

S2: Annotated Conceptual Framework

Level	Components/Factors
Individual	<ul style="list-style-type: none"> • Life-course - know about the illness - a) how it manifests (symptoms), b) illness experience, c) care needed for different stages of life <ul style="list-style-type: none"> ○ Key ones - neonatal, child, adolescent, adult ○ Special category - pregnant women- maternal, elderly • Health seeking behaviours: <ul style="list-style-type: none"> ○ Seeking care in outreach programs - screening programs, access to outreach ○ Care seeking at facilities for prevention, treatment and rehabilitation, and complications ○ Self-care + self-reliance
Population	<ul style="list-style-type: none"> • Epidemiology <ul style="list-style-type: none"> ○ Prevalence (disease burden) and estimates (quality of life) ○ Associated risk factors <ul style="list-style-type: none"> ▪ Individual level ▪ Population level ○ Coverage - whether populations have been studied, gaps if any ○ Access to care • Community based intervention - anything involving a health outside a health facility <ul style="list-style-type: none"> ○ Awareness (e.g. a play), health delivery (health promotion & outreach) ○ Implemented by any government ○ Population driven activities for a community
Health Services	<ul style="list-style-type: none"> • Diagnostics- point of care <ul style="list-style-type: none"> ○ Early detection • Treatment + clinical care • Rehabilitative services • Quality of Care - evidence on high admissions due to co-morbidities – a gap in India • Healthcare outcomes • Knowledge/awareness
Health System	<ul style="list-style-type: none"> • Financing <ul style="list-style-type: none"> ○ Funding allocation for programs ○ Insurance (state/private) <ul style="list-style-type: none"> ▪ Completeness of coverage ○ Out of pocket payments • Health information systems <ul style="list-style-type: none"> ○ Registries ○ Long-term monitoring/surveillance • Governance <ul style="list-style-type: none"> ○ Who is leading the care/financing of SCD - NGO and State interventions have papers, private orgs??

	<ul style="list-style-type: none">○ Policy - state/national level● Community engagement - strategies for including ppl in treatment, screening<ul style="list-style-type: none">○ Multiple ways - patient support groups
Context	<p>Any studies that use this lens:</p> <ul style="list-style-type: none">● Socioeconomic - inequalities in care/coverage of all of the above● Political - Adivasi, social action by tribal groups on SCD care seeking, community organization for a goal● Cultural - how does SC pan out in Adviasi/non-Adivasi landscape, traditional medicine