

Codebook

AI: Background Information (Demographics and Context)

Code	Subcode	Definition
AI_Duration_Active	N/A	The period during which the respondent has been working as a patient representative.
AI_Age	N/A	The age of the respondent at the time of the interview.
AI_Organization	N/A	The specific foundation, association, or institute the respondent represents.
AI_Patient_Status	N/A	The respondent's personal relationship to the condition.

JD: Job Demands

Code	Subcode	Definition
JD_Perceived_Pressure	N/A	The general perception of workload or tension associated with the role.
	JD_Pressure_Time_Deadlines	Pressure arising from planning and workload scope.
	JD_Pressure_Emotional_Personal	Pressure affecting the individual and their private life.
	JD_Pressure_Responsibility	Pressure stemming from the substantive responsibility or seriousness of the role.
	JD_Pressure_Continuity_Dropout	Pressure caused by feeling indispensable or lacking replacement.
JD_Conflicts_Challenges	N/A	General barriers: experiences of resistance or obstacles in performing tasks.
	JD_Conflict_Role_Tension	Interpersonal barriers: tensions when working directly with others.
	JD_Conflict_System	Organizational barriers: lack of budget, rigid institutional rules, system constraints.
	JD_Conflict_Tokenism	Symbolic barriers: feeling included only superficially (as a "token patient").
	JD_Conflict_Capacity	Personal barriers: struggles with personal health and a limited pool of active representatives.

JD_Roles	N/A	General role interpretation: descriptions of tasks without focus on a specific domain.
	JD_Role_Strategic_Policy	Participation in high-level decision-making to safeguard patient interests in healthcare policy and research.
	JD_Role_Knowledge_Translation	Acting as a bridge between the medical-scientific field and patient groups.
	JD_Role_Peer_Organization	Maintaining the organization and facilitating peer support among patients.
JD_Emotional_Burden	N/A	Psychological strain resulting directly from the work content and exposure to illness.
JD_Lack_of_Resources	N/A	Insufficient tools or facilities to perform the role effectively.
JD_Support_Guidance	N/A	The degree to which the representative receives support or guidance from the organization (or lack thereof).

JR: Job Resources

Code	Subcode	Definition
JR_Autonomy	N/A	The extent to which the volunteer has control over their time, work methods, and decisions.
JR_Meaningful_Collaboration	N/A	Energy and support derived from interactions with others in the field.
JR_Compotence_Development	N/A	Opportunities for intellectual growth and acquiring new skills or knowledge.
JR_Recognition_Appreciation	N/A	Formal and informal signals that the volunteer's efforts are valued.

IM: Impact & Meaning

Code	Subcode	Definition
IM_Visible_Impact	N/A	Overall impact: tangible results (or lack thereof) in care, policy, or research.
	IM_Impact_High	Successes: positive changes attributable to the patient representative's input.
	IM_Impact_Low	Frustrations: lack of results despite significant effort; feeling ignored.
IM_Meaningfulness	N/A	The existential value of the role; turning personal setbacks into societal contribution.
IM_Personal_Growth_Development	N/A	Transformation of identity and increased self-confidence within the role.

MC: Motivation & Continuity

Code	Subcode	Definition
MC_Intrinsic_Motivation	N/A	Motivation arising from the task itself: enjoyment, intellectual challenge, or passion.
MC_Extrinsic_Motivation	N/A	Motivation driven by external factors outside the task content.
MC_Retention_Factors	N/A	Specific reasons or anchors that keep the volunteer engaged despite pressure.
MC_Doubt_Stopping_Moments	N/A	Moments of demotivation or situations where quitting was considered.
MC_Needs_Support_Motivation	N/A	Concrete needs or suggestions required to sustain motivation.

WC: Appreciation & Compensation

Code	Subcode	Definition
WC_Importance_of_Appreciation	N/A	The subjective importance the volunteer places on receiving recognition.
WC_Policy_Compensation	N/A	Knowledge and experience regarding official organizational rules on reimbursements.
WC_Experienced_Compensation_Financial	N/A	Experiences with monetary compensation.
WC_Experienced_Compensation_NonFinancial	N/A	Experiences with tangible or intangible non-monetary rewards.
WC_Opinion_on_Compensation	N/A	Evaluation of whether compensation is fair, sufficient, or appropriate relative to effort.
WC_Preference_Compensation_Type	N/A	Preferred type of reward (e.g., financial, development, status).

RA: Reflection & Closure

Code	Subcode	Definition
RA_Overall_Satisfaction	N/A	The respondent's overall subjective evaluation of the role.
RA_Role_Continuity	N/A	The respondent's expectation of how long and under what conditions they will continue in the role.
RA_Suggestions_Improvement_Role	N/A	Concrete recommendations to improve role conditions or content.
RA_Additional_Comments	N/A	Information shared by the respondent that was not covered in earlier questions.