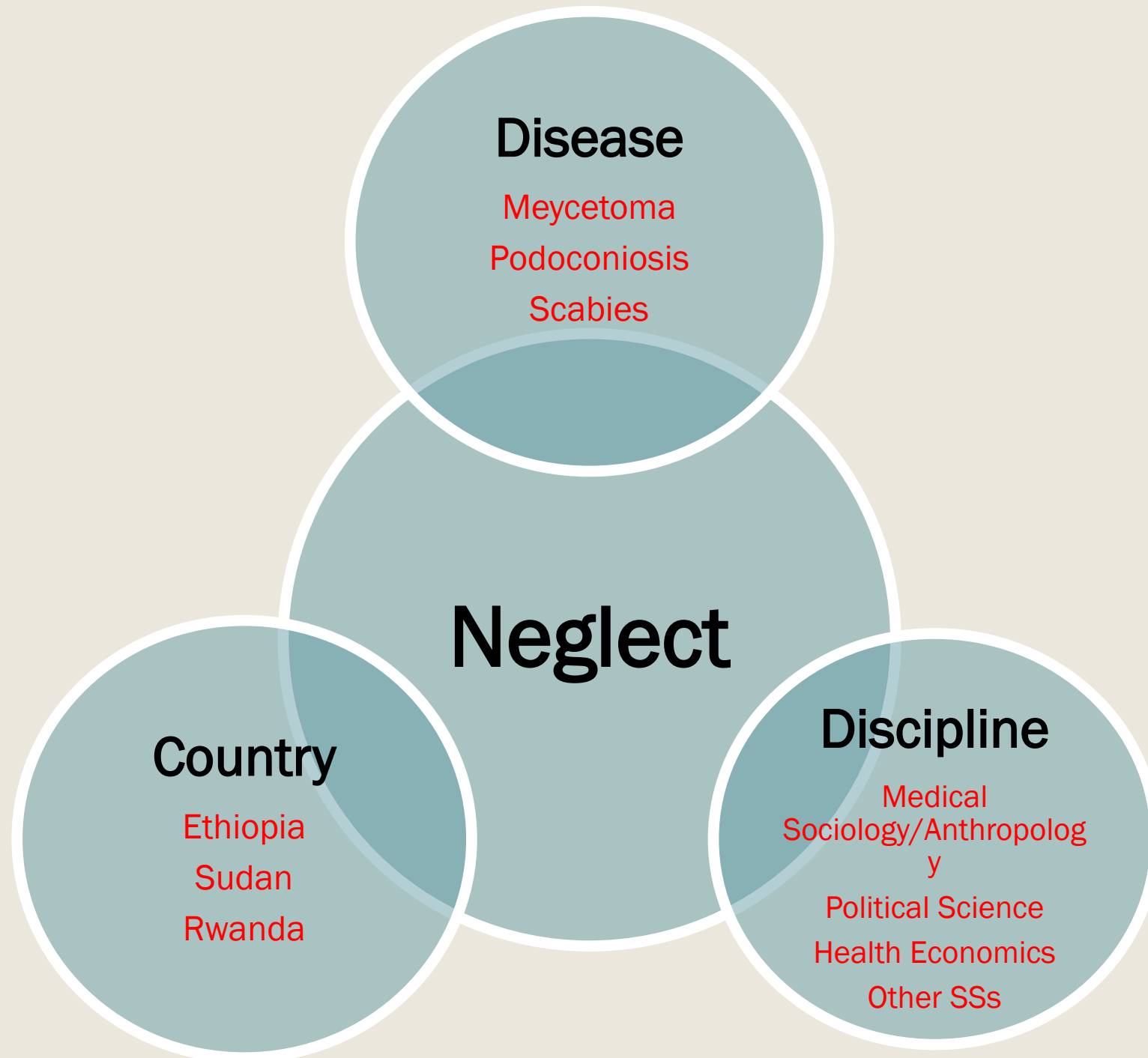# SOCIAL SCIENCES FOR SEVERE STIGMATISING SKIN DISEASES
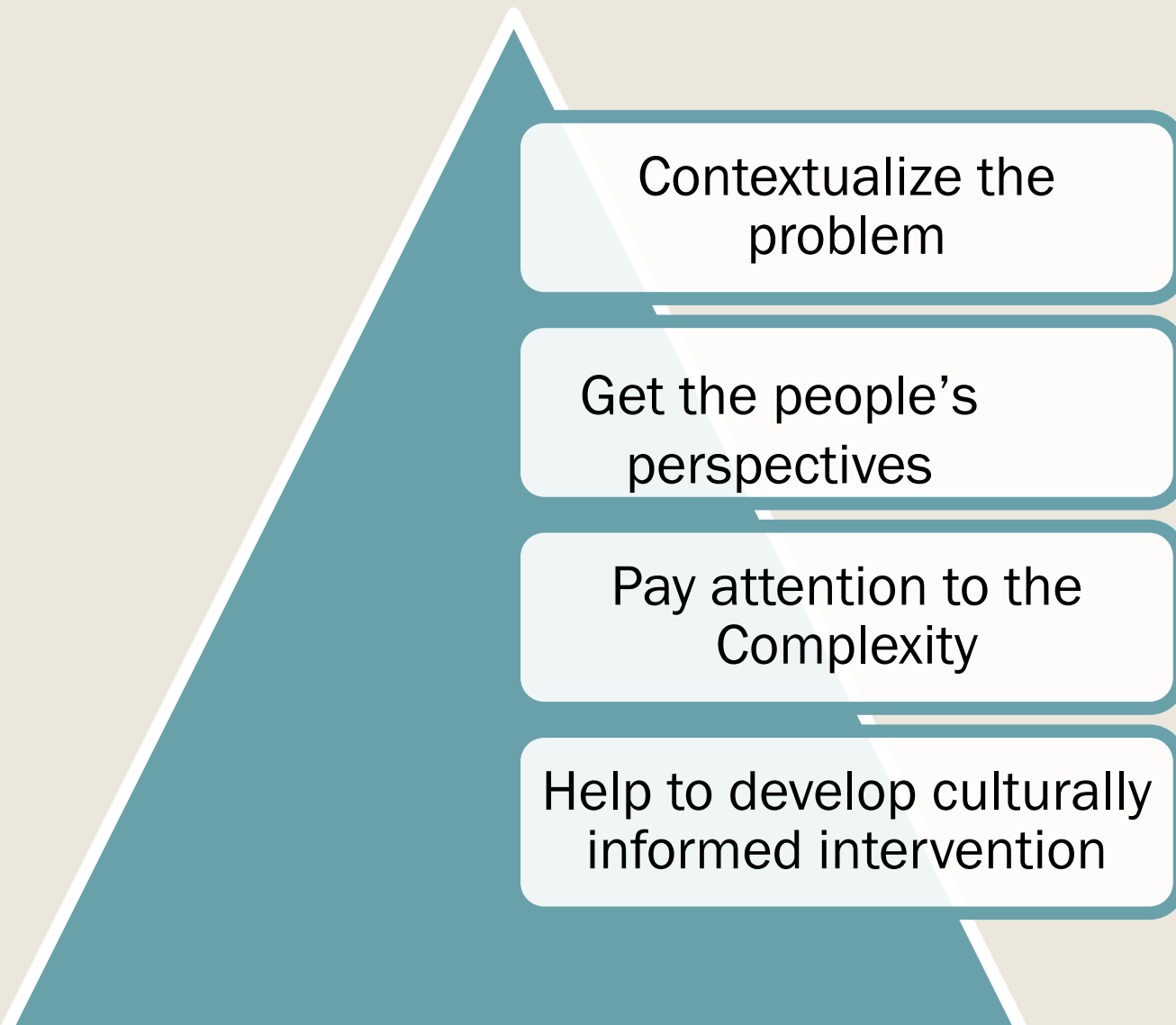
Vision of the 5S Foundation

■ to end neglect apparent at three levels; neglect of conditions, countries and disciplines.

  – *I) neglect of three heavily stigmatising skin conditions: podoconiosis, mycetoma and scabies;*

  – *II) neglect of affected patients and communities at different levels in three countries, Ethiopia, Sudan and Rwanda; and*

  – *III) neglect of the social sciences as vital global health disciplines through interdisciplinary capacity strengthening in the above countries.*

  In terms of research, intervention and local, national and global priority

Growing Awareness About

- Representations of the health 'problem' as biological and the 'solution' as technological is flawed

- Health is a biosocial issue and requires a biosocial approach

- Understanding the cultural, political, economic, and historical context in which health and health care is operating is crucial

- Stigmatized diseases need both medical and non-medical interventions

How can social science contribute

Contextualize the problem

Get the people's perspectives

Pay attention to the Complexity

Help to develop culturally informed intervention

Aims of the 5S project

- **Situational Aims**
  - *To examine the cultural logics and social and economic contexts of the selected NTDs, utilizing cross cutting social science perspectives;*
  - *To understand the dynamics and dimensions of stigma;*
  - *To investigate how all three diseases have been conceptualized at the national and international policy levels;*
  - *To evaluate existing interventions in areas in which they have already been developed;*

- **Strategic Aims**
  - *To refine a framework developed to identify gaps in understanding of the social contexts and consequences of podoconiosis, mycetoma and scabies;*
  - *To develop a comprehensive intervention strategy for each disease utilising all the evidence gathered from the above;*

- **Capacity Building Aims**
  - *To support endemic-country training posts (PhD and postdoctoral) in a manner that will leave enduring capacity for social science research across a range of local health priorities, including NTDs;*
  - *To facilitate South-South and North-South sharing of best practice in research and advocacy applicable to a wide range of stigmatising conditions in low-resource, low-literacy settings.*
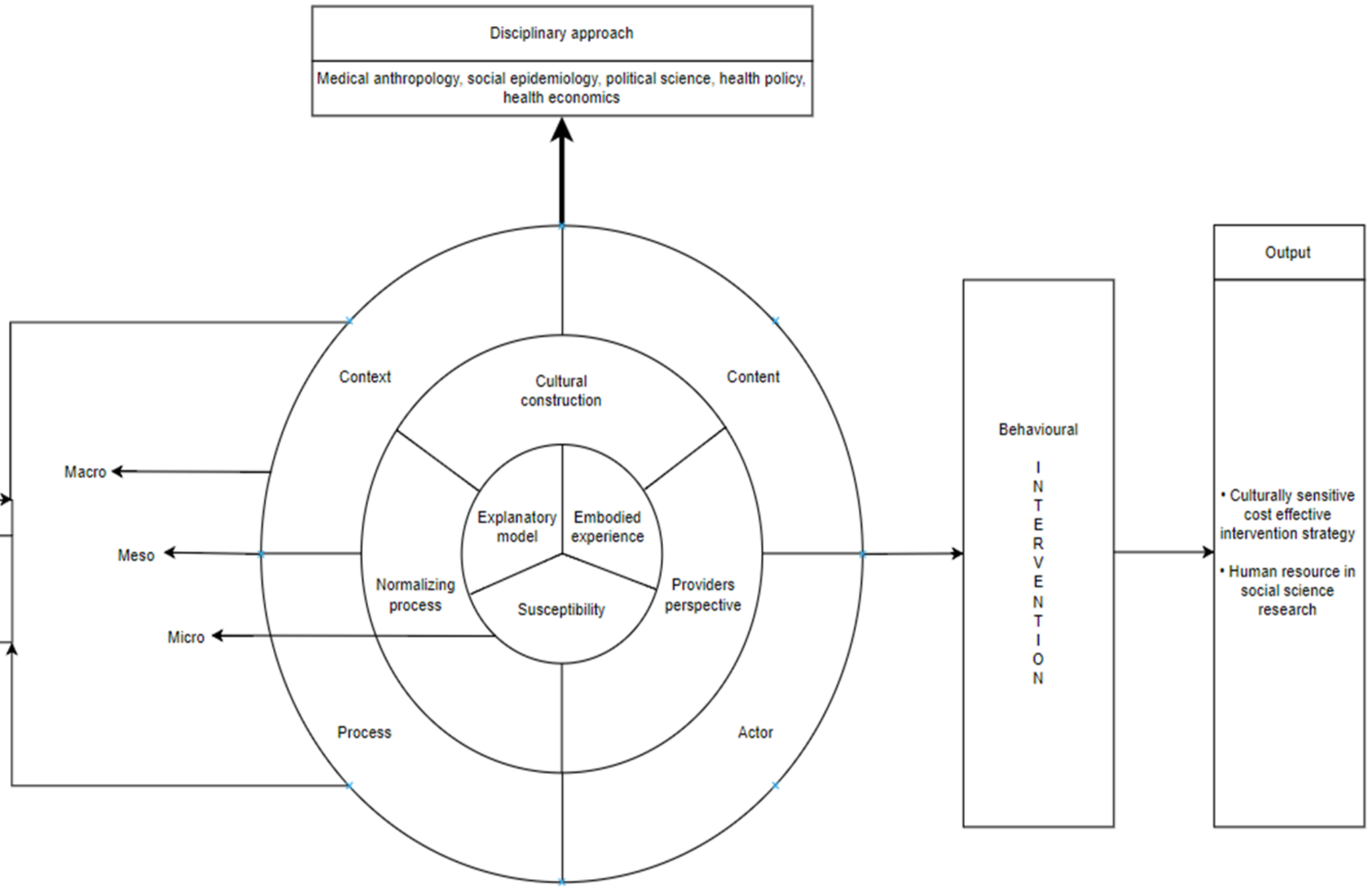
Source: Dahlgren and Whitehead, 1991

Social determinants of Health

'Paying attention to Causes of Causes'

Socio-Ecological Model
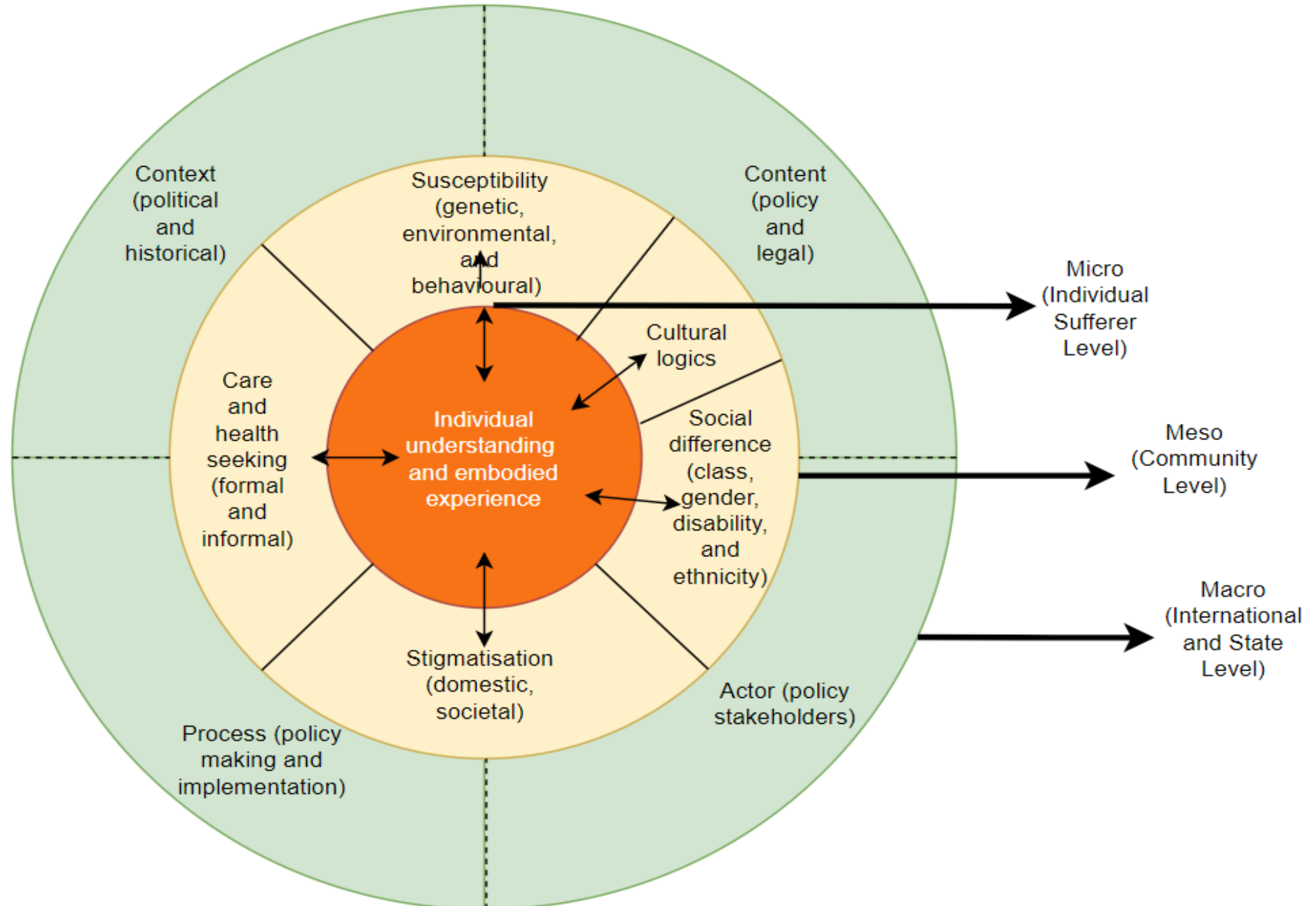

Socio-ecological framework (Theobold:2018)

Disciplinary approach

Medical anthropology, social epidemiology, political science, health policy, health economics

Context

Content

Cultural construction

Explanatory model

Embodied experience

Normalizing process

Susceptibility

Providers perspective

Process

Actor

Macro

Meso

Micro

Country

Sudan

Ethiopia

Rwanda

ondition

ma

Behavioural

INTERVENTION

Output

• Culturally sensitive cost effective intervention strategy

• Human resource in social science research

Framework 5S: Social Science for Severe Stigmatizing Skin Diseases

Macro-level situation

■ Two sets of data will be collected from the macro or national level.

   – *Existing Heath systems, facilities and interventions*

   – *Current Health policy environment*

Data will be collected on the following four issues:

- Context: To explore the social, historical, economic and political context of health related policies in Ethiopia.

- Content: To analyse the existence and content of relevant policies and strategies around the two skin diseases at national (international levels), and examine how these diseases have been conceptualized.

- Actors: To identify the key actors and their activities in the health domain in the country. This will include a wide range of national, international, government and non-government stakeholders.

- Process: To examine the process of policy-making and implementation, in particular, the roles of research and other national and international agendas.

Data Sources:

- Using a semi-structured template, information about existing country-specific health systems and facilities will be collected from secondary sources, and, if needed, primary sources through key informant interviews with relevant stakeholders.

- Secondary sources include documents on national and international health (and other) policies, strategies and guidelines; journal articles; grey literature (including reports, newspapers and blogs); and any other organisational or archival documents that shed light on the social, historical and political contexts of the above.

- Primary sources of information about the policy-making and implementation processes will include policy makers and other key decision makers within public, private and NGO domains. Methods will include document analysis (secondary data) and key informant interviews with primary sources.

At the meso level, two sets of data will be collected:

■ A) Community members' conceptualisation of the target diseases (given community might have plural views).

■ This will be explored by investigating a range of themes including -

    – *Cultural logics: what are the local names for the target diseases, what are the meanings and myths?*

    – *Social difference: how does social difference, in terms of class, gender, disability and ethnicity, influence the experience of the target diseases?*

    – *Stigmatisation: what is the nature and level of stigma attached to the target diseases? Stigma would be a core theme of this project . We will explore family- and community-level stigma as well as possible stigma generated through 'systematic exclusion' by state policies.*

    – *Care of the patient: what are the formal and informal sources of care available for those affected by the target skin conditions?*

    – *Susceptibility: what are the genetic, environmental and behavioural susceptibilities to the target diseases?*

Data

- Meso-level data will be collected from community members and leaders and from formal and informal health and social care providers in urban and rural settings including health care settings.

- Data will be gathered through focus group discussions, key informant interviews, focussed ethnography and record review (to glean economic data for cost analysis of existing interventions).

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Meso level

- B. Evaluation of Community Interventions

  - At the meso level, existing community interventions against the target diseases will be evaluated.
  - As part of the macro level situation analysis, we will list all the existing community engagement activities in the country and then select one for evaluation
  - The interventions include public health interventions or education interventions such as social media campaigns, community theatre, and other forms of public engagement like ' community conversation through coffee ceremony
  - A mixed methods evaluation framework

Micro-level situation: Two sets of data will be collected:

- A. Individual level embodied experience of the NTD-affected person will be explored. This will include:
  - *Affected person's understandings of the causes of the NTD and their management of the condition*
  - *Health seeking behaviour of the affected person and responses to the disease*
  - *Dynamics and dimensions of stigma experienced by the affected person*
  - *Social and emotional consequences of the disease on the affected person's life.*
- B.Care givers experience at the household level
  - *The factors that inhibit or encourage caregiving at the household levels*
  - *Household economic costing in relation to the disease*

Data

- Data will be gathered from adults and children affected by podoconiosis and scabies, and their household-level caregivers using life history and in depth interview methods, as well as semi-structured economic costing questionnaire

capacity building aims

- not just to conduct research, but also to develop social science capacity on a range of local health priorities, including NTDs, through training PhDs and Post doc

- Mentors or supervisors from both north and south

- Capacity Development lead

- skills audit and training plan

- Workshops and events

Public engagement

- "Public engagement is the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit."

    – *National Coordinator Centre for Public Engagement NCCP,* *www.publicengagement.ac.uk/about-engagement/what-public-engagement*

By 'public' we mean stakeholders at national and community level including patients .

Public Engagement

- In order to ensure impact of the 5S Foundation, public engagement has been integrated into the project plan.

- developed an impact, communications and engagement strategy to ensure that we maximise the impact locally, nationally and internationally

- work will be participatory and include patients, community representatives, implementers and policy makers

- SAB

- Community level PE activities

Ultimately

■ All the effort at macro, meso and micro level will provide us with insight on the following issues -

– *Gaps within and between the different levels*

– *Factors enabling and disabling interventions to enhance the wellbeing of affected persons*

– *The challenges of conducting projects to address severely stigmatized diseases (through a process evaluation)*

– *Culturally sensitive and cost effective intervention strategies*

Built human resource capacity