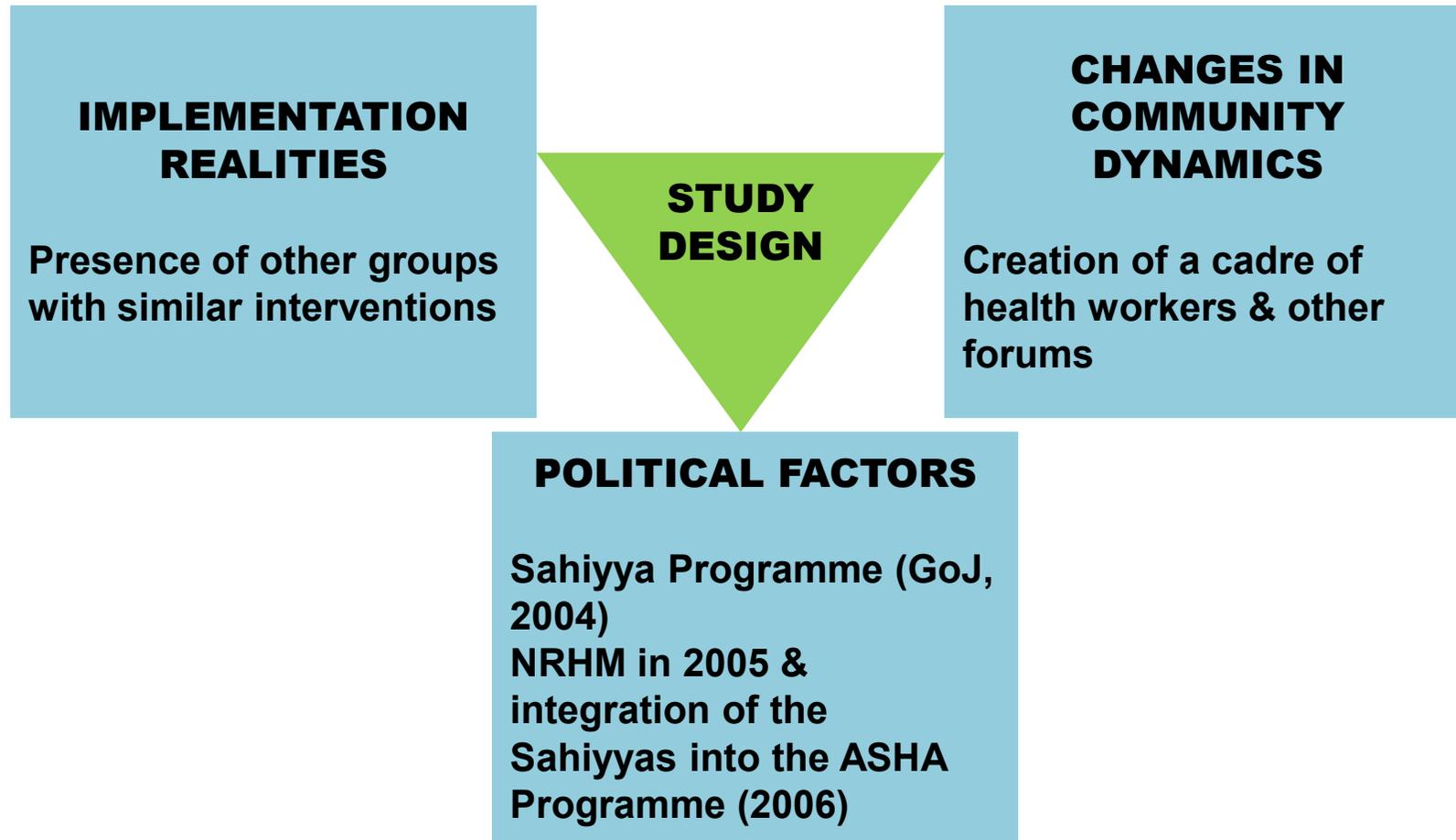
Key interventions



The study design



How the study design evolved...



Sahiyyas & VHCs (“T2 – collective action”) intervention across all blocks in Jharkhand, including T1 and T0 areas

Ethical enquiry

- Principles of biomedical ethics proposed by Beauchamp and Childress (1979)
 - ***Beneficence*** - which denotes the obligation to provide benefits and balance benefits against risks
 - ***Non-maleficence*** - which signifies the obligation to avoid the causation of harm
 - ***Autonomy*** - the obligation to respect the decision-making capacities of autonomous persons. Associated with several ideas, such as, privacy, voluntariness, choosing freely, participating, and accepting responsibility for one's choices
 - ***Justice*** - indicates the obligations of fairness in the distribution of benefits and burdens. Justice, as an ethical principle, attends to the wider inequalities in health and health care provision

Ethical dilemmas faced...

Do we support the government scale-up, or dissuade GoJ in order to maintain the study design & answer the research questions?

Given the extremely poor health context of Jharkhand, do we maintain a comparison area?

Cultural respect for local beliefs & practices v/s behaviour change based on scientific/medical knowledge

Did we scale-up an intervention that we did not conclusively know to be beneficial?

Can we attribute the positive outcomes of the research project to the interventions, since the rigour of the design was not preserved?

Do we not owe conclusive rigorous research findings to the communities – as research participants?

Ethical dilemmas in action research for public health

AUTONOMY

Research design: allocating 'intervention' & 'control' to communities randomly

Intervention design: based on theories assuming community needs

BENEFICENCE

How do we establish what is 'most beneficial' without research?

In the context of poverty, vulnerability & information asymmetry, can the community make an informed choice?

NON-MALEFICENCE

In asking research questions, some people will be denied the (seemingly beneficial) intervention

Could it be harmful to have scaled-up/universalised public health interventions without 'evidence'?

JUSTICE

Do we compromise beneficence (through pursuit of knowledge) for justice (through universalisation of the intervention)?

If the evidence of a beneficial intervention is not translated to practice and made available & accessible to all

Re-thinking ethics, public health and research

- **Positivist approach to research, action and health**
- **Ethical reductionism?**
- **Principlism versus communitarianism – moving beyond individualistic biases**
- **Ethical relativism v/s ethical universalism**

Rethinking the 4 ethical principles

- ***Autonomy*** – Not simply to make one's own choices, but to distinguish between a good and a bad choice
- ***Non-Maleficence*** – Not simply the prevention of physical harm or interference with liberty, but also threats posed to values. Social relationships and political welfare
- ***Beneficence*** – To include community reflection and support to determine what is beneficial
- ***Justice*** – Not only a judgment about what constitutes a fair distribution of health resources, but, especially in the context of scarce resources, determine what constitutes appropriate resources to distribute or should be created through research

Thank You