Master Design - Thesis

# Bridging Indian rehabilitation networks

## connecting patients and informal caregivers undergoing rare chronic conditions to the care networks in India

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# Abstract

The healthcare system in India remains fragmented in its approach to chronic care management, with limited structures for supporting patients with rare chronic conditions through the transition from treatment to rehabilitation. Patients face complex challenges including limited access to information, fragmented healthcare services, and emotional strain. Informal caregivers, typically family members, experience parallel burdens of stress, uncertainty, and burnout while supporting the patient at home, often without training or institutional support.

This research explores these challenges through a bottom-up perspective, drawing on the lived experiences of patients and informal caregivers to identify unmet needs in rehabilitation. The findings reveal a lack of personalised guidance, empathetic support, and integrated care structures, resulting in cycles of confusion, isolation, and trial-and-error care management. The study identifies five foundational dimensions of rehabilitation, sensemaking and education, care planning and goal setting, resource and system access, monitoring and feedback, and emotional and psychological support, as the framework for structured and holistic intervention.

Building on these findings, the design thesis proposes Co-Care, a three-sided service platform connecting patients and informal caregivers, as a dyad, to verified care coaches through three sequential interventions: Prepare, Align, and Act. The service positions the platform as a mediator between an overburdened clinical system and the rehabilitation journey that follows discharge, orchestrating the emerging role of the care coach into a structured, verifiable, and scalable support model.

The study concludes that while system-level reform remains necessary in the long term, grounding interventions in patient and caregiver realities, and orchestrating existing roles and infrastructure rather than replacing them, offers a replicable and human-centred pathway for rare chronic care in India.

**Keywords: Rare chronic conditions, care management, support systems, service design, rehabilitation care, care coaching, dyad, care networks**

# Affidavit

I hereby solemnly declare that I have independently prepared this final year thesis.
Ideas directly or indirectly taken from outside sources are indicated as such.
The work has not previously been presented to another examination authority nor otherwise published either in the same or in similar form.

When writing the thesis, I used the AI-powered writing tools [ChatGPT, Claude] to optimize and refine the clarity and coherence of the text. All ideas, structure and content are my own unless stated otherwise.

Sharaya Deepak Naik
Lucerne, 8 June 2026

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# Acknowledgements

This thesis would not have been possible without the guidance, support, and generosity of many people across two countries and two years of work.

My deepest gratitude goes to my supervisors, Prof. Jan Christoph-Zoels and Dr. Andrew Polaine, who accompanied this project from its earliest and most uncertain moments through to its resolution. They offered direction when I felt stuck, asked the questions that sharpened my thinking, and consistently trusted me to find my own way while making sure I did not lose the thread. I am also grateful to Prof. Dr. Axel Vogelsang for his guidance and engagement with the work, and to Minh-Nguyet Le for her support during the research thesis phase. To the MAD faculty who were consistently reachable throughout the project, thank you for the openness and the guidance offered beyond the formal supervision structure.

To the patients and informal caregivers who participated in this research, thank you for the trust it took to share your stories, your struggles, and your everyday realities with a stranger. This thesis is built on your experiences and I hope it reflects them with the care they deserve. To the care coach and physiotherapist who gave their time and expertise, your perspectives shaped the service in ways that research alone could not have.

To my Service Design and MAD batchmates at HSLU, thank you for the conversations, the feedback, and the solidarity of going through this together. To HSLU as an institution, thank you for the space, the resources, and the environment to do work that matters. To the National Institute of Design, where my curiosity as a designer was first shaped, thank you for making me who I am.

To my family, my mother Bhagyashri, my father Deepak, and my brother Soham, thank you for your unwavering support from India, for every call, every word of encouragement, and for never once doubting that this was worth doing. To Ankita and Deeksha, thank you for listening to every struggle and every small victory as I found my footing abroad. And to Arijit, thank you for the constant support and motivation that carried me through the hardest stretches of this project.

# 1. Introduction

Chronic patients require holistic care that extends beyond symptom management to ensure long- term well-being. It involves a comprehensive approach that addresses physical, emotional, social, and psychological aspects of health.

In the initial stages, as patients' condition is assessed, they often undergo repeated cycles of diagnosis and treatment. Once diagnosed, they typically receive supportive treatment aimed at managing symptoms and preventing complications. This transition phase into rehabilitation and adjusting into new normal requires beyond symptomatic treatment and requires a holistic approach that integrates medical care, psychological support, and rehabilitation into a 'new lifestyle.'

Globally, adherence to rehabilitation practices remains a major challenge: according to World Health Organisation (World Health Organisation, Rehabilitation 2024), access to the course of rehabilitation is limited in developing countries, while in early findings by World Health Organisation (World Health Organisation, 2003) indicate that nearly 50% of chronic patients struggle to follow prescribed treatment plans. In India, limited access to information, financial resources, inadequate infrastructure and shortage of healthcare professionals, and rehabilitation infrastructure exacerbates these challenges.

The situation is even more precarious for patients with rare chronic conditions. Unlike more common illnesses that benefit from structured treatment pathways and broader public awareness, rare conditions often lack defined protocols, infrastructure, and support systems.

Consequently, patients with rare conditions encounter overlapping challenges not solely due to the illness, but also due to the inadequacies of the healthcare system. Informal caregivers, typically family members, accompany them in adapting to this new reality. Their care often hinges on patient sensemaking, self-advocacy, observation and improvisation, yet they remain largely invisible in public health narratives. At times, the cancer patients visit the care coaches who provide support, guidance, and resources to individuals and their families to navigate health challenges, caregiving responsibilities, or personal development goals. But the similar structure or system to receive support and guidance for rare chronic conditions is not widespread or accessible.

This research project focuses on exploring how the patients and their informal caregivers are navigating and managing their rare chronic conditions especially during the transitioning from treatment to rehabilitation in urban cities (Tier 1) in India. It explores their emotional and practical challenges, support needs, and access to healthcare information and services. The study examines the dynamics between patients, caregivers and care coaches to identify ways to strengthen communication and trust. This research understands the challenges and blockers the patients and informal caregivers go through during their navigation in the rehabilitation phase and early new normal days.

## 1.1 Healthcare Policies in India

The Indian government first announced the Ayushman Bharat Yojana as a universal health care plan in February 2018 in the 2018 Union budget of India. This policy with its sub- consisting pillar of PM-JAY will onboard the 40% of Indian population from the economically weaker sector by providing financial support to access healthcare.
It onboards the individuals towards an insurance-based system and makes the public and private healthcare more accessible to the individuals with lower economic classes (National Health Authority, 2019). These policies will cover the wide range of treatments and financial support during and after 15 days of hospitalisation in both public and private hospitals.

The policy has two pillars PM-JAY and Health and Wellness Centres. The PM-JAY focuses on the health insurance onboarding and making healthcare more accessible and affordable while the other pillar of Health and Wellness centres provide continuous, free and common Non-Communicable Diseases (NCD) conditions support.

## 1.2 Opportunity Scope and Knowledge Gap

Currently, hospitals and clinics provide care during the patient’s stay and at the time of diagnosis, but this support often ends at discharge. Boult, Karm, and Groves (2008) highlight a growing mismatch between the chronic care needs of aging populations and healthcare systems are still oriented toward acute care. They argue that managing long-term, complex conditions within a system designed for short-term illnesses leads to poor outcomes and stress the urgent need for systemic redesign.

Once patients and their informal caregivers are offboarded from the centre of care, they are often given only basic instructions for self-care. As a result, their navigation into a “new normal” is largely unsupported and marked by emotional uncertainty and doubt.

Patients with rare chronic conditions experience not only physiological pain but also the psychological shock of diagnosis. For those with rare chronic conditions, this emotional burden is heightened by the absence of established care pathways. In India, these challenges are compounded by factors such as:

- Limited access to information on adapting to a new normal
- Financial strain in making lifestyle adjustments
- Difficulties adhering to rehabilitation plans

- Low awareness of the condition and its management
- Poor accessibility to rehabilitation resources

These barriers often affect patients' social and professional lives, undermining their self-confidence and overall well-being.

Informal caregivers, typically family members face parallel challenges. They are rarely trained to manage chronic, and especially rare chronic, conditions. They must learn about the condition and its care requirements while balancing their personal, professional, and social responsibilities, which can lead to emotional strain and burnout.

While policies under the Ayushman Bharat Yojana aim to improve access to healthcare, their primary focus is on treatment affordability and universal coverage. Rehabilitation paths, particularly for the rare chronic conditions, remains underdeveloped, and it will take time before these schemes translate into tangible improvements in post-treatment support.

Overall, significant gaps persist in supporting patients and informal caregivers as they adjust to their new normal, especially in terms of information systems, emotional well-being, and social integration. Existing research rarely addresses the specific care management needs of rare chronic conditions or examines how patients and caregivers can be better supported during the rehabilitation phase.

# 2. Research Approach

## 2.1. Research Question

While there has been studies and research done on chronic conditions in India, the Indian government has started taking further steps to move towards Universal Healthcare by initiating the Health Insurance Policies and providing access to care. The research and policy interventions still lack the area of rare chronic conditions and its impact on the healthcare system and individuals' health in India.

The research question is majorly divided into two sections the pre and the during. Pre-rehabilitation is the phase where they are getting onboarded into the rehabilitation phase and start facing challenges due to gaps in the system to access necessary resources and information. The next phase that they enter is navigating and how do they access support systems and what are the key requirements and when do they need to access support.

> *- How do patients and caregivers navigate the Indian healthcare system post-treatment, and what gaps or challenges do they encounter in accessing necessary resources and information?*
>
> No major studies have taken place that focus on how the patient with rare chronic condition navigates in rehabilitation in India. To learn and understand how patients and informal caregivers proceed to navigate themselves in the rehabilitation phase. To know where the system does not really help and gaps of information and access to care is missing. To understand what types of challenges they face and how they resolve them.
>
> *- What are the key support needs of rare chronic patients and their informal caregivers during the transition from treatment to rehabilitation and long-term care management?*
>
> To learn and understand how the patient and informal caregiver identify what support they need, when they seek it, and how they construct their own systems of care in the absence of structured pathways. Understanding this helps identify where and how interventions could most meaningfully reduce the burden of self-navigation during a period of significant emotional and practical uncertainty.

## 2.2. Research Hypothesis

The rehabilitation journey for rare chronic conditions is often navigated by patients and informal caregivers through exploratory methods and a process of trial and error. This approach frequently results in cyclical “spirals” (see Figure 01), where individuals move back and forthbetween the rehabilitation phase and earlier stages of treatment or diagnosis. Over time, these spirals may diminish as patterns emerge and a structure for the “new normal” becomes clear and established.

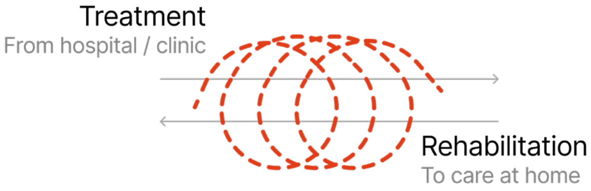


*Fig 01: Cyclical spirals in rehabilitation journey*

Such spirals are often triggered by inadequate offboarding at the end of treatment and the absence of structured onboarding into rehabilitation gaps that are particularly pronounced in rare conditions, where dedicated infrastructure is lacking.

This study hypothesises that by providing targeted support structures at critical points, where these spirals tend to occur, can reduce dependence on the healthcare system. By equipping patients and informal caregivers with the right tools, knowledge, and guidance, they can navigate rehabilitation more independently, alleviating pressure on overburdened hospital systems and making them more independent from the system. In turn, this shift allows the healthcare system to redirect focus from a predominantly treatment-based approach toward a more preventive and proactive model of care.

# 3. State of Art

During the desk research, literature review, books, research papers, reports and case studies on human-centred healthcare, patient empowerment, emotional hurdles and transitional support systems were identified to read and refer for the future study.

The identified literature creates the foundation for further work on how we can empower the patient and informal caregiver. It was further enriched with in depth review with identified metrics.

## 3.1. Healthcare system in India

To understand the challenges faced by the patients with rare chronic conditions and their informal caregivers, it is first necessary to understand the structural context of the Indian healthcare system (see Figure 02). Unlike European healthcare models, characterised by referral pathways, universal insurance coverage, digital health records, and regulated discharge protocols, the Indian system operates on fundamentally different logic.

### 3.1.1. A parallel Public and Private system

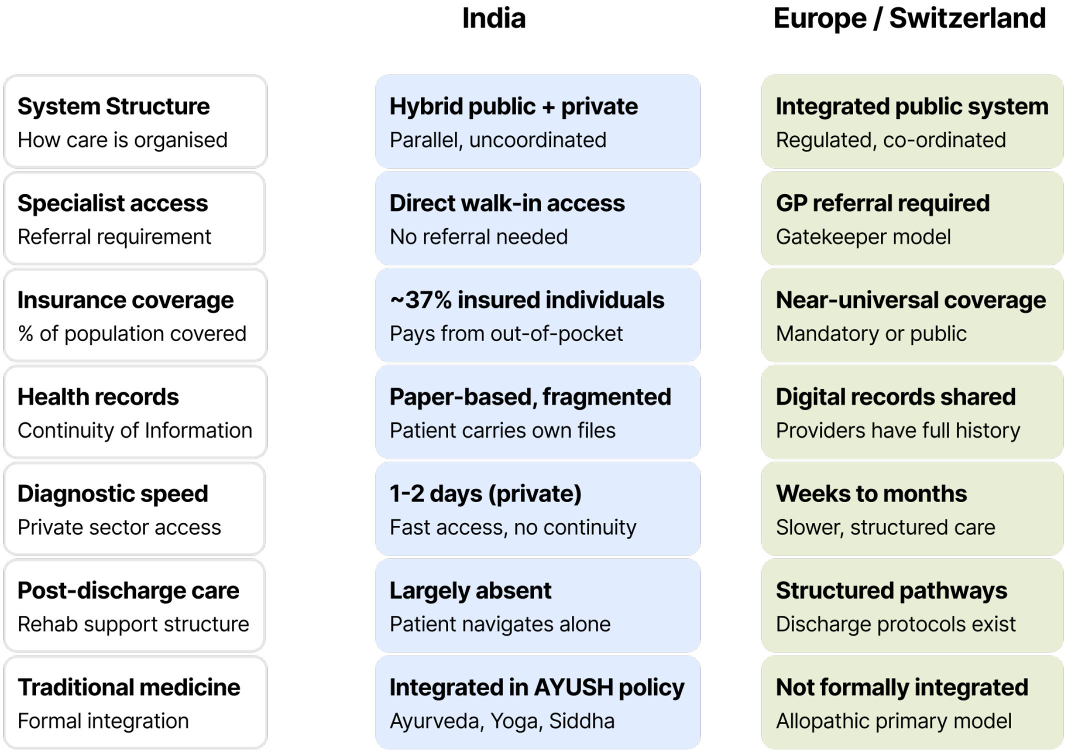
India has a hybrid healthcare system made up of both public and private providers largely parallel than in co-ordination. The public healthcare system offers free or subsidised services and is accessible and open for all, but is widely burdened by staff shortages, infrastructure gaps, long waiting times, and limited availability of specialists. Many patients, especially those managing complex or rare chronic conditions, find the public system ill-equipped for their needs and turn to the private sector, which offers faster access, and specialised care, though at significant personal cost.

In addition to hospitals, a vast network of small private clinics, independent general practitioners and informal local providers forms the primary point of contact for everyday healthcare. These providers require no referral to access, operate largely without digital systems, and play a central role in early stages of illness navigation.

Patients with long term conditions frequently end up navigating multiple clinics, diagnosis labs, and specialists, often on their own. The burden of rehabilitation falls on patients and informal caregivers to co-ordinate care in this fragmented system where the public hospitals are overcrowded, and private ones are expensive.

### 3.1.2 No gatekeeping: Direct access to specialists

Unlike many European healthcare systems, where patients must be referred by a general practitioner before accessing specialist care, India operates largely without a gatekeeping



| | India | Europe / Switzerland |
|---|---|---|
| **System Structure**<br>How care is organised | **Hybrid public + private**<br>Parallel, uncoordinated | **Integrated public system**<br>Regulated, co-ordinated |
| **Specialist access**<br>Referral requirement | **Direct walk-in access**<br>No referral needed | **GP referral required**<br>Gatekeeper model |
| **Insurance coverage**<br>% of population covered | **~37% insured individuals**<br>Pays from out-of-pocket | **Near-universal coverage**<br>Mandatory or public |
| **Health records**<br>Continuity of Information | **Paper-based, fragmented**<br>Patient carries own files | **Digital records shared**<br>Providers have full history |
| **Diagnostic speed**<br>Private sector access | **1-2 days (private)**<br>Fast access, no continuity | **Weeks to months**<br>Slower, structured care |
| **Post-discharge care**<br>Rehab support structure | **Largely absent**<br>Patient navigates alone | **Structured pathways**<br>Discharge protocols exist |
| **Traditional medicine**<br>Formal integration | **Integrated in AYUSH policy**<br>Ayurveda, Yoga, Siddha | **Not formally integrated**<br>Allopathic primary model |

*Fig 02: Healthcare landscape differences between India and Europe / Switzerland*

structure, particularly in the private sector. Patients can consult a specialist directly, book appointments independently, and move between providers without institutional coordination. There is no one responsible for the coherence of the patient's journey. The burden of navigation during initial stages of all care phases - deciding whom to see, when, and in what order falls entirely on the patient and the family.

This structural reality is visible throughout the primary research. Participants described consulting four to five doctors across different clinics and specialities within weeks, driven by mis-diagnosis and fragmented advice. Without a coordinating structure and each visit being disconnected from the last.

### 3.1.3. Out of Pocket Spending

The Indian healthcare system still heavily relies on out-of-pocket expenditure. In India approximately 37% of the population is covered under the health insurance scheme in 2021 (Statista, 2021, as cited by Pradhan D. in Forbes, 2024), meaning the majority of patients pay for consultations, diagnostics, medications, and rehabilitation entirely from personal funds and are almost never reimbursed.

This financial burden for rare chronic conditions or long term care conditions can be devastating especially during their rehabilitation journeys. As the adjustment to a new normal comes with major changes in life, starting from diet, exercise, mental health, medicines and many other factors where the adaptation needs financial support.

### 3.1.4. Speed of Access, Absence of Continuity

One of the distinguished aspects of Indian healthcare system is the speed of access to diagnostics and procedures. MRI scans, CT scans, biopsies, and even surgeries can in many cases be arranged within a few days in the private sector, compared to the waiting periods of weeks or months that are common with nationalised healthcare systems. This speed is often experienced positively by patients who can afford it.

However, speed of access does not translate to continuity of care. There is not shared digital health record system connecting providers. A patient who sees a cardiologist, a neurologist and a physiotherapist in different clinics across the same city will arrive at each appointment carrying files digital or paper or sometimes nothing at all. Each provider then assesses the patient in isolation.

The integrated care model, where a care team has visibility of the patient's full history, does not exist as a default condition in the Indian care system. It must be actively constructed by the patient or their family, if it exists at all.

### 3.1.5. Integration of Traditional Medicines

A further dimension that shapes the Indian healthcare navigation is the formal integration of traditional medicine systems into the health infrastructure. Many traditional practices like - Ayurveda, Homeopathy, Naturopathy etc carry institutional legitimacy and are actively used alongside allopathic treatment by a significant portion of the population. These practices reflect deeply held cultural beliefs about the relationship between body, mind and environment that inform how patients and caregivers make sense of healing.

The parallel use of traditional and allopathic approaches is common across chronic care management in India., pointing to a significant role that cultural and traditional practices play in how people build adherence, make sense of their condition and sustain emotional resilience.

## 3.2. Policy for Rehabilitation and Infrastructures

### 3.2.1. Healthcare policy in India

To make healthcare more accessible and affordable, the Government of India has launched flagship initiatives like Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana (AB-PM- JAY) and the establishment of Health and Wellness Centres (HWCs) across the country. As discussed in the Introduction chapter, these schemes primarily aim to reduce financial barriers to healthcare access, with AB-PM-JAY focusing on insurance-based coverage for secondary and tertiary care.

On the other hand, HWCs are designed to strengthen primary healthcare by delivering comprehensive and holistic care, especially for patients with common chronic conditions. While HWCs offer preventive, promotive, curative, palliative, and rehabilitative services, their current scope predominantly includes high-burden and commonly occurring chronic diseases such as diabetes, hypertension, and asthma.

However, rare conditions often remain outside the scope of care provided at the HWC level. Furthermore, while financial support at hospitalisation is a critical step, integration of post discharge rehabilitation, long term care and inclusion of informal caregiver support remain limited in the current policy framework. This hampers the patients' transition into sustainable rehabilitation phases, impacting the health outcomes and quality of life.

### 3.2.2. Rare Conditions Policy in India

India launched the National Policy for Rare Diseases (NPRD) in 2021, that defined and categorised 63 rare diseases. It offers up to Rs. 50 Lakhs (around Swiss Francs 47,000) in financial aid as per 2025 data per patient for treatment at 12 designated Centres of Excellence (CoE). Despite all of this, the policy is constrained by limited reach and low awareness, so far only 1118 patients (Press Information Bureau [PIB], Ministry of Health and Family Welfare, 2024) have benefited, and access depends on factors like confirmed diagnosis, proximity to CoE and awareness. Many rare diseases remain uncovered, and funding does not always match the long-term nature of these conditions. This limited reach affects the patients' transition into rehabilitation and impact on their lifestyle adaption.

### 3.2.3. Rare Disease Policy in Switzerland

Switzerland offers a particularly relevant point of comparison for this study. As one of the few counties with a dedicated national network of framework specifically addressing rare diseases, including cross-diagnostic reference centres, patient registry systems, and long-term support structures. It also represents a model where policy has moved beyond treatment access toward sustained patient and caregiver support. The author's situatedness in Switzerland during this research also enables direct access to knowledge, conversations and service examples that would otherwise have been different to reach from elsewhere.

Switzerland has made significant progress in rare disease care through its National Rare Disease Policy (2014–2019), which aimed to enhance access to diagnosis, therapy, and long-term care while promoting research and patient support. The policy fostered the development of cross-diagnostic and disease-specific reference centres, promoting interdisciplinary collaboration.

Switzerland's rare disease registry systems, such as the Swiss Rare Diseases Registry and

Orphanet Switzerland, enhance healthcare surveillance and research capabilities. Ongoing priorities include expanding specialised care structures, enhancing patient registry systems, and supporting ProRaris, the umbrella organisation for patients. These coordinated efforts demonstrate Switzerland's long-term commitment to equitable, patient-centred care for people living with rare conditions. (Federal Office of Public Health [FOPH], n.d.) Switzerland's approach exemplifies how a well-structured, long-term policy framework can go beyond symptomatic treatment to address the broader needs of people living with rare conditions.

By investing in cross-sectoral collaboration, specialised infrastructure, and national registries, the Swiss system ensures continuity of care. This model highlights the importance of moving beyond financial aid alone to create a supportive ecosystem that empowers patients and their families, an approach that can serve as a valuable reference for countries like India as they evolve their own rare disease strategies.

## 3.3. Community level interventions Rehabilitation

### 3.3.1. Organisations in India

**Indian Organisation for Rare Diseases-**
Given the gaps in policy and systemic support, non-profit organisations like the Indian Organisation for Rare Diseases (IORD) has taken a leading role. Since 2005, IORD has worked to unite patients, informal caregivers, doctors, and policymakers, while also advocating for improved rare disease care across India. They conduct awareness campaigns, organise academic conferences, and foster knowledge-sharing to bring rare conditions into mainstream conversations. (National Organisation for Rare Diseases India, 2020).

Despite IORD's extensive contributions from connecting patients with support groups, facilitating registries, advocating policy change, enabling expert volunteering, and promoting awareness a significant gap remains in its visibility and accessibility. Many patients, informal caregivers, and even frontline healthcare workers remain unaware of the organisation and its offerings.

As a result, those who could benefit the most are often left unsupported during critical moments in their care journey, let alone the rehabilitation services and supports. To create a truly inclusive and supportive rare disease ecosystem, it is essential that such initiatives are more widely integrated into public health channels, local healthcare systems, and digital platforms. A major gap lies in the lack of practical, on-the-ground resources for rehabilitation. IORD does not currently provide or enable access to home-based rehabilitation programs, peer support structures, or trained psychosocial support or care coach systems.

**Organisation for Rare Diseases India-**
The Organisation for Rare Diseases India

(ORDI) serves as a national umbrella body advocating for the rights and needs of individuals with rare diseases. It focuses on policy advocacy, public awareness, international collaboration, and promoting early diagnosis and orphan drug development. ORDI has made meaningful contributions by influencing the formulation of India’s National Policy for Rare Diseases (NPRD), promoting early diagnosis, and facilitating partnerships across sectors (Organisation for Rare Diseases India [ORDI], 2025). These efforts are vital for creating a strong macro-level foundation for rare disease care.

However, despite its policy influence, ORDI offers limited support across key patient-facing dimensions of rehabilitation. Its current scope does not extend into post-diagnostic care, which is where most rare condition families begin struggling with long-term adaptation. When viewed through the lens of the five rehabilitation support metrics (explained at end of this chapter), the gaps become more evident in patient sensemaking and education, care planning and monitoring and feedback.

Despite its stated mission of ensuring equal access to resources, current initiatives do not extend to tangible rehabilitation support such as care coordination, psychosocial support, or access to daily living aids and long-term recovery services. This creates a significant gap for individuals and family’s post-diagnosis, especially in navigating life with rare chronic, progressive, or disabling rare conditions.

### 3.3.2. Organisations in Switzerland

Switzerland’s NGOs in the field of chronic care management examples demonstrate a dual approach: professionalised care ensuring medical and logistic stability, and soft accompaniment fostering patient and caregiver emotional resilience. The lack of comparable services in India marks a critical opportunity to explore culturally and structurally appropriate adaptation of such models.

**Spitex-**
Spitex offers a strong example of structured, professional care integrated within the Swiss health system (Spitex, n.d.). Its model ensures that patients receive coordinated medical, personal, and household support within their homes, with formal needs assessments and insurance coverage enabling continuity of care. While not digitally driven, Spitex recognises the logistical burden on informal caregivers by acknowledging their limits in deciding when transitions to inpatient care are necessary.

However, the service is more clinical and system-led, lacking the softer, emotional onboarding, guided sensemaking, or everyday confidence-building tools. Spitex highlights the importance of infrastructure and coordination, while also revealing an opportunity for more human-centred, emotionally responsive support systems within professional home care. While such an approach is inspiring, adapting it to India would require weaving in cultural and traditional practices, informal care networks, and community-based trust- building that are central to the Indian caregiving experience.

**Cafe Med-**

Café Med, offered by the Academy of Human Medicine in Switzerland, is a free, conversation-based support space for patients, informal caregivers, and health professionals. It provides one-time guidance and decision support through on-site interactions with doctors, psychologists, and social workers without offering clinical treatment (Academy of Human Medicine, n.d.).

A key feature is the accompaniment service, where trained volunteers join patients during medical consultations to help them process information, ask questions, and feel emotionally supported. This model builds confidence and promotes shared decision-making addressing many emotional and cognitive challenges. However, Café Med is periodic, offline-only, and lacks long-term care continuity or digital access. Importantly, this service does not exist in India, highlighting both a contextual gap and an opportunity for adapting similar informal caregiver-inclusive interventions within Indian chronic care systems.

**Swiss Centre for Design and Healthcare-**

The Swiss Centre for Design and Health (SCDH), established in 2019 as a public and private partnership, represents Switzerland's only technology centre of excellence dedicated to design research in the healthcare sector. Funded by the state, the Canton of Bern, and private partners, the SCDH positions itself at the intersection of design, technology, and healthcare innovation. Its research and practice are structured around three primary domains: visual communication, objects and environments, and systems and processes. This tripartite focus reflects a holistic understanding of how design can influence health, spanning spaces, objects, digital products, services, and processes (Swiss Centre for Design and Healthcare, 2025).

In discussions with experts at SCDH, several emerging trends and challenges were highlighted. One of the most prominent shifts in the Swiss healthcare landscape concerns the transition of care from hospitals to the home, where recovery environments are increasingly personalised, and patient centred. Closely linked to this development are trends in the digitalisation of healthcare services and products, as well as advances in personalised medicine, enabling tailored interventions and individualised patient journeys. However, the experts also noted that despite these advancements, the healthcare industry often progresses at a relatively slow pace compared to other sectors, partly due to structural and regulatory constraints.

During the discussions, it was also highlighted that Switzerland is currently facing major workforce shortages in hospitals, adding further strain to the healthcare system. At the same time, there is a growing societal emphasis on preventive health, lifestyle awareness, adherence to care protocols, and holistic approaches, including complementary and alternative medicine. Furthermore, the integration of medical technologies, biomarkers, Internet of Things (IoT) devices, and measurable digital tools was identified as an area of rapid development, with considerable potential to support both clinical evaluation and patient experience.

Overall, the SCDH illustrates how the integration of design and healthcare can foster innovation not only at the level of medical technologies and systems but also in shaping patient experiences, promoting well-being, and enabling sustainable models of care delivery.

### 3.3.3. Care coaches in India

Care coaches play a crucial role in supporting patients and informal caregivers as they adapt to life with a chronic condition. They provide emotional support, empower individuals with knowledge to make informed decisions, and guide them through the complexities of the rehabilitation journey. By facilitating access to relevant resources and helping structure routines for adherence to treatment plans, care coaches ensure continuity and confidence in care (O’Connor, Stacey, & Légaré, 2008).

As outlined by O’Connor et al. (2008), care coaching can be conceptualised in three distinct phases: preparing for the clinical consultation, supporting deliberation about treatment options, and facilitating the implementation of behaviour or treatment change.

This phased approach is particularly relevant for patients with rare conditions, where care decisions are often preference-sensitive and emotionally complex.

In India, care coaching remains fragmented and largely privatised, with minimal integration into public healthcare systems such as Ayushman Bharat or government-led rehabilitation services. These services are typically offered through private hospitals, wellness startups, or disease-specific NGOs, leading to inconsistent quality, limited reach, and a lack of standardisation. Access is especially restricted for patients in smaller towns or rural areas, as services are predominantly concentrated in Tier 1 cities - large metropolitan cities with more with population typically above 5 million. This imbalance and fragmentation also lead to a significant lack of awareness among patients and informal caregivers, as they remain unaware of the role care coaches can play and are left to self- navigate the complexities of long-term care and rehabilitation.

Care coaches are commonly seen to provide guidance to cancer patients, where their role is relatively more structured and recognised. In contrast, care coaches for rare chronic conditions are scarce, limiting availability for those who might benefit most.

As care coaches are not embedded within official discharge protocols or treatment plans, there is no institutional obligation to assign them or ensure continuity of their involvement. The absence of national guidelines or role definitions further creates ambiguity around their responsibilities, making it difficult to measure or monitor their impact on patient outcomes. Despite evidence supporting the efficacy of health coaching, O’Connor et al. (2008) notes that its integration into clinical practice remains limited. This highlights the need for care coaching to be embedded into care coordination and not isolated in centres or external programs.

Without systemic accountability, their potential to support adaptation to a new normal in chronic conditions remains largely untapped. The future of health coaching lies in adaptive systems that blend digital tools with human support. O’Connor et al. (2008) suggest that electronic self-reports can serve as prompts for coaching interventions allowing for timely, personalised, and clinically linked support.

## 3.4. Dimensions of Rehabilitation

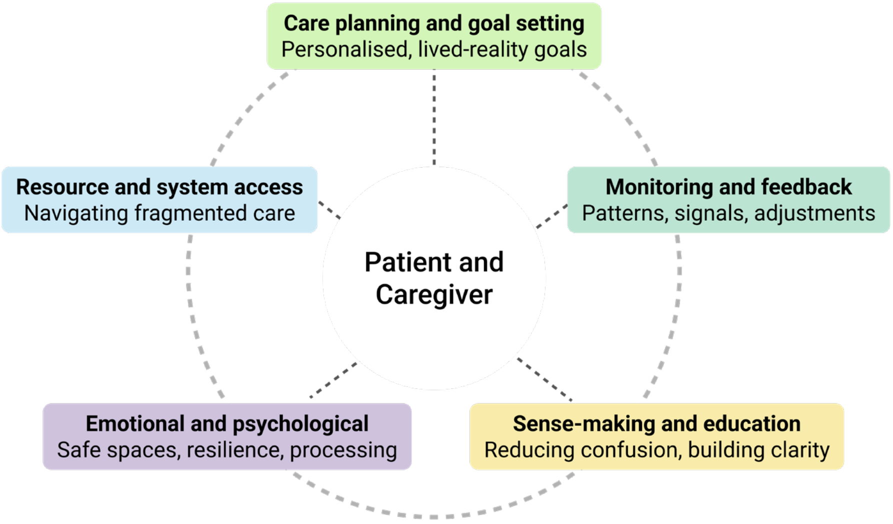


*Fig 03: Dimensions of Rehabilitation*

Based on a literature review of literature and insights drawn from relevant case studies, this research identifies five foundational dimensions that will inform the remainder of the study.

In the Indian context, patients diagnosed with rare chronic conditions often encounter an ambiguous and unsupported phase once treatment commences or concludes. With limited formal guidance, both patients and their families are frequently left to navigate the transition to a new normal one that demands sustained lifestyle changes, emotional adjustment, and ongoing self-education.

This transitional period highlights the need for a structured and empathetic onboarding into rehabilitation, where support mechanisms are in place to foster clarity, continuity, and a sense of shared experience. For such a framework to be effective, several core components must be established: access to reliable information, individualised care planning, emotional and psychosocial support, systems for feedback and reflection, and navigational guidance through the care journey. These foundational dimensions (see Figure 03) serve to make the rehabilitation experience more coherent, human-centred, and sustainable over time.

### 3.4.1. Sensemaking and Education

It is essential for rare chronic condition patients and informal caregivers to access clear, relevant information about the rehabilitation journey, their condition, and the actions they need to take. This rehabilitation phase often marks the beginning of their exploration journey where curiosity and a desire to understand are deeply entangled with fear and uncertainty.

As Jones,P. (2013) articulates, patients often “do not know what they don’t know” by the end of their search. Health information seeking is rarely linear or conclusive; it is complex, emotional, and frequently without a clearly defined goal or endpoint. Unlike goal-based information seeking, here the individual’s end state is unknowable both in terms of medical outcomes and personal adaptation. This creates a challenge where patients and caregivers are searching for answers to questions they don’t yet know how to ask. To support them, a well-structured and responsive information system is needed, one that offers timely, layered, and context-sensitive content. Such systems reduce cognitive load, lower emotional stress, and empower individuals to gradually make sense of their new reality.

### 3.4.2. Care Planning and Goal Setting

As patients and informal caregivers are onboarded into their rehabilitation journey, there is a need for structured care planning that is personalised to the individual’s health status and shaped by their economic, social, and cultural context. A one-size-fits-all approach is insufficient care and must adapt to the realities of each person’s life, including their capabilities, constraints, and available support systems.

For care planning to be effective and for meaningful goals to be set, there must be consistent and open two-way communication between patients, informal caregivers, and healthcare professionals. Communication is not an add-on; it is a foundational enabler of planning. It allows care teams to understand what matters most to the patient, to surface challenges early, and to align clinical objectives with the patient’s lived reality. Studies have shown that structured and personalised care planning and consistent two-way communication can help in early detection of complications and alignment of care goals (Misky, Wald, & Coleman, 2010).

Goal setting is an integral part of this process. Rather than focusing solely on medical milestones, goals should be rooted in the patient’s personal aspirations such as returning to work, resuming household roles, or participating in social and spiritual life. It gives rare chronic condition patients and informal caregivers something meaningful to work toward, even in the face of uncertainty or long recovery timelines.

### 3.4.3. Resources and System Access

As patients and informal caregivers begin to adapt to their new normal, they are often provided with limited information about available resources. Many are unaware of their options for expert care, medical equipment, or financial support. Access is further limited by factors such as socioeconomic status, geography, health and digital literacy, and cultural norms.

In rare or chronic conditions, the situation is even more fragmented, policies and support systems often don't reach those who need them, and awareness remains low. Patient associations and NGOs can play a key role in rising awareness and bridging gaps in access, while government schemes can provide financial and infrastructural support. Doctors and rehabilitation specialists can guide families towards trusted services, and care coaches can help co-ordinate between these different resources. By improving this network of support, families are better able to connect with expert guidance, necessary tools, and financial aid. Effective care co-ordination can significantly reduce the stress of navigating the system and improve continuity of care.

### 3.4.4. Monitoring and Feedback

Monitoring and feedback are essential parts of the rehabilitation journey, especially in the early stages for patients and informal caregivers managing rare or chronic conditions. Consistent and ongoing tracking symptoms, signs, and triggers helps identify patterns and build a clearer understanding of what works and what doesn't.

When a system for monitoring is in place, it provides structure to an otherwise uncertain journey, and supports timely interventions, and avoids repeated mistakes (Hetermann, 2024). It not only empowers patients by giving them the control over their health but also reduces the frequency of hospital visits and associated health costs.

Feedback whether from the patient, caregiver, or healthcare provider helps adapt the care plan over time and improves adherence. Furthermore, technology-enabled monitoring and integrated care teams can provide continuous support, enhancing convenience, comfort, and quality of life. Together, monitoring and feedback make the rehabilitation process more intentional, responsive, and easier to navigate.

### 3.4.5. Emotional and Psychological Support

The early years of rehabilitation can be emotionally challenging for both patients and informal caregivers. As they adjust to a new normal, they often face fear, anxiety, and isolation. Support for emotional and psychological well-being is essential during this phase. Studies have shown that both caregivers and patients frequently experience emotional distress post-discharge, with caregivers reporting feelings of overload and patients expressing guilt about being a burden (Lilleheie, Debesay, Bye, & Bergland, 2021).

In conditions like cancer, structured systems such as support groups or counselling are more commonly available and aware, helping individuals feel heard and understood.

However, such support is often lacking in other chronic or rare conditions. The absence of structured emotional support can exacerbate the stress experienced by both parties during rehabilitation (Lilleheie et al., 2020). Providing safe spaces for expression and connection can make the rehabilitation journey more manageable and less overwhelming.

**Summary**
These five dimensions: sensemaking and education, personalised care planning, resource access, monitoring and feedback, and emotional support form an interrelated framework essential for supporting patients and informal caregivers through the complexities of rare chronic condition rehabilitation.

In the following section, this framework will be used to critically analyse existing individual-level interventions, including digital applications and analogue methods, to identify current strengths, gaps, and opportunities for scalable, holistic care support in the Indian context.

## 3.5. Individual level Rehabilitation

Rehabilitation at the individual level unfolds across multiple layers. Patients and informal caregivers have distinct roles and responsibilities, with some overlapping and others remaining unique. Both parties must monitor, manage, store, process, and make sense of a range of health-related information while adapting to a new normal.

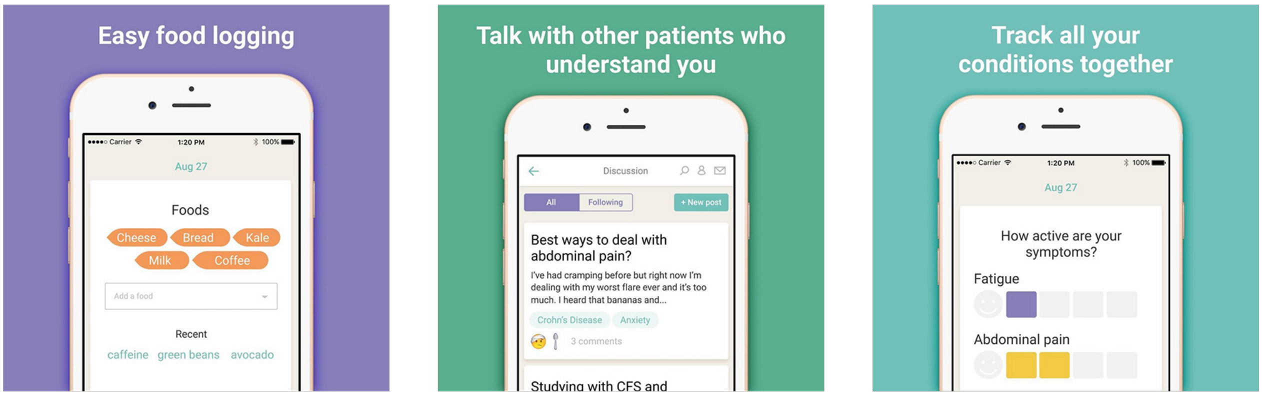
Chronic care management involves a combination of digital and analogue methods, each serving different needs and contexts. Digital tools such as apps, wearables, and remote monitoring systems offer scalable, data-driven support for tracking, education, and coordination. In contrast, analogue approaches like diaries, printed materials, in-person coaching, and family reminders remain essential, particularly for those with limited digital access or a preference for more personal, human-centred support. In India, these approaches coexist to form a hybrid ecosystem that reflects the country’s diverse patient needs and healthcare access realities.

Chronic care applications typically focus on specific aspects of the rehabilitation and care journey. The key functional categories include, monitoring and tracking, care planning and management, reflection and emotional expression, data storage and digitisation, and support-seeking or engagement.

Well-regarded within niche communities,

applications such as Flaredown, Bearable, and Curable, along with Tatva and HealthifyMe in India, represent varying models, some focused on a particular condition or function, while others aim for a more holistic approach. These apps reflect how digital tools can support rehabilitation process in different yet complementary ways.

## 3.5.1. Flaredown



Best ways to deal with abdominal pain?
I've had cramping before but right now I'm dealing with my worst flare ever and it's too much. I heard that bananas and...

Studying with CFS and

*Fig 04: Flaredown application*

Flaredown was founded in 2014 in New York City, USA. Flaredown is a symptom tracking platform designed to help individuals with chronic conditions identify patterns, triggers, and treatment effectiveness across multiple domains including food, medication, supplements, mental health, sleep, and weather. The app offers daily check-ins, customisable symptom tracking, and visual reports that can be shared with doctors or loved ones. It also enables peer interaction through community sharing (Flaredown, n.d.).

However, Flaredown primarily centres on individual self-tracking and lacks structured pathways for informal caregivers to engage in the journey meaningfully. It does not offer guided education, goal-oriented care planning, or system navigation tools that are essential during the uncertain and complex rehabilitation phase especially for patients with rare conditions. As such, it plays a supportive but limited role in the broader ecosystem of chronic care management and adaptation.

### 3.5.2. Bearable

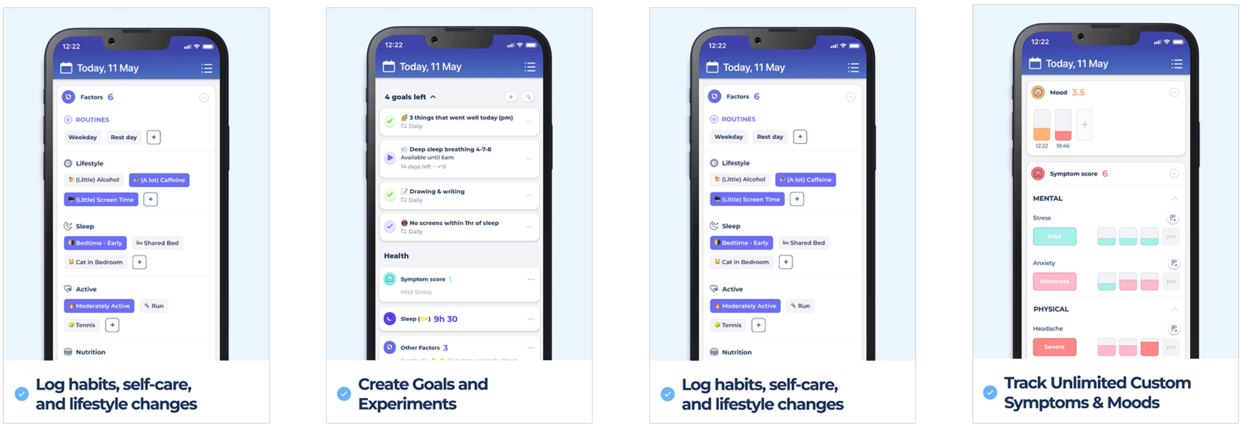


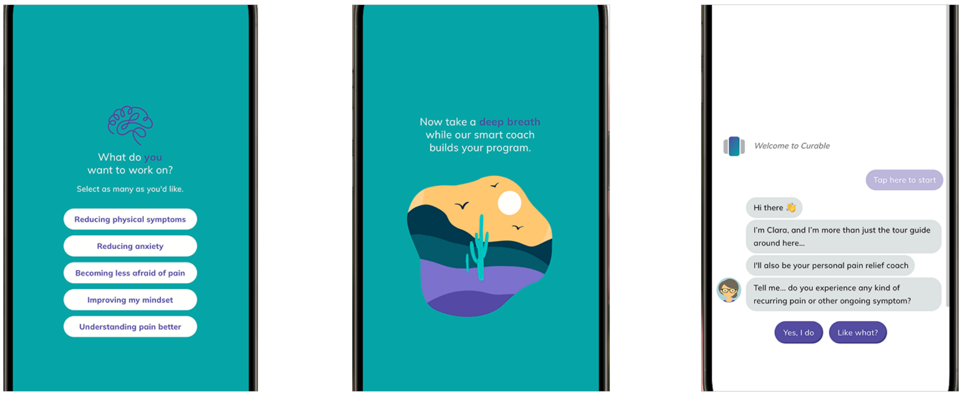
*Fig 05: Bearable application*

Bearable founded in 2019, is a highly customisable symptom and mood tracking platform designed for people managing chronic physical and mental health conditions. Beyond tracking, Bearable enables users to correlate lifestyle factors such as sleep, nutrition, medication, mood, stress, and daily activities with changes in symptoms and well-being. The platform includes habit formation tools, guided content, and supports integration with Apple Health and Google Fit, allowing for both passive and active data collection. It allows users to track and manage the signs and symptoms through free subscription or paid for more features (Bearable, 2025).

Bearable stands out for its human-centred design, shaped by feedback from chronic condition patients, doctors, and researchers. It supports individuals in building self-awareness, communicating more effectively with healthcare providers. In this sense, it is particularly useful for those seeking to manage symptoms, prevent flare-ups, and develop sustainable habits.

While it helps patients communicate better with doctors, it lacks explicit support for informal caregivers, structured education, and system navigation. The app is strong in personalised tracking and reflection but does not address care planning or access to broader support systems essential for rare condition rehabilitation.

## 3.5.3. Curable



What do you
want to work on?

Select as many as you'd like.

Now take a deep breath
while our smart coach
builds your program.

Welcome to Curable

Hi there 👋

I'm Clara, and I'm more than just the tour guide around here...

I'll also be your personal pain relief coach

Tell me... do you experience any kind of recurring pain or other ongoing symptom?

Fig 06: Curable application

Curable, founded in 2016, is a digital therapeutic platform built to help people manage and reduce chronic pain through a structured combination of pain neuroscience education, cognitive behavioural therapy (CBT), guided meditation, visualisation, and expressive writing exercises. Unlike conventional symptom trackers, Curable claims to guide users through personalised lessons and exercises that reinforce neuroplastic recovery and emotional processing, aiming not just to alleviate symptoms but to address the root perceptual and neurological causes of chronic pain (Curable, 2025).

The app emphasises self-awareness, empowerment, and emotional healing, offering a safe, introspective space for individuals navigating long-term pain. It is particularly suited for those seeking to better understand the nature of their pain, actively manage it, and track their progress over time. Curable also fosters a sense of connection through audio-based community stories, which offer narrative-based reassurance and reflection, though without direct interaction or peer support.

Despite its therapeutic depth, Curable's model remains strongly individual-centric and is subscription based. It provides minimal integration of informal caregivers, and lacks tools for system navigation, care coordination, or access to broader healthcare resources. While it excels in emotional and educational support, it does not fully address the structural and relational needs of rare chronic condition rehabilitation.

## 3.5.4. TatvaCare

*Fig 07: TatvaCare application*

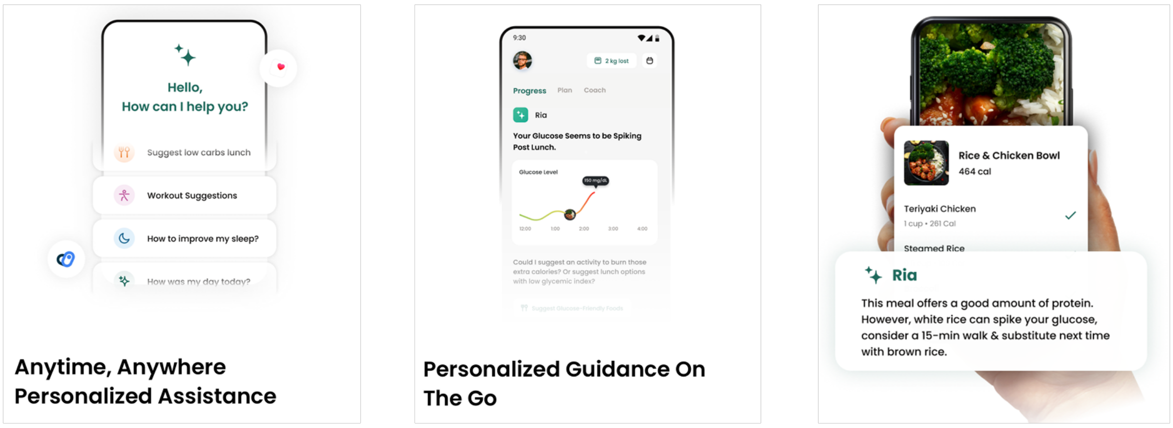
TatvaCare founded in 2020, is an India-based digital chronic care ecosystem designed to support both healthcare professionals and individuals managing chronic conditions. It operates through a dual-platform model: TatvaPractice, a clinic digitisation and patient management system for doctors, and GoodFlip, a patient-facing digital therapeutics app offering personalised, condition-specific care programs. GoodFlip includes features such as lifestyle coaching, adherence tracking, lab and medication ordering, and intelligent prompts designed to encourage healthier routines and improve treatment outcomes (TatvaCare, 2025).

Functionally, TatvaCare positions itself as a follow-up and consultation tool, guiding patients through outcome-focused, proactive steps. It allows users to track progress, reflect on their health status, and access next-step guidance. In this way, it supports both monitoring and planning, particularly in more structured care settings.

However, while the platform emphasises individual empowerment and coordination with healthcare providers, it currently lacks features for engaging informal caregivers or addressing broader psychosocial and educational needs. System navigation and emotional support remain underdeveloped, which limits its usefulness for more complex or rare condition rehabilitation scenarios.

Nonetheless, TatvaCare offers a valuable perspective on India's evolving digital chronic care landscape, bridging gaps between provider-side infrastructure and patient-side health behaviour.

## 3.5.5. Healthify



Your Glucose Seems to be Spiking Post Lunch.

Could I suggest an activity to burn those extra calories? Or suggest lunch options with low glycemic index?

This meal offers a good amount of protein. However, white rice can spike your glucose, consider a 15-min walk & substitute next time with brown rice.

Fig 08: Healthify application

HealthifyMe founded in 2012, is a widely used Indian platform that promotes tech-enabled, personalised lifestyle management through AI and human coaching. It supports users in tracking various aspects of health such as diet, exercise, hydration, and sleep and provides habit-building tools, goal setting, and real-time nudges aimed at improving long-term wellness outcomes. The platform relies heavily on AI-based feedback and behavioural prompts to guide users toward healthier decisions (HealthifyMe, 2025).

Unlike condition-specific chronic care applications, Healthify is not designed with a focus on any particular illness. Instead, it adopts a generalised and holistic approach targeted primarily at health-conscious individuals seeking to optimise fitness and nutrition. Its strength lies in personalisation, habit reinforcement, and outcome-oriented coaching rather than disease-specific care planning or support.

However, the app lacks focus on emotional support features, health system navigation, patient education, and inclusion of informal caregivers, which are essential for long-term rehabilitation. While Healthify exemplifies scalable digital health innovation in India, it remains limited in its ability to support patients with specialised or long-term rehabilitation needs.

### 3.5.6. Additional Platforms Integrating Emotional Support and Informal Caregivers

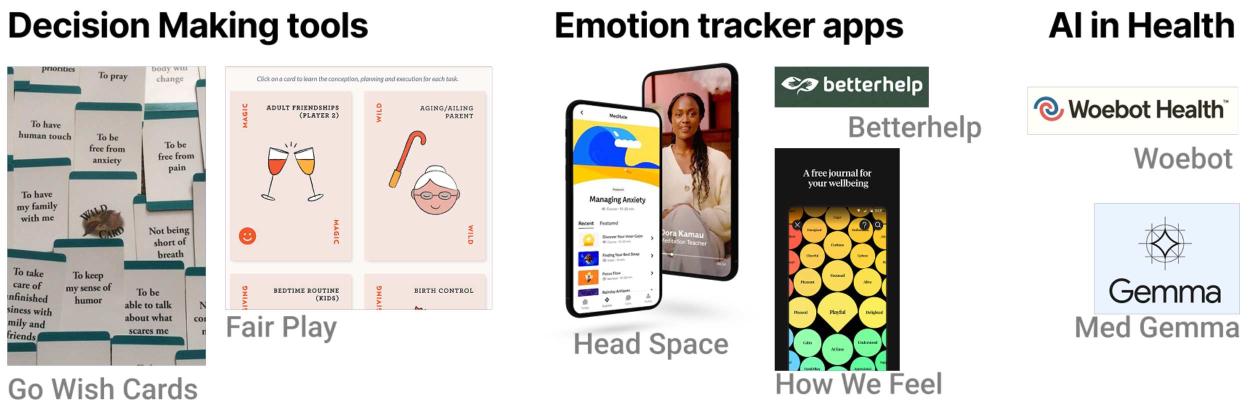


*Fig 09: Additional platforms examples having similar goals*

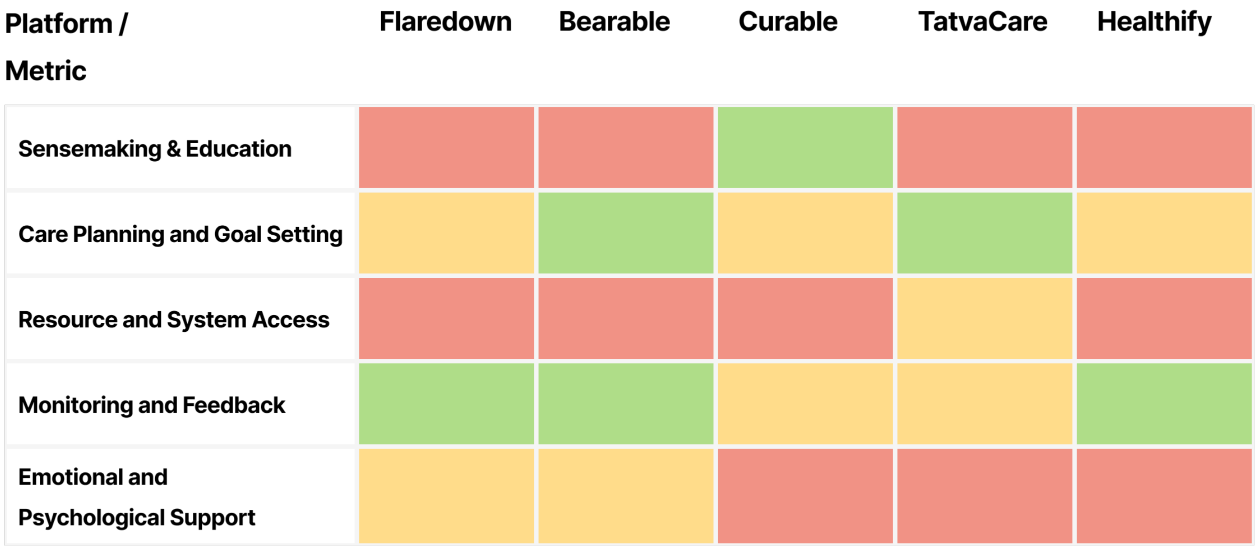
There are a few emerging platforms and tools both digital and analogue that attempt to include informal caregivers and emotional wellbeing as part of the broader care experience.

For instance, Go Wish (Coda Alliance, 2025) is a card-based tool that helps individuals, and their families engage in meaningful end-of-life conversations, making complex preferences easier to articulate and discuss. Fair Play (Fair Play Life, 2024) offers couples a structured framework to divide household and caregiving responsibilities more equitably, which can be particularly useful in reducing caregiver burnout and tension in daily life. On the other hand, apps like Headspace (Headspace, 2025) and How We Feel (How we Feel, n.d.) focus on individual emotional regulation through meditation, mindfulness, or real- time emotion tracking to support mental wellbeing during stressful periods such as illness or caregiving.

While these tools bring attention to emotional and relational dimensions of care, they tend to focus on the individual or specific touchpoints in the care journey. What remains missing is a truly relationship-centred approach that nurtures mutual emotional sharing, structured rehabilitation support, and space for role-based sensemaking between patients and their informal caregivers.

The absence of such systems creates a gap in ongoing, co- experienced healing journeys through an integrated and emotionally grounded care support model. Aspects of managing care are not closed to recording data and analysis but also requires motivation, information and guidance. This supports the initial adjustment to new normal and the sensemaking progress. And improves adherence to rehabilitation journeys.

## 3.6. Review conclusion



| Platform / Metric | Flaredown | Bearable | Curable | TatvaCare | Healthify |
|---|---|---|---|---|---|
| **Sensemaking & Education** | 🟥 | 🟥 | 🟩 | 🟥 | 🟥 |
| **Care Planning and Goal Setting** | 🟨 | 🟩 | 🟨 | 🟩 | 🟨 |
| **Resource and System Access** | 🟥 | 🟥 | 🟥 | 🟨 | 🟥 |
| **Monitoring and Feedback** | 🟩 | 🟩 | 🟨 | 🟨 | 🟩 |
| **Emotional and Psychological Support** | 🟨 | 🟨 | 🟥 | 🟥 | 🟥 |

*Fig 10: Evaluation of existing chronic care applications against the five dimensions of rehabilitation*

Global health literature widely recognises the transitional and rehabilitative support for chronic conditions. Yet most studies focus on common chronic conditions and short- or medium-term adaptation, overlooking the unique complexities faced by patients and caregivers dealing with rare chronic diseases in India. The few Indian studies often treat informal caregivers as peripheral, overlooking their roles in negotiation, adaptation, and emotional labour.

Globally emerging models such as navigation, care coaching, and peer support are not adapted in India on large scale, while tools like follow-ups, coordination, or mental health support are scarce.

Despite useful frameworks on chronic diseases management and caregiver burden, a major gap persists at the intersection of rare chronic conditions, rehabilitation, and caregiver adaption, requiring tailored extensions of existing models.

This gap highlights the relevance of the present research and defines its contribution: documenting transitional journeys, the burdens born by both patients and caregivers, and the potential for structural and informational support to transform this experience.

# 4. Design Approach

For this project, a patient centric approach on top of a double diamond design approach was chosen. This approach is iterative and reframing, which keeps the patient at the centre of the desires of care. The four stages of Double Diamond - Discover, Define, Develop and Deliver were explored, starting from Discover stage where the initial problem identification and area of work, widening the scope with secondary research and learning more about the Healthcare landscape in India.

The further narrowing down or converging in Define stage was done with primary research by conducting semi structured interviews with patients and informal caregivers, care coaches, psychologist, physiotherapist and other experts in the domain. These discussions and interview insights helped in problem definition.

The next step involves revisiting and refining the problem definition, followed by ideation to explore potential design directions informed by the interview discussions and qualitative data analysis. In the Develop stage, these ideas will be translated into prototypes, broadening the scope of design possibilities for testing. Iterative testing with end users and incorporating their feedback will guide the refinement of prototypes, ultimately converging towards the most effective solution in the Deliver stage.

The project was started in Switzerland and is focused on the Indian Healthcare system and patient and informal caregivers in India. The connections to patients and informal caregivers were done over phone calls and later the field visit to India was done. Theearlier conversations were small and unstructured to share the project brief and get an overall idea about their condition and support for confirmation on giving time and sharing their journeys.

As the research was happening from a geographical distance, most of the contact approaches with the NGOs, doctors and hospitals were done over email communications. Most of them did not respond.

## 4.1. Ethics

A psychologist was consulted for giving feedback on the semi structured interview and the workshop approach to make sure the approach is safe given the topic is sensitive in nature. Based on feedback, narrations and small tweaks were done in the workshop and questions in the interview.

A manifesto was designed that shared the author’s education background, project brief and design approach. It also shared the values that will be kept in mind while doing this project, ensuring that participant and informal caregiver dignity, privacy, and well-being remain a priority. All interviewees whose responses were included in the research gave their consent.

## 4.2. Secondary Research

Research papers, medical articles and journals, news, policies and other social media channels were referred to understand the current situation of healthcare in India with respect to rare chronic conditions and rehabilitation. Apart from this global level interventions were searched for rare chronic conditions. Other non-communicable diseases which are in higher numbers like cancer, diabetes and hypertension structures were observed to get inspired.

This secondary research was done during the initial phase of Discovery and while converging or narrowing down in the Define phase to get more concise with information and direction.

## 4.3. Primary Research

This project aimed at a patient centric approach and focused on the aspects of how patients and informal caregivers navigate their journey of rehabilitation and what structures of support do they need during this transition phase.

The semi structured interviews were taken with the 3 rare condition patients, 2 informal caregivers, 1 cancer survivor and 1 chronic condition patient. In total 2 interviews with patients were conducted online over a Zoom call and all other interviews with patients, informal caregivers and professionals were conducted in person in India. All the patients and informal caregivers are currently living and undertaking their treatment in Tier 1 cities in India. Their age range is between 21 years to 60 years. The interview duration ranged from 50 minutes to 90 minutes.

Apart from these interviews with professionals like a psychologist, a physiotherapist and a care coach were conducted. These professionals are working in Tier 1 cities and their interviews lasted for about 40-60 minutes.

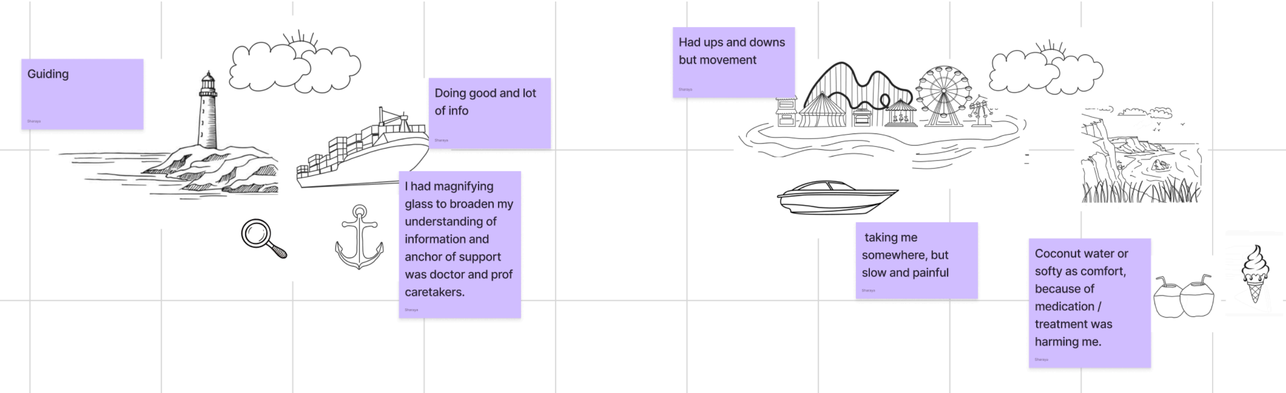
### 4.3.1. Interview with patients and informal caregivers

For this a qualitative study was focused where a complete journey of condition was mapped from -

- Awareness of signs or symptoms phase
- Diagnosis phase
- Treatment phase
- Rehabilitation phase

The topics touched in this were awareness of condition, access of resources and human power, affordability and finance, emotions, support or assistance taken or required, information resources, accountability, self-care management, impact on social and professional life. And this was followed by open discussion at the end where their goals, wishes and desires were discussed.

## Workshop



Guiding

Doing good and lot of info

I had magnifying glass to broaden my understanding of information and anchor of support was doctor and prof caretakers.

Had ups and downs but movement

taking me somewhere, but slow and painful

Coconut water or softy as comfort, because of medication / treatment was harming me.

*Fig 11: Journey mapping workshop using the ocean analogy*

As the topic is very sensitive and with consultation of psychologist, the approach to connecting the topic to another analogy makes it easier for the patients and informal caregivers to speak about their experiences.

For this, the analogy of ocean journey - ‘Voyage of Care’ (see figure 11) was taken as inspiration where the islands respresented the care touchpoints in Indian healthcare system and to reach them requires different resources which can be interpreted in many ways.

In the journey mapping workshop, the patients and caregivers would need to assign different visuals of ocean journey like islands, tools, vessels, weather to the 4 phases of journey.

Patients and informal caregivers assigned the phases of journey with these visuals (see figure 12) where Islands represented how they perceived the space, experience and phase of their journey, while weather represented their emotions.

In figure 13, tools represented the symbolic objects to support them in those specific challenges, while transport represented the way they experienced the journey path.

This workshop helped in getting more detailed conversation and experiences of the patient and informal caregiver and setting a clear picture of the healthcare system and their journey.

Following this the workshop included a card sorting activity (see figure 14) in which patients and informal caregivers organised the cards into categories. This exercise provided insights into how they navigated the rehabilitation stage and the activities undertaken during the transition or off-boarding phase from treatment phase.

## Islands

*Fig 12: Elements of sea journey workshop - Islands*

## Tools

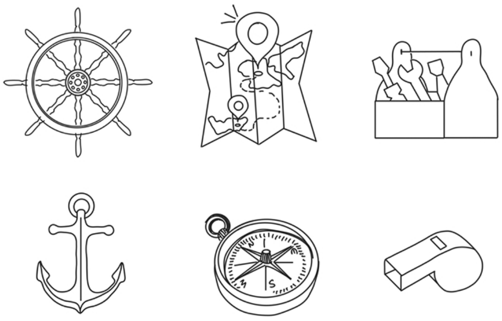


*Fig 13: Elements of sea journey workshop - Tools*

## Transport

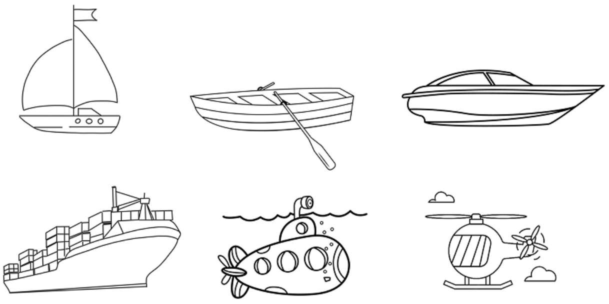


*Fig 14: Elements of sea journey workshop - Transport*

### 4.3.2. Interview with professionals

The structured interview with professionals like psychologist, physiotherapist, care coaches in India and few experts in design working in healthcare field working in Switzerland were conducted. These interviews were structured based on the experts' field of work.

In India, a psychologist was consulted to make sure the approach with patients and informal caregivers are addressed with empathy and a safe space is created for them. The visit at the physiotherapist centre helped in understanding the equipment, space and the methods the physiotherapist use to help in adherence to rehabilitation with respect to exercises and regaining strength. With the care coach the interview was more focused to understand their role and how they consult their patients and informal caregivers (clients). Along with this the topics like their challenges, problem areas and trends in the market were discussed with the professionals. These connected insights are expanded in Chapter 5.

## 4.4. Ideation Method

The ideation approach was rooted in a synthesis of primary and secondary research. The workshop and the open-ended conversations at the end of semi-structured interviews with patients and informal caregivers revealed deeply personal narratives about navigating care after treatment often marked by uncertainty, emotional exhaustion, and fragmented support systems. These narratives offered a grounded understanding of how people experience rare chronic conditions in real-time.

In parallel, secondary research including academic literature, existing policy documents, and service models in chronic care helped frame these personal experiences within larger systemic patterns. It revealed how India's healthcare landscape continues to lack structured support during the transition from treatment to rehabilitation, particularly for rare conditions where protocols are often absent. This synthesis allowed the project to move from isolated problem-solving toward a holistic and layered understanding of care journeys. It shaped the design direction to be:

- Patient-centric, centring the lived realities of patients and informal caregivers
- Service-oriented, addressing the invisible transitions and interactions between stakeholders, touchpoints, and systems
- Co-designed, recognising the experiential knowledge that patients and informal caregivers hold, and valuing their input as co-creators of care strategies.

### 4.4.1. Brainstorming and Intervention Mapping

The brainstorming phase played a critical role in translating research insights into concrete intervention areas and identifying levels of impact across the care ecosystem. It helped sketch out not only what to design but also where and for whom within the broader system of rare chronic condition care.

Building on the synthesis of primary and secondary research, the project's direction continued to evolve within a systems thinking and future-oriented inquiry framework. The structural gaps, emotional tension, and informal burden revealed by the research highlighted the need to reimagine care pathways that extend beyond the clinic and into the lived spaces of patients and informal caregivers. This stage was guided by design principles focused on:

- Emotional resilience - supporting patients and informal caregivers through moments of fatigue, confusion, and emotional strain
- Shared responsibility - enabling collaborative care rather than one-sided burden
- Decentralised care support - designing tools that work outside formal health systems and empower everyday action

The brainstorming also focused on identifying entry points for intervention across different layers of the stakeholder map:

**At the individual level:**
How might patients and informal caregivers be supported at home through tools that reduce overwhelming feeling, improve communication, and build confidence in navigating care?

**At the care coach level:**
What structures can be designed to support care coaches in creating smooth, compassionate, and effective support experiences for both patients and caregivers?

**At the healthcare provider level:**
Can interventions act as empathetic provocations helping doctors better understand the emotional and logistical realities of life post-treatment? How might we break the wall between clinical authority and lived experience to invite greater empathy and collaboration?

Rather than addressing isolated problems, this ideation process aimed to map the interdependencies, reframe stakeholder roles, and design supports for the ambiguous in- between phases of care, especially the transition into rehabilitation. The goal was not just to fill gaps, but to build relational and structural bridges between individuals and systems, and it always ensured that solutions were culturally grounded and practically feasible in the Indian context.

# 5. Insights and Observations

The study focused on semi-structured interviews to examine the experiences of individuals managing rare or complex health conditions. Initial interviews addressed a wide spectrum of topics, including awareness of the condition, accessibility of healthcare resources and personnel, financial considerations, emotional responses, support systems utilised or required, information resources, accountability, self-management practices, and the impact on social and professional life.

The later interviews-maintained discussion on these topics, but had greater emphasis on emotional experiences, support mechanisms, access to information, self-care management, and the influence of the condition on daily personal and professional functioning.
This methodological approach facilitated a comprehensive understanding of both the overarching and nuanced aspects of patients' healthcare journeys.

In the following content, the 4 patients are referred as P1, P2, P3 and P4 and informal caregivers as C1, C2, C3 and C4.

## 5.1. Insights

The interviews and observations from field visits are analysed and explained in detail. First the insights from patient and informal caregiver interviews and then the experts in the field - the care coach and physiotherapist. At the end the observations and prototyping and interventions areas.

### 5.1.1. Emotion

Patients and informal caregivers navigating rare or complex health conditions experience a wide and often intense spectrum of emotions throughout their healthcare journey. These emotions evolve across the phases of awareness, diagnosis, treatment and rehabilitation, shaped by both systemic barriers and personal circumstances.

**Awareness and Early Diagnosis**

**Feeling of Dismissed**
Before entering the rehabilitation phase, patients and informal caregivers experience an initial wave of emotional turbulence. During the awareness phase, patients often attempt home remedies or self-management strategies. When their pain or symptoms are dismissed by family members as common or inconsequential, they feel invisible, misunderstood, and emotionally isolated. P4 described how numbness in his hands affected his

swimming performance, causing him to lose practice matches while his family held high expectations, leading to shame and embarrassment. Similarly, patients P2, P3 and P4 reported feeling frustrated and angry when their early concerns were not taken seriously, compounded by the difficulty of conveying invisible symptoms.

#### Loss of trust in healthcare system

As patients sought formal diagnosis, the process often involved consulting multiple doctors, with participants reporting an average of four to five doctors within two months. Frequent misdiagnoses, delays, and contradictory opinions triggered fear, anxiety, and helplessness, while informal caregivers experienced worry and frustration as they struggled to navigate the healthcare system.

Misdiagnosis that labelled patients with mental health conditions intensified emotional distress. Patients reported feeling isolated, misunderstood, and sometimes disbelieved, while caregivers struggled to relate to the experience, heightening tension and negative emotions within the household.

### Treatment and Transition to Rehabilitation

#### Redefined Trust

Finding the right specialist marked a pivotal emotional shift. P1-P4 emphasised that for the first time, they felt truly heard and understood, fostering relief, renewed trust, and hope in the healthcare system. This empathetic approach alleviated anxiety and reinstated confidence, allowing patients and caregivers to engage more constructively in the treatment phase.

P3 and P4 highlighted moments of guilt and self-blame when family members assumed their habits or choices contributed to their condition. But with proper information sharing from healthcare professionals C3 and C4 started believing what P3 and P4 were saying.

#### Need for Personalised Care

However, the transition from hospital to home-based rehabilitation introduced new emotional challenges. Although patients were provided with contacts and guidance for home care, issues such as limited accessibility, financial constraints, or lack of effective support left patients feeling overwhelmed, abandoned, and unsupported. Both patients and informal caregivers expressed a need for personalised care strategies tailored to their health status, goals, and resources.

Adapting to a new normal often involves recalibrating life goals and confronting limitations. P4 expressed loss and worry upon realising he could no longer pursue competitive swimming, while P3 reported concern and frustration as his condition began affecting education and professional pursuits.

**Coping and Emotional Resilience**
Despite these challenges, patients demonstrated remarkable resilience, self-motivation, and gradual empowerment. P1 engaged in new hobbies to maintain positivity, while P2 and P3 embraced self-monitoring of triggers and flare-ups, turning rehabilitation into an exploratory and empowering process. P4 emphasised the importance of setting small, achievable goals, which helped sustain motivation and fostered a sense of agency.

Caregivers' emotional journeys were equally profound. During interviews, C1 had tears while revisiting experiences, highlighting the suppressed, often traumatic emotional load carried by informal caregivers. Patients acknowledged that caregivers rarely had opportunities to express or process their emotions, emphasising the need for systemic attention to caregiver well-being alongside patient care.

**Summary**
Across all participants, the emotional journey was characterised by an interplay of negative emotions, fear, anxiety, shame, guilt, frustration, isolation, and hopelessness, and positive emotional transitions, relief, trust, hope, resilience, and empowerment. These emotions were not only shaped due to stress by the medical condition itself but also by the responsiveness, empathy, and accessibility of healthcare systems and support networks. Recognising and addressing these emotional dimensions is critical for designing patient-centred and caregiver-inclusive rehabilitation interventions.

## Insights

**01. Relief and Trust Upon Finding the Right Specialist**
Empathetic and attentive doctors restore patients' trust and instil hope and confidence.
*Explanation: When patients finally found specialists who listened and understood their symptoms (P1–P4), they experienced relief and regained trust in the healthcare system.*

**02. Emotional Overload in finding Resources**
Transitioning to home care causes feelings of being overwhelmed, unsupported, and anxious due to lack of guidance and accessible resources.
*Explanation: P2, P3, and P4 had to navigate rehabilitation largely on their own because physiotherapists or care contacts were unavailable, leading to emotional stress.*

**03. Goal Disruption and Loss in Adapting to New Normal**
Patients face sadness, worry, and frustration when their previous life goals (sports, academics, professional aspirations) are disrupted.
*Explanation: P4 could not continue competitive swimming, while P3 experienced educational and professional impact, highlighting the emotional burden of adjusting to limitations.*

**04. Self-Motivation and Engagement as Positive Coping**

Patients regain a sense of control and optimism through self-directed activities and goal setting.

*Explanation: P1 engaged in hobbies, P2 and P3 tracked flare-up triggers, and P4 set gradual goals, all fostering positivity and acceptance of their new normal.*

**05. Caregivers' Emotional Strain**

Informal caregivers experience suppressed emotions, stress, and trauma, often without adequate support or opportunities to process them.

*Explanation: P1 noted caregiver cried during interviews and rarely had open conversations during the diagnosis phase, showing the emotional burden is largely unaddressed.*

## 5.1.2. Support and Assistance for Care at Home

Across all participants, the need for support beyond hospital-based medical care was strongly emphasised. Patients and caregivers required multiple layers of assistance at home ranging from physiotherapy and nutrition to alternative medicine, peer guidance, and emotional reassurance.

**Physiotherapy**

P1 and P4 described physiotherapy as central to regaining strength and adapting to their new normal. While both were advised to pursue physiotherapy, accessibility issues created significant barriers. In P4's case, the referred physiotherapist was located 30 km away and later became unavailable, forcing him to rely temporarily on his sports coach for strength training. This gap of unusable contacts or no contacts led both P1 and P4 to actively search for physiotherapists who could better meet their needs.

**Nutrition**

Nutritional guidance emerged as another domain of fragmented support. P3 sought help from a nutritionist but was advised to follow a “trial and elimination” method for identifying food triggers. Without structured tools or clear guidance, P3 found limited value in continuing follow-ups. By contrast, P2 did not consult a nutritionist and managed dietary triggers independently, while P2 and P3 both highlighted the lack of systematic frameworks to support dietary self-management.

**Alternative Therapies**

Three participants (P1, P2, and P3) also explored alternative medicine, particularly Ayurveda, and reported feeling more positive when combining it with allopathic treatment. They perceived this dual approach as more holistic and better aligned with their lived experiences of chronic illness.

**Friends and Family**

Beyond professional experts, participants emphasised the central role of family and friends. Families provided daily care and emotional support, while friends offered recommendations for alternative experts and treatments, which were often seen as both thoughtful and beneficial.

However, informal caregivers described the heavy responsibilities of managing home care. Caregivers without medical training were expected to coordinate services, assist with physiotherapy, and track dietary triggers. This created feelings of worry, fear of making mistakes, and emotional burnout, as caregiving responsibilities often conflicted with their own personal and professional lives.

In parallel, participants also developed self-directed support strategies. P2 relied on and experimented with AI tools to better understand his condition, finding these resources unexpectedly informative and empowering. Such informal and digital tools provided reassurance when formal healthcare structures fell short.

**Summary**

Overall, while patients and caregivers sought diverse forms of support, their journeys were characterised by accessibility challenges, limited personalisation of services, and the need to “figure it out themselves.” This led to frustration but also fostered resilience, creativity, and the development of hybrid and personalised support systems at home.

## Insights

**06. Accessibility gaps in physiotherapy**

Patients highlighted physiotherapy as essential for recovery, but systemic referral gaps (distance, unavailability) forced them to self-source or rely on substitutes.

*Explanation: P1 and P4 highlighted the need for physiotherapy to regain strength, but systemic issues like distance (30 km away) and unavailability forced them to self-source or rely on substitutes like a sports coach.*

**07. Lack of structured nutritional support**

Trial-and-error dietary advice without systematic tracking frustrated patients, leading some to disengage from professional nutritionists and rely on self-discovery.

*Explanation: P3 experienced trial-and-error dietary guidance without a clear tracking system. This caused frustration and disengagement, showing the need for structured support in managing diet-related triggers.*

**08. Hybrid care models provide reassurance**

Combining allopathic medicine with Ayurveda created a sense of holistic treatment, perceived as more effective and personally meaningful.

*Explanation: P1, P2, and P3 combined allopathic and Ayurvedic treatments, finding it more holistic and personally meaningful, which increased their confidence in the care process.*

**09. Informal caregivers carry disproportionate burden and trauma**
Informal caregivers without medical training managed key responsibilities at home, leading to fear of mistakes, emotional burnout, and suppressed trauma.
*Explanation: Informal caregivers managed physiotherapy, nutrition, and monitoring without formal training. P1 and C1 noted stress and emotional strain, highlighting the need for guided caregiver support.*

**10. Informal networks and technology as emerging supports**
Online communities, AI tools, and peer recommendations became valuable sources of empowerment, supplementing gaps in formal care systems.
*Explanation: P2 used AI to track dietary triggers, and all participants found friends or online groups helpful in supplementing gaps in formal care systems.*

## 5.1.3. Information Sources

For patients living with rare chronic conditions, information becomes a vital yet complex resource. Across all participants, the most trusted source of knowledge was healthcare experts, as reliable public or peer-based information on rare conditions was scarce.

However, the path to trustworthy knowledge was often complicated by repeated misdiagnoses and contradictory advice from different doctors. This not only delayed treatment but also created distrust toward the healthcare system, leaving both patients and caregivers uncertain about which information to rely on.

**Lack of empathetic communication**
Even when specialists provided accurate medical explanations, participants described a lack of empathetic communication and practical guidance. Patients and informal caregivers frequently felt “stuck” in trying to identify triggers, interpret medical terminology, or translate advice into everyday practices. They expressed the need for more supportive, step-by-step communication from experts that acknowledges their struggles with sense-making.

**Reliance on self-exploration**
In the absence of clear direction, families and friends became important secondary information sources. P2, for instance, was connected to an Ayurvedic practitioner through a friend, which provided both practical guidance and renewed hope. These informal networks, although not medically structured, often served as crucial bridges to alternative experts, therapies, or experiential knowledge. While P4 relied on his sports coach for a more personalised approach in his strength regaining through physiotherapy.

**Digitals tools as guide**
Digital platforms also played a significant role. All four participants reported using the internet to search for information,

peer communities, or stories from people with similar conditions. However, unlike more common chronic conditions (such as cancer or diabetes), there were no established support groups for their rare diagnoses. This highlighted a gap in community-based knowledge exchange. Patients often alternated between information overload encountering alarming or conflicting material online and information scarcity, where no relevant content was available.

P2 uniquely described experimenting with an AI model to explore dietary triggers. While not a substitute for medical expertise, the AI provided actionable suggestions that gave him a greater sense of agency. This demonstrates the growing role of digital tools in supplementing gaps left by formal healthcare systems.

**Summary**
Overall, information-seeking for rare chronic conditions is characterised by contradiction, fragmentation, and self-driven exploration. The absence of structured, empathetic guidance from professionals pushes patients and caregivers to rely on personal networks and digital resources, blending formal and informal knowledge in their rehabilitation journey.

## Insights

**11. Misdiagnosis affects information trust**
Repeated misdiagnoses and conflicting advice undermined patients' confidence in medical information, creating uncertainty and fear.
*Explanation: Repeated misdiagnoses and conflicting advice caused patients and caregivers (P2–P4) to distrust medical information, creating confusion and fear.*

**12. Lack of translation into practical guidance**
Even when correct, information was often not communicated empathetically or in actionable terms, leaving patients and caregivers “stuck.”
*Explanation: Even accurate advice was often not actionable or empathetically delivered. Patients and informal caregivers reported feeling “stuck” in implementing guidance.*

**13. Digital tools expand agency**
Emerging resources like AI provided practical support in areas such as diet management, empowering patients to take greater control in the absence of structured guidance.
*Explanation: Tools like AI helped P2 manage diet, demonstrating how digital resources can enhance self-efficacy when formal guidance is lacking.*

## 5.1.4. Self-Care Management Structures

Managing rare chronic conditions at home often required patients and caregivers to develop their own self-care management structures, as hospitals and clinics provided little guidance beyond initial treatment protocols.

While participants received discharge instructions, they were left without clear frameworks to track, monitor, and prevent flare-ups, forcing them to invent personal strategies.

**Visual management structures**
P1 and C1 exemplified this adaptive effort. They created a pin-up board at home to track prescribed exercises and medications. This visual structure reduced C1's cognitive load, enabled clear scheduling, and offered a sense of order during a demanding six-to-eight-month rehabilitation period. Beyond practical organisation, the system also provided emotional reassurance by giving the caregiver a sense of control over a complex situation.

**Digital tracking systems**
P2 developed a dietary tracking system after adopting Ayurvedic treatment, where he was advised to avoid certain foods. Through weekly logging and observation, he gradually identified food patterns linked to ulcer flare-ups. This method gave him clarity and a feeling of empowerment. P3, by contrast, faced a similar need but received only vague instructions from his nutritionist to "try and eliminate foods." Without structured tools, P3 struggled to systematise his tracking, highlighting a gap between professional advice and practical application.

**Self-management**
P4's self-management structures were less medicalised but equally personal. While physiotherapy and nutrition were overseen by his coach and sports nutritionist, he independently tracked his goal of returning to swimming. This goal-oriented monitoring provided motivation and a sense of progress, even in the absence of formal tools.

**Summary**
Across participants, self-care management was thus marked by improvisation, personalisation, and trial-and-error learning. Rather than receiving structured guidance from professionals, patients and caregivers relied on self-created tools to track their rehabilitation journeys. The lack of standardised structures emphasises the need for more patient-centred, practical frameworks that support long-term condition management at home.

## Insights

**14. Improvised self-care management tools**
In the absence of structured guidance, patients and caregivers designed their own tools (e.g., pin-up boards, journals) to manage daily care. These also help in reducing informal caregiver burden.

*Explanation: P1 and C1 used pin-up boards and journals to track exercises, medications, and care schedules, illustrating self-initiated organisation strategies. Structured tracking tools helped caregivers manage tasks, reducing cognitive load and emotional stress.*

**15. Trial-and-error leads to personalisation**
Patients refined their self-care structures through experimentation (e.g., food triggers), creating systems deeply tied to their individual contexts.
*Explanation: Patients (P2, P3) refined self-care routines through experimentation (food triggers, exercises), creating personalised, context-specific management systems.*

**16. Professional advice lacked practical frameworks**
While experts provided general guidance (e.g., elimination diets), they rarely offered structured methods, leaving patients to “fill the gap” themselves.
*Explanation: Experts often provided general guidance (e.g., elimination diets) without structured methods, forcing patients to create their own tracking systems.*

**17. Goal-oriented tracking motivates adaptation**
Monitoring personal goals (e.g., resuming sports) became a meaningful way of sustaining motivation in rehabilitation.
*Explanation: P4 tracked progress toward resuming swimming; patients used gradual goal setting to stay motivated during rehabilitation.*

## 5.1.5. Personal & Professional Life

The rehabilitation journey not only reshaped patients’ health practices but also deeply influenced their personal identities, professional trajectories, and social participation.

Living with a rare chronic condition often required participants to recalibrate their aspirations and reconfigure everyday routines to “blend into” what they perceived as a normal lifestyle.

**Recalibrate life goal**
For P4, this recalibration was particularly pronounced. As a competitive swimmer, his diagnosis and subsequent limitations marked a profound disruption to his identity and life goals. The inability to participate in competitions or even swim regularly in the initial years was described as a loss of purpose. Over time, however, he discovered photography as a creative outlet, which later evolved into a professional pursuit and source of resilience.

**Professional life**
Across participants (P1–P4), professional life was consistently reported as being adversely affected. P3 and P4 noted that chronic pain and discomfort subtly but persistently impaired their productivity. They also struggled with the communicative burden of explaining rare conditions to colleagues, highlighting the invisibility of their illness and the lack of social understanding.

**Social life**
Social participation was similarly constrained. P2, P3, and P4 described diminished confidence in the early stages of rehabilitation, resulting in social

withdrawal and difficulty re-engaging with pre-illness lifestyles.

Informal caregivers and their social and professional lives Informal caregivers experienced comparable disruptions. C2, who managed a home-based business, reported significant stress while balancing professional responsibilities with the demands of monitoring and managing care. C1 expressed frustration over the erosion of her social life, as caregiving responsibilities left little room for personal time. This underscores the double burden borne by caregivers, who are simultaneously expected to maintain professional or household roles while managing intensive care needs.

**Summary**

Together, these accounts demonstrate that rare chronic conditions extend their impact far beyond the clinic, reshaping patients' and caregivers' personal identities, professional productivity, and social integration. They also illustrate how adaptation may emerge through both hardship and resilience where new identities, goals, and roles are forged in response to loss.

## Insight

**18. Invisible illness affects professional productivity**

Chronic pain and discomfort, though not outwardly visible, hinder professional performance and require patients to exert extra effort to maintain normalcy.

*Explanation: Mild but continuous pain affected P3 and P4's work, requiring extra effort to maintain normal productivity.*

**19. Communication burden creates social strain**

Patients with rare conditions face the challenge of repeatedly explaining their illness, leading to feelings of misunderstanding and isolation.

*Explanation: Patients had to repeatedly explain their rare condition to colleagues and friends, leading to misunderstanding and isolation.*

**20. Rehabilitation impacts social confidence**

Early stages of adaptation often reduce confidence, resulting in temporary or prolonged withdrawal from social participation.

*Explanation: Patients social confidence reduced due to multiple factors, causing temporary withdrawal from social engagements (P2, P3, P4).*

**21. Caregivers face double burden**

Informal caregivers must juggle professional, domestic, and emotional labour, often at the expense of their own social lives and well-being.

*Explanation: C1 and C2 balanced professional work, domestic tasks, and emotional care, often sacrificing their own social life and well-being.*

**22. Resilience emerges through new roles**

Some patients adapt by discovering new hobbies, professions, or ways of framing their condition, turning loss into opportunities for redefined identity.

*Explanation: Patients discovered new hobbies (P4: photography) or reframed their professional paths, transforming limitations into opportunities for personal growth.*

## 5.2. Insights and Observations from Experts

Following are the insights and observations done at field visits at the experts connect. A care coach and sports physiotherapy clinic were visited and interviewed with experts to learn more about their approach of care management, challenges and learn more about the trends in healthcare management. These two sectors are untapped and fragmented in the Indian healthcare system providing unique insights and information on how care is structured and managed at the rehabilitation phase.

### 5.2.1. Care Coach

Interviewing the care coach, an expert who not only guides patients but has also experienced the journey herself, provided deeper insights. She is a cancer research scientist who worked in carcinogenesis at a Mumbai Cancer Research Centre.

At 36, she was diagnosed with ovarian cancer, which she partly self-identified. She said her expertise and resilience helped her accept the diagnosis and cope through knowledge, routine, and support from medical peers. After her diagnosis, she had to change her professional journey and shifted to her husband's IT business.

For the past 10+ years, she has counselled cancer patients free of charge, guiding them on financial aid, access to specialists, and hospitals. She focuses on awareness, education, and bridging communication between patients and caregivers. Her counselling includes individual and joint sessions to ensure clarity and open dialogue.

**Her counselling philosophy:**
- Mind–body connection: She teaches patients and families about the importance of this relationship. She promotes positivity and explains how it links to body hormones. She encourages routines, reflection at night, and thinking positively before sleep, since nighttime thoughts shape the start of the next day. She advises patients to stay grateful, engage in hobbies, and use positive words daily. She specifically recommends maintaining three hobbies to stay distracted from negative thoughts.
- Communication: She encourages open dialogue between patients and families, helping both sides share emotions, frustrations, and fears. She guides families to avoid "over-care," noting that family members often struggle more than patients themselves feeling angry, irritated, and unprepared. She positions herself as a bridge between patients and families, fostering teamwork and understanding.
- Holistic care: She emphasises combining mindset with cultural practices common in India such as Ayurveda and yoga, which

focus on overall health and fitness. She believes holistic care is essential in managing conditions and fostering improvement.

- Financial support: She provides patients with different options through government schemes, NGOs, and charitable trusts.

**Her concerns**

She expressed worry about the spread of misinformation on cancer through social media and unverified applications, which often lead patients to follow random suggestions with no positive outcomes, worsening both health and mental state. She feels her role sometimes extends to offering “second opinions” to counter misinformation and help patients find clarity.

**Her core principles**

- Connection with the body: Stay attentive to body and mind, seek root causes, and act on them.
- Commitment to treatment: Accept the condition but also adhere to treatment and rehabilitation.
- Staying engaged: Keep yourself occupied with at least three hobbies to maintain positivity.

## Insights

**CC1. Mind-body connection as therapeutic practice**

Patients benefit from structured routines, reflection, and positivity, which help regulate emotional states and indirectly support physical rehabilitation.

*Explanation: The coach encourages gratitude, reflection before sleep, and positive engagement through hobbies to build resilience.*

**CC2. Communication bridge reduce family strain**

Open dialogue between patients and families alleviates frustration and prevents “over-care,” strengthening trust and teamwork.

*Explanation: The coach positions herself as a bridge, encouraging families to share emotions and balance caregiving roles.*

**CC3. Holistic care fosters acceptance and healing**

Integrating Ayurveda, yoga, and mindset practices with medical treatment provides patients with a sense of balance and empowerment.

*Explanation: The coach emphasises blending cultural practices with treatment, promoting whole-person care.*

**CC4. Core principles of engagement support resilience**

Commitment to treatment, staying engaged through hobbies, and staying connected with the body and mind are foundational to sustained rehabilitation.

*Explanation: The coach distils her philosophy into three guiding principles that structure long-term adaptation.*

### 5.2.2. Physiotherapist

The sports physiotherapy centre is a large multi-specialty facility offering services beyond physical exercises, including strength and conditioning, nutrition, psychology, biomechanics, and recovery. I spoke with the Head of Management of the centre.

**Types of patients**
The centre caters to people recovering from injuries or surgeries, as well as athletes dealing with muscle injuries. These cases range from chronic conditions to acute or “cold” cases.

**Challenges in the field**

The Head of Management highlighted two main challenges:

1. Marketing and accessibility - reaching people effectively and making services more visible.
2. Awareness - many people still do not understand that physiotherapy is as important as medication in recovery.

They noted that 50-60% of informal caregivers are involved in physiotherapy sessions and show interest in learning how to provide care at home.

**Adherence and follow-ups**
Physiotherapy requires patience, often showing results only after 6–7 sessions. To ensure adherence, the centre follows up through multiple methods: in-centre visits, reminder calls, trackers, and even home services. Despite this, many patients tend to drop out once the pain reduces, which often leads to flare-ups or relapses.

To improve adherence, home exercise plans are kept under 30 minutes. Family members are encouraged to record exercise demonstrations on their phones, which helps patients reduce doubts, build confidence, and practice correctly at home.

**Holistic approach**
The Head of Management emphasised that rehabilitation goes beyond physical activity:

- Nutrition plays a key role in muscle development.
- Psychological factors matter, as patients may face trauma or fear when resuming certain activities.
- Massages and recovery techniques are prescribed to support rehabilitation and adaptation to a new normal.

Key messages to spread awareness:

1. Walking is not a substitute for exercise.
2. Physiotherapy and adherence are critical for recovery.
3. Many surgeries can be avoided or prevented through proper body care and physiotherapy.

**Use of technology**
The centre has developed its own application, Athlex, which uses the phone’s front camera to scan body movement and monitor exercises. It supports strength and conditioning programs,

evaluates personal goals, and tracks progress. Importantly, the app is linked to Ayushman Bharat, India's national digital health policy, which aims to consolidate and digitise healthcare services.

## Insights

**PT1. Multi-disciplinary care enhances rehabilitation outcomes**
Incorporating nutrition, psychology, biomechanics, and recovery services addresses the multi-dimensional needs of patients beyond physical exercises.
*Explanation: The centre expands rehabilitation beyond exercise, integrating complementary domains for holistic recovery.*

**PT2. Awareness gaps limit physiotherapy's role**
Patients often underestimate physiotherapy, perceiving it as optional, despite its proven role in preventing relapses and avoiding surgeries.
*Explanation: The Head of Management highlighted lack of public awareness as a barrier.*

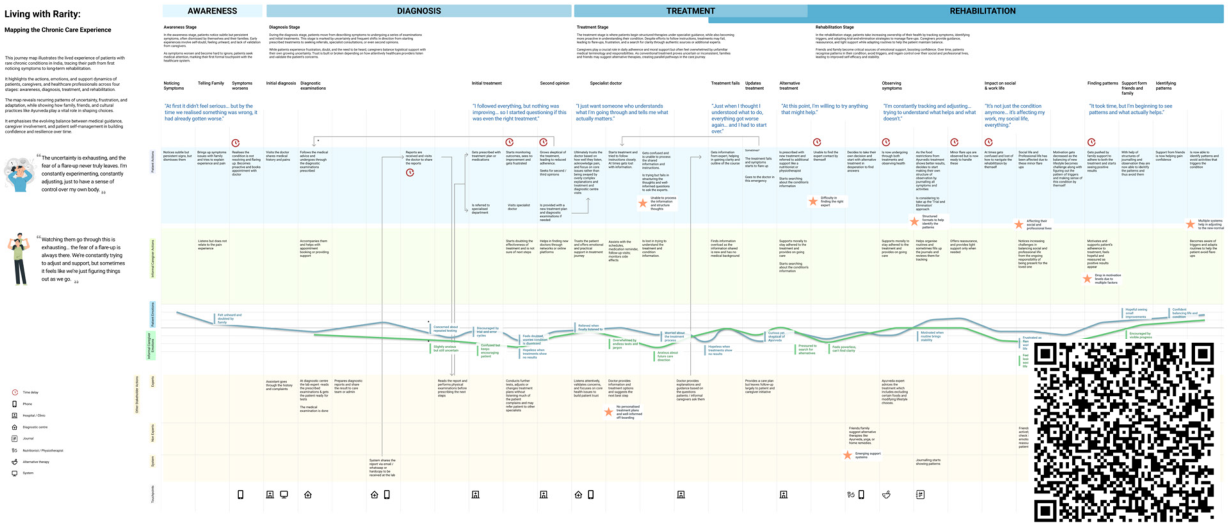
**PT3. Caregivers as active rehabilitation partners**
50–60% of informal caregivers participate in physiotherapy sessions, acting as co-therapists at home.
*Explanation: Families record exercise demonstrations and provide continuity of care at home, extending professional guidance.*

**PT4. Adherence is fragile and requires systemic reinforcement**
Patients often discontinue therapy once pain reduces, leading to relapses. Structured follow-ups, reminders, and short home plans improve adherence.
*Explanation: The centre uses trackers, calls, and simplified routines to improve compliance.*

**PT5. Psychological safety is part of recovery**
Patients often carry trauma and fear in resuming activities, requiring physiotherapy to address both emotional and physical readiness.
*Explanation: Psychological support is considered essential alongside physical recovery.*

**PT6. Technology as an enabler of continuity**
Digital tools (e.g., Athlex app) provide remote monitoring, exercise tracking, and alignment with national health policy (Ayushman Bharat).
*Explanation: Technology bridges gaps in follow-up, supports self-management, and integrates into larger health systems.*

**PT7. Awareness campaigns are crucial**
Clear messages such as “walking is not a substitute for exercise” help reshape public understanding of rehabilitation.
*Explanation: Spreading simple, corrective messages can shift misconceptions and improve uptake of physiotherapy services.*



*https://tinyurl.com/2s25kyn4*

*Fig 15: Patient journey through the current rehabilitation pathway for rare chronic conditions in India.*

## 5.3 Journey Mapping

The journey map synthesises the lived experience of the patients and informal caregivers across the 4 phases of care into a single narrative story. Rather than representing one individual, it draws on patterns observed across all the interviews to reveal where the journey had gaps and how the informal support steps in.

The map (see figure 15) helps in visualising the journey and makes the individual insights visible. When mapped together they revealed how the patient and informal caregivers enter the rehabilitation phase already exhausted, distrustful and already relying on self-constructed systems.

The starred moments on the map mark these specific points of system failure, where the absence of structured support is most acute and where the consequences extend beyond the clinical into the social, professional, and emotional dimensions of life. These moments define the intervention space of this research, the six opportunity areas emerge in:

**Diagnosis / Follow ups**
Patients and informal caregivers often struggle to process and organise the information they receive from healthcare providers. They arrive at appointments underprepared and thus leaving them overwhelmed, unable to structure their thoughts or formulate meaningful questions.

**Diagnosis to Treatment**
The absence of personalised off-boarding at discharge leaves patients without a structured entry point into rehabilitation, no clear next steps, no continuity, and no guided handoff between clinical care and life at home.
**Treatment**
Patients and informal caregivers find it difficult in locating the right expert forces into informal

networks with no reliable pathway to find appropriate support.

**Treatment to Rehabilitation**
The need for structured formats to track symptoms, triggers and patterns is universal yet patients are left to design these tools themselves, improvising with journals, pin-up boards, and self-devised systems.

**Rehabilitation**
The support ecosystem that patients and informal caregivers structure are fragmented across multiple informal sources, placing disproportionate burden on caregivers and reducing their capacity to sustain support over time.

Social and professional life is progressively affected as the ongoing demands of self-managed rehabilitation reduce individuals' confidence, productivity and participation for both patient and informal caregiver. physiotherapy services.

## 5.4. Opportunity Framing

To synthesise the qualitative data collected from patients, informal caregivers, and experts, a process of affinity mapping and thematic analysis was undertaken. Each insight and observation from the interviews were first documented and numbered. These were then organised on a whiteboard by clustering related insights together, contrasting what was working effectively with what was not. This approach enabled the identification of tensions and coping mechanisms, and further allowed the formulation of opportunity areas where services could address existing gaps. Based on this synthesis, following major clusters were developed, which serve as the foundation for the ideation of prototypes and potential working areas.

**Structure and Support -**
Patients and caregivers struggled with vague or absent frameworks for physiotherapy, nutrition, and daily care (Insights 06, 07, 12, 16), forcing them to design improvised self-care tools and rely on trial-and-error. The absence of personalised frameworks leads to discontinuity and disengagement. Apart from this they also visit the care coaches which helps them in finding guidance and progress in the right direction. From research we saw that rare chronic conditions patients and caregivers improvised their own management structures (pin-up boards, food diaries, self-devised trackers) and refined them through trial-and-error or informal contacts (friends, family, sports coaches).

Experts reinforced this gap, noting that adherence requires clear, structured methods, multi-disciplinary integration, and caregiver participation (PT1, PT3, PT4). Strengthening post-diagnosis support with personalised guidance and accessible frameworks would ease the transition into rehabilitation, reduce informal caregiver burden, and improve long-term adherence. This could enhance adherence to rehabilitation, reduce strain on caregivers, and prevent patients from being left to “figure it out” alone.

**Enable the emergence of new support relationships -**
Families and friend’s networks initially face mistrust, over-care, and strain (05, 09, 21). Over time, however, new collaborative roles emerge where caregivers act as partners in rehabilitation (PT3) and communication bridges reduce emotional overload (CC2). Informal networks, hybrid care models, and digital tools (08, 10, 13) further strengthen this shift, creating new relational dynamics of belonging and accountability. Designing guided pathways to nurture these evolving relationships can help patients and informal caregivers move from strain to sustainable support.

**Create structures for processing emotions and building resilience-**
Patients and informal caregivers face overwhelming emotions during rehabilitation, from anxiety, fear, and loss of confidence (Insights 02,03,05,18,21) to informal caregiver trauma and social withdrawal (09,21). Currently, there are no structured ways to process these emotions.

Both experts emphasised the importance of addressing this gap: the care coach highlighted mind–body connection, routines, and positive engagement (CC1, CC4), while the physiotherapist underlined psychological safety as integral to physical recovery (PT5). Designing emotional scaffolds, such as counselling, peer spaces, or guided reflection practices, could help families process uncertainty, reduce strain, and transform emotional overload into resilience.

**Foster adaptive goal setting and identity reconstruction-**
The disruption of life goals, from sports and careers to education, challenges patients’ sense of identity and purpose (Insights 03, 17, 22). Yet many patients found meaning and motivation through small, self-set goals and hobbies (Insights 04, 17, 22), gradually building acceptance of the “new normal.”

Experts reinforced this: the care coach stressed staying engaged through hobbies and commitments (CC1, CC4), while physiotherapists used gradual rehabilitation targets to sustain adherence (PT4). Designing supportive frameworks that normalise and guide in adaptive goal setting, encourage exploration of new roles, and build visible progress markers can help patients and caregivers sustain motivation and reconstruct identity with confidence.

## 5.5. Further Intervention Proposals

The following proposals emerged after synthesising patient, informal caregiver, and expert insights. These interventions are positioned at three levels, individual, relational, and systemic, and will be prioritised for prototyping in the next project phase.

**Individual Level (Patients and Informal Caregivers)**
- Tool: Tracking structures - Digital or physical aids to help patients and informal caregivers record triggers, exercises, medication, and progress, reducing cognitive load.
- Motivational scaffolding - Small nudges (reminders, reflection prompts, streaks) to sustain adherence to rehabilitation routines.
- Communication kit - Structured formats (journaling, care calendars, symptom logs) that support caregivers in sharing observations and patients in expressing needs.

**Relational Level (Care Coaches, Physiotherapists, Nutritionists, Friends, Families)**
- Shared platforms - Tools that allow patients, caregivers, and coaches/therapists to align goals, track routines, and exchange feedback in real time.
- Mediation practices - Structured communication exercises facilitated by care coaches to reduce family strain and balance caregiving responsibilities.
- Peer-support communities - Small circles (online/offline) of patients and informal caregivers sharing coping strategies, recipes, or exercise adherence stories.

**Systemic Level (Hospitals, Doctors, Institutions)**
- Continuity mechanisms - Post-discharge care pathways ensuring patients receive follow-up guidance and don’t have to build structures alone.
- Integration with policy/digital infrastructure
- Linking rehabilitation tracking with national health programmes (e.g., Ayushman Bharat) to improve monitoring, affordability, and scaling.

## 5.6. Prototyping

The prototyping phase was carried out with the intention of responding directly to the four final insights and the requirements expressed by key stakeholders. Rather than aiming for finished solutions, the prototypes were designed as exploratory interventions that test ways to provide clarity, structure, and emotional support in the rehabilitation journey.

Each prototype addresses different but interconnected needs, ranging from individual self-management and patient and informal caregiver communication to systemic awareness within healthcare professionals, thereby creating entry points for reflection, motivation, and relationship-building in the care process.

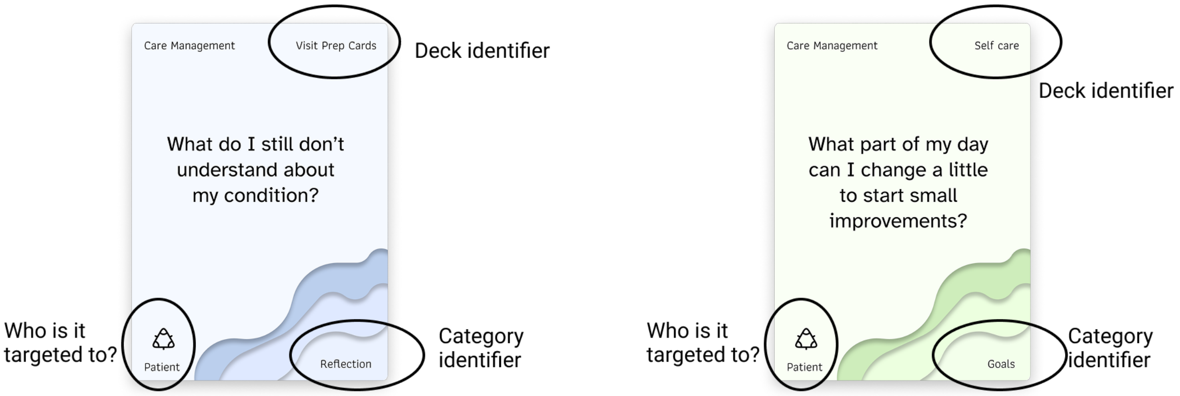


*Fig 16: Structure of the Prepare cards, illustrated with examples from the Visit Prep (left) and Self Care (right) deck.*

## Prototype A - Iteration 1

It can be used before a doctor's or care coach's appointment to structure conversations and reduce redundant visits (see figure 16), during home routines or check-ins to track progress, set realistic goals, reflect, and realign objectives, and in moments of emotional overwhelm or feeling lost as a grounding and motivating resource.

### What

A two-deck physical card tool designed to:

- Equip patients and caregivers with clarity and confidence for their expert visits
- Foster self-care and personal growth through prompts spanning emotional, physical, social, and mental well-being

**Deck 1: Doctor Visit Preparation Cards**

Guides users in organising thoughts, questions, and documents ahead of appointments. Encourages meaningful dialogue, self-advocacy, and active participation in care.

**Deck 2: Self-Care & Development Goal Cards**

Invites reflection and realistic goal setting across emotional, physical, social, and mental domains. Stimulates curiosity, nurtures motivation, and supports gradual, sustainable growth.

### Where

At home - during weekly caregiver–patient reflections or solo self-check-ins.
Before and during medical appointments - as a structured guide to support communication.

In community or coaching sessions - facilitated by care coaches or therapists.

Users select cards from either deck based on their current needs, preparing for a doctor or care coach appointment, or focusing on self-care and personal development.

Each card provides prompts, questions, or exercises that guide reflection, conversation, or goal-setting. Patients and informal caregivers can use the cards individually or together, helping structure discussions, clarify thoughts, track progress, and explore emotions.
Over time, this practice fosters confidence, motivation, and a sustainable rhythm of care.

Prototype A was designed to address several insights from the study. The card decks help manage emotional overload (Insight 02) with aim to provide structured prompts for reflection and grounding, and they support caregivers' emotional strain and burden (05, 09) by reducing cognitive load and offering a framework for care at home. By formalising improvised self-care strategies (14) and encouraging personalised experimentation (15), the tool enables patients to track goals and progress (17) while bridging gaps in rehabilitation resources and guidance (06).

**Feedback**
The concept, when discussed with an expert, showed that it could be a support for patients and informal caregivers to structure their thoughts, information and proceed more with involvement, information and motivation. The content needs to be worked on with an expert (care coach) as they have a set of structure when they provide guidance.

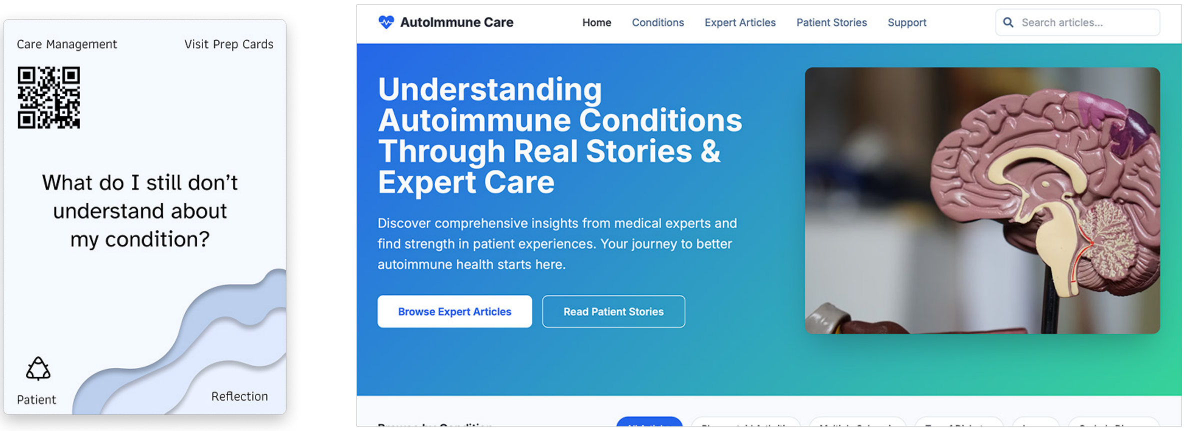
**Possibility**
Considering the technology interventions and patients and informal caregivers are looking. Using such tech solutions, the cards can be linked to a digital platform that provides them with more information and updated information.

**Prototype A - Iteration 2**

In this iteration, each card is enhanced with a QR code that connects users to a related screen of the service platform (see figure 17), with regularly updated articles and resources. This approach combines the clarity and tangibility of physical cards with the adaptability of digital content.

Patients and caregivers can scan the barcode to access reliable, curated information tailored to the card's theme, such as treatment guidelines, checklists, and insurance updates for doctor visit preparation, or mental health exercises, physiotherapy routines, and caregiver stories for self-care and development. By layering the cards with evolving digital content, the tool remains both practical and current, offering users a simple entry point for reflection while ensuring they stay informed with the most relevant knowledge. This iteration helped in getting more conversations and clear idea of what are the important features and information that are fetched and important to the stakeholders. The iteration was developed with a prompt-based AI assistant - Replit (Replit, n.d.) to quickly create mock-ups for discussing features and key information.

Further feedback is awaited to refine this iteration and explore how best to balance the physical and digital elements for ease of use, accessibility, and long-term engagement.



What do I still don't understand about my condition?

# Understanding Autoimmune Conditions Through Real Stories & Expert Care

Discover comprehensive insights from medical experts and find strength in patient experiences. Your journey to better autoimmune health starts here.

*Fig 17: Updated card with QR code linking to the digital service.*

Fig 18: Journey mapping using the sea analogy

**Prototype B - Iteration 1**

The first iteration of Prototype B is the workshop that was conducted with patients and informal caregivers, where they were introduced to 4 stages of care journey - Awareness, Diagnosis, Treatment and Rehabilitation.

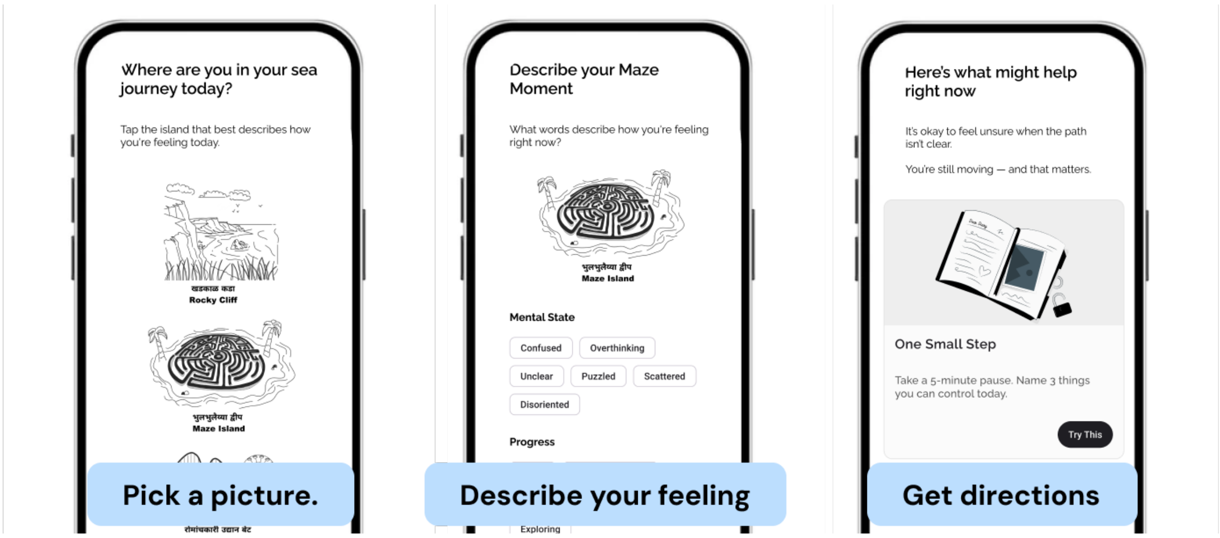
For each stage, participants were provided with sea-journey visuals (as shown in Chapter 4) and asked to relate these symbolic images to their own experience. Through a structured set of questions, the exercise aimed to understand whether the visuals resonated with participants, how they associated them with their situations, and whether this metaphorical framing could support reflection and communication (see figure 18).

Prototype B uses metaphorical sea-journey visuals to help patients and caregivers reflect on their care journeys and communicate more openly. It surfaced experiences of disrupted goals and loss (03) while giving voice to caregivers' hidden strain (05, 09). By providing a symbolic language, it eased the tension between emotions and practical communication (12) and built on the improvised tools families already use for sensemaking (14). The journey framing encouraged realistic, goal-oriented reflection (17) and allowed participants to reframe challenges as stories of resilience and growth (22). The visuals also acted as bridges for family dialogue (CC2) and created safe ground for expression, aligning with the need for psychological safety in recovery (PT5).

**Feedback**

Feedback from a psychologist highlighted that this method could be a valuable tool for expressing emotions without directly revisiting or reliving traumatic experiences, making it a safer entry point for reflection. From observation, it was also evident that the visuals served as effective conversation starters, encouraging participants to open up and share more detailed aspects of their experiences.

**Possibility**
The possibility for this iteration lies in leveraging digitalisation to transform the prototype into a more interactive format that gently nudges users toward reflection and engagement.


Where are you in your sea journey today?

Tap the island that best describes how you're feeling today.

Describe your Maze Moment

What words describe how you're feeling right now?

Here's what might help right now

It's okay to feel unsure when the path isn't clear.

You're still moving — and that matters.

One Small Step

Take a 5-minute pause. Name 3 things you can control today.

Fig 19: Digital service prototype facilitating logging and sharing the emotional journal

**Prototype B - Iteration 2**

Taking the prototype 2 iteration 1 further, the app is designed primarily for patients diagnosed with rare conditions and their informal caregivers, with care coaches or therapists as secondary users (see figure 19). It is intended for daily or periodic use, with gentle reminders to log mood once or twice a day, and weekly summaries to reflect on emotional patterns and shifts.

**What**
A mood feedback app using a sea-journey metaphor, allowing users to log emotional states via symbolic visuals (islands, weather, tools, ships).

Generates:

- Mood reflections & personalised emotional prompts
- Joint activities or communication starters (when needed)
- Weekly composite “map” of emotional landscape

**Where**

- On smartphones; accessible at home, or quiet moments
- Used individually by patient and caregiver, it is visually and emotionally linked with each other via shared weekly reflections

Both patients and caregivers download the app and set up personal profiles. They log their moods using metaphorical visuals, such as islands, weather, tools, or ships, and briefly describe why they chose each symbol.

Based on these inputs, the app provides personalised suggestions like rest, journaling, or clarity exercises, and occasionally shares joint prompts to foster connection.

At the end of each week, a composite visual journey of the emotional landscape is generated, which can optionally be shared with a care coach or therapist for holistic support and guidance.

**Feedback**

This prototype was tested in both physical and digital workshops and received very positive feedback. The visual approach allowed participants to express their emotions and current situation safely, without having to directly confront potentially overwhelming feelings. It also provided a window into their thoughts and emotional state, helping to understand what they were really experiencing. Although the concept was later adapted into a mobile app, maintaining consistent engagement and reliably measuring its impact will be more challenging.

**Possibility**

This application can go beyond a simple journal or diary by actively connecting patients and informal caregivers. Instead of just sharing emotions, it provides prompts and suggestions for actions they can take together.

A physical version can also be used by care coaches during sessions, helping them gain deeper insight into what both patients and caregivers are thinking and feeling.

### Prototype C - Iteration 1

In healthcare, patients often feel misunderstood, caregivers' unseen, and doctors constrained by systemic pressures. Research showed that acknowledgment and empathetic listening mattered more than immediate solutions. This workshop uses light-hearted role play and storytelling to let participants experience others' perspectives, reflect on emotions, and explore biases in a safe, warm, and occasionally humorous environment (see figure 20).

The workshop is designed for a range of healthcare stakeholders, including medical, nursing, and psychology students, health administrators, policy makers, cross-functional care teams, and leaders who shape healthcare training and environments. It can be used during design or research sprints in service development, policy design labs to gather grounded insights, or onboarding sessions for new care staff, interns or NGO workers. The flexible format allows it to be incorporated into medical educational institutes, simulation labs, staff retreats, or policy workshops, providing emotionally safe spaces where participants can pause, reflect, and step into the perspectives of the patients and caregivers.

*Fig 20: Role-play workshop using one of real case study from the patient interview*

**What**

An open-ended, scenario-based role play that:

- Encourages professionals to experience the perspectives of patients and informal caregivers
- Makes invisible dynamics visible and tangible
- Is modular, adaptable to paediatric care, chronic illness, mental health, palliative care, and more.

**Where**

- Classrooms, conference rooms, or simulation labs adapted into emotionally safe spaces
- Optional use in policy workshops or staff retreats to support culture change

The workshop is conducted using an experiential, role-based approach inspired by the Karpman Drama Triangle (Karpman Drama Triangle, n.d.), where participants step into the emotional perspectives of patients, informal caregivers, and healthcare professionals. Through light-hearted role play, scenario cards, and storytelling, participants enact real-life moments from health journeys, exploring the tensions, frustrations, and misunderstandings that often remain invisible.

Open-ended roles allow individuals to bring their own biases, assumptions, and emotional responses, while prompts and reflections guide them to notice emotions, unmet needs, and relational dynamics. The structure fosters safe, playful exploration, encouraging reflection, dialogue, and compassionate curiosity rather than judgment or performance.

Prototype C invites healthcare professionals and policymakers to “step into the shoes” of patients and informal caregivers, breaking down barriers and letting them experience what happens inside the consultation room or care environment.

It brings to life insights such as the heavy burden on caregivers (09), gaps in actionable guidance and communication (12, 19), and the ways patients cultivate resilience through new roles (22). By using structured role play, the workshop fosters empathy through open dialogue (CC2), re-thinking for holistic care approaches (CC3), and attention to psychological safety (PT5), allowing participants to deeply feel the challenges, emotions, and relational dynamics that shape healthcare journeys and consider ways to create more supportive, human-centred systems.

### Feedback

The workshop received positive feedback during testing with students in a school setting. It sparked enriching conversations that demonstrated how effectively the Kafka Triangle framework helps participants understand multiple perspectives. Students reported gaining insight into what occurs inside a doctor’s consultation, while those playing the role of doctors appreciated the complexity and difficult of real-life decision-making.

Overall, the exercise highlighted the workshop’s potential to foster empathy, reflective thinking, and a deeper understanding of healthcare dynamics.

### Possibility

The next possibility for this workshop lies in testing it across different scenarios and healthcare contexts, exploring its adaptability and effectiveness in fostering empathy, reflection and understanding among diverse participation.

### Prototype C - Iteration 2

The next phase of testing involved applying workshop in a new scenario during the Service Design Day help in Bern on 1 June 2025. Along with Martina De Felice (Service Design student at HSLU) the prototype was re-contextualised, and the scenario was focused on the workplace, specifically highlighting the experience of an employee with ADHD and decision making by other stakeholders.

Using the same workshop structure, conversations were prompted through a selective scenario to explore how participants navigated and understood workplace dynamics, challenges and perspective within this context.

### Feedback

The participants engaged meaningfully in the ADHD workplace scenario. However, observations highlighted the need to strengthen the workshop by including structured methods to collect richer qualitative data and by incorporating a dedicated brainstorming session at end.

# 6. Conclusion

The current healthcare landscape in India lacks structured systems for chronic care management, particularly for rare chronic conditions. This research has shown that patients and their informal caregivers face significant challenges during the transition from treatment to rehabilitation at home, as they attempt to adapt to a “new normal.” These challenges span across multiple dimensions, managing care independently, navigating unreliable or overwhelming information, addressing emotional turbulence, and dealing with the impact on social and professional life.

The findings reveal that the existing system, while offering directions for rehabilitation services, falls short in providing personalised, empathetic, and holistic support. Patients and informal caregivers are left to create their own care management structures through trial and error, which often results in spirals of confusion, isolation, and uncertainty. Their strong need for sensemaking, patient education, structured monitoring, and personalised guidance highlights the inadequacy of a fragmented and siloed system.

This thesis argues for introducing structured, personalised support, such as a care coach model and range of interventions at multiple levels. These range of interventions guided by the five foundational dimensions of rehabilitation identified in the study - sensemaking and education, care planning and goal setting, resource and system access, monitoring and feedback, and emotional and psychological. These five dimensions creates a framework for more holistic, compassionate and effective healthcare experience.

This research positions care coaching and personalised structured support as catalysts for better rehabilitation journeys. By integrating personalised guidance, emotional anchoring, and practical direction into India’s healthcare landscape, patients and caregivers can be empowered to manage their conditions with greater confidence, reduced burden, and improved quality of life. While policy gaps and it’s limited awareness remains, this research identifies actionable approaches to build scalable and patient-centric models for rare chronic conditions in India.

# Design Thesis

The following section constitutes the design thesis component of this project. Building on the findings, insights, and opportunity areas identified in the research thesis, it documents the translation of research into design, from early concept prototyping through to a resolved service intervention.

The design thesis manifests the opportunity space identified in Part 1 through Co-Care, a digital and physical service prototype that addresses the gap in structured rehabilitation support for rare chronic condition patients and their informal caregivers in urban India. The resulting prototypes and the service system, were developed iteratively with research participants, tested for relevance and impact, and exhibited at the Lucerne School of Art and Design's annual degree show, Werkschau. Together they represent a designed response to a contemporary and underaddressed challenge in the Indian healthcare landscape.

# 7. Potential Design Interventions

## 7.1 From Research to Design

Research thesis showed how patients and informal caregivers were navigating rehabilitation without structured guidance, constructing their own tools through trial and error, and accessing support through fragmented informal networks. The foundation of five dimensions of rehabilitation,identified in Chapter 3 - sensemaking and education, care planning and goal setting, resource and system access, monitoring and feedback, and emotional and psychological support, were largely unmet in the current Indian healthcare rehabilitation landscape. Each unresolved moment compounded into a cycle of confusion, disengagement, and condition relapse. But it also helped in identifying the design directions through the interview insights and things that are working and supporting patients and informal caregivers in managing long term care.

## 7.2 Overview

Three prototypes were developed during the research phase to explore how these gaps might be addressed. Prototype A, the physical card deck, tested whether structured prompts could help patients and caregivers organise their thoughts, prepare for clinical appointments, and begin articulating goals for their rehabilitation journey. Prototype B explored emotional logging through a sea-journey metaphor, testing whether visual and symbolic tools could help patients and caregivers reflect on and communicate their emotional states over time. Prototype C tested empathy and perspective-taking through role play with healthcare professionals and students.

Of these, Prototype A showed the strongest signal for development. It gave language to experiences participants had not yet been able to articulate. This became the foundation for the Prepare intervention in Co-Care. Prototype B, while positively received in testing, raised questions around scalability and measurable impact and was deliberately set aside as a future development direction. Prototype C informed the systemic framing of the service but did not evolve into a direct intervention within the platform.

The second major design direction emerged from a convergence of research threads. The care coach interview in Chapter 5, combined with field visit findings on fragmented and privatised coaching in India, and the recurring pattern across patient interviews of seeking guidance from informal networks, all pointed toward the same gap.

Care coaching as a role existed but was unstructured, inaccessible, and unverified. The opportunity was not to invent a new role but to orchestrate an emerging one, to build the systemic infrastructure that would make care coaching legible, matchable, and trustworthy at scale. This insight generated the platform logic for Prepare, Align and Act interventions and defined Co-Care with a dyad-centric service approach, connecting patients and caregivers to verified care coaches through structured programmes.

# 8. Prototyping and Design Process

To develop the Prototype A (research thesis) intervention further and to test the viability of a care coach platform in the Indian context, a structured prototyping sequence was designed. Given that no comparable service currently exists in India, the primary challenge was not to test a known format but was to introduce an unfamiliar concept and understand whether it resonated, what values participants brought to it, and what conditions would make them trust and use it.

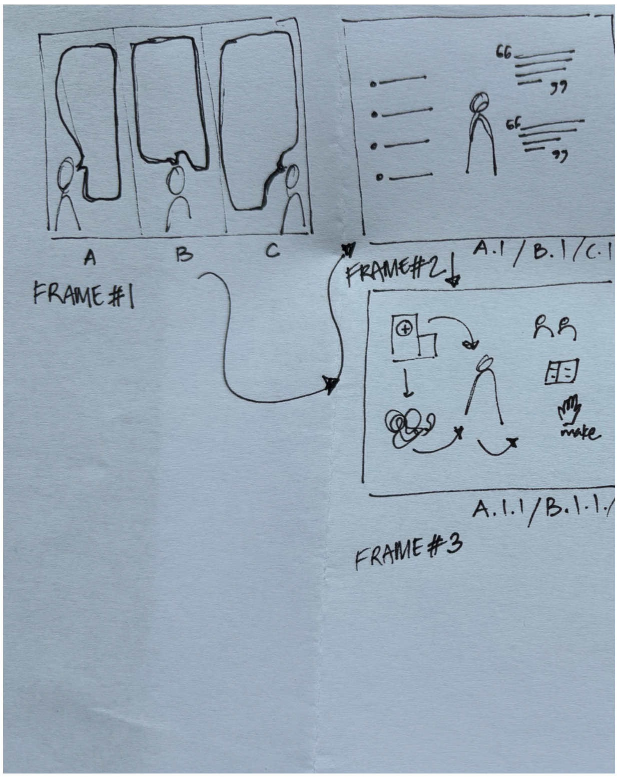


*Fig 21: Storyboard sketch for the service video*

**Concept Video**
The first step was a concept video presenting Co-Care, which was shared with the same participant group with lived experiences from the research thesis. The core question at this stage was simple: whether they would opt for this kind of service.

**Survey**
Following the video, participants completed a structured survey with open-ended sections for qualitative responses. The survey captured what participants valued in a support service, what they would look for when selecting a coach, under what circumstances they would use the service, and what would prevent them from using it. The open-ended sections produced specific and actionable responses that directly shaped subsequent design decisions.

**Workshop**

The workshop introduced the service in greater depth, walking participants through how each of the three stages would work in practice. Because the concept had no existing reference point in India, the workshop was structured as introduction first, demonstration second, and response third. Participants engaged with the logic of moving from Prepare through to Align and Act, and were asked to respond to specific moments in the flow, the coach selection experience, the booking process, and the subscription structure (see figure 22).

*Fig 22.1: Participant exploring prototype - Prepare*

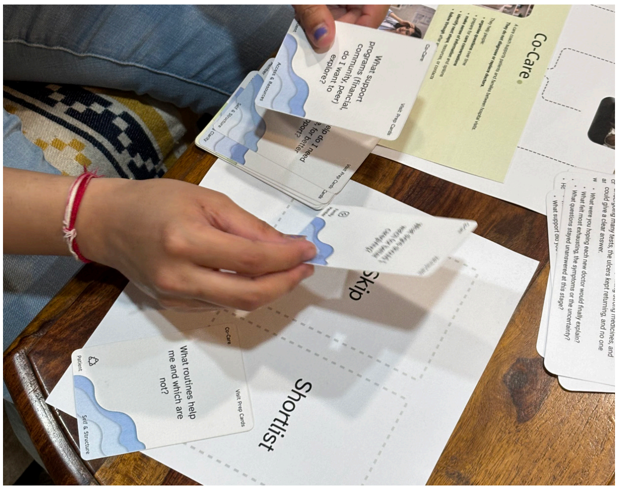


*Fig 22.2: Participant exploring prototype - Prepare*

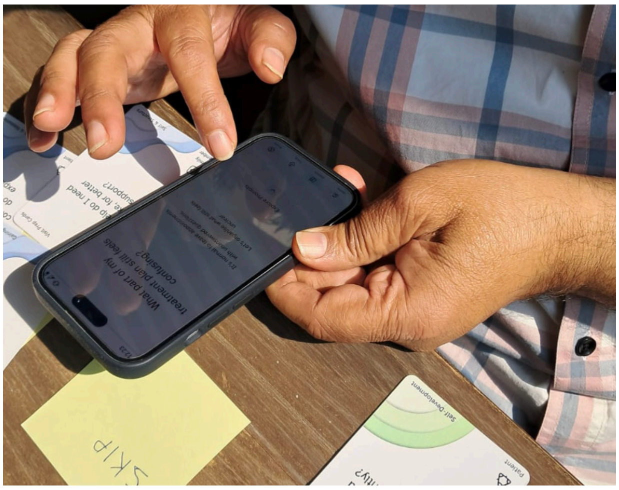


*Fig 22.3: Participant exploring prototype - Prepare*

# 9. Proposed

Drawing on the research findings and the prototyping process, the proposed intervention is Co-Care, a three-sided service platform that addresses the structural gap between clinical discharge and long-term rehabilitation for patients with rare chronic conditions and their informal caregivers in Tier 1 cities in India. The service connects patients and caregivers to verified care coaches through a structured support model built around three sequential interventions: Prepare, Align, and Act. Together these form a continuous loop that can be re-entered at any point, responding to the cyclical and non-linear nature of the rehabilitation journey that the research consistently revealed.

Co-Care holds three stakeholders in balance. On one side are patients and their informal caregivers, the dyad that the research identified as the true unit of care. On the other side are verified care coaches, certified trained, non-clinical support persons who accompany the dyad through the dimensions of rehabilitation that fall outside clinical scope. In the middle is the platform itself, acting as the mediator, handling matching, scheduling, progress tracking, and quality monitoring so that both sides can focus on the work of care.

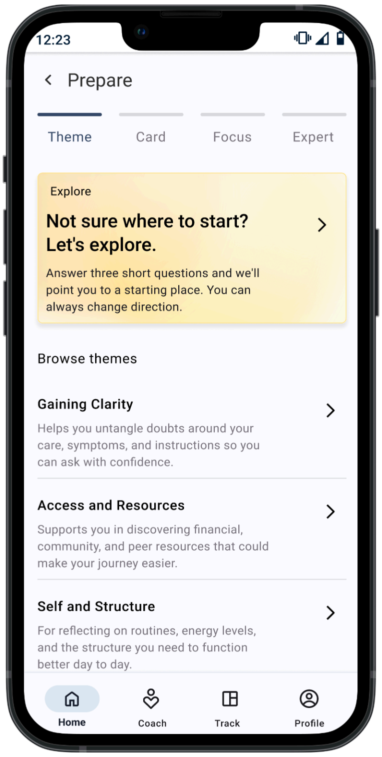
## 9.1 For Patients and Informal Caregivers

The patient in this service is an adult living with a rare chronic condition in a Tier 1 city in India, navigating rehabilitation largely without structured support, managing symptoms, lifestyle adjustments, and emotional uncertainty simultaneously. The informal caregiver is a family member, friend, or loved one who has taken on the responsibility of supporting the patient’s care at home, often without training, often at significant personal cost to their own social and professional life. Either can be the primary user of the platform. Both have their own role-specific needs, and the service treats them as co-equal participants rather than positioning the caregiver as secondary.

### 9.1.1 Prepare

Prepare addresses the first and most consistent gap the research identified, the absence of a structured entry point into rehabilitation. Patients and caregivers leave clinical care overwhelmed, unable to organise their thoughts, and without the vocabulary to articulate what they need.

Prepare gives them that vocabulary. Through a set of thematic questions, users move through categories of need across the five rehabilitation dimensions: sensemaking and education, care planning and goal setting, resource and system access, monitoring and feedback, and emotional and psychological support. Selecting topics is itself a sensemaking act, further they narrow the topic into the focus and thus filters down their recommendation to choose the right coach.



Explore

**Not sure where to start? Let's explore.**

Answer three short questions and we'll point you to a starting place. You can always change direction.

Browse themes

**Gaining Clarity**

Helps you untangle doubts around your care, symptoms, and instructions so you can ask with confidence.

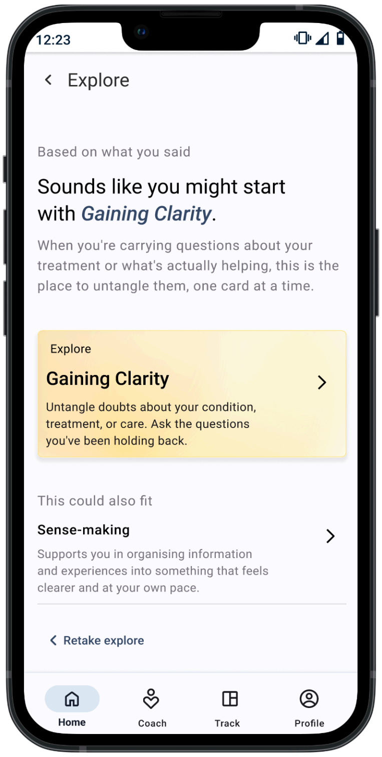
**Access and Resources**

Supports you in discovering financial, community, and peer resources that could make your journey easier.

**Self and Structure**

For reflecting on routines, energy levels, and the structure you need to function better day to day.

*Fig 23.1: Co-Care application - Prepare - Theme*



Based on what you said

Sounds like you might start with ***Gaining Clarity***.

When you're carrying questions about your treatment or what's actually helping, this is the place to untangle them, one card at a time.

Explore

**Gaining Clarity**

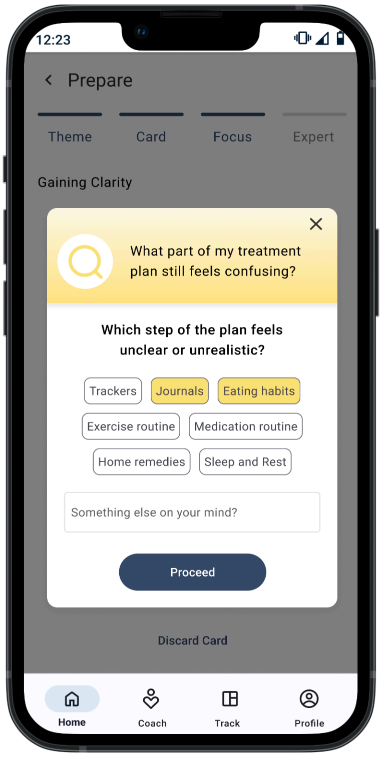
Untangle doubts about your condition, treatment, or care. Ask the questions you've been holding back.

This could also fit

**Sense-making**

Supports you in organising information and experiences into something that feels clearer and at your own pace.

*Fig 23.2: Co-Care application - Prepare - Explore*

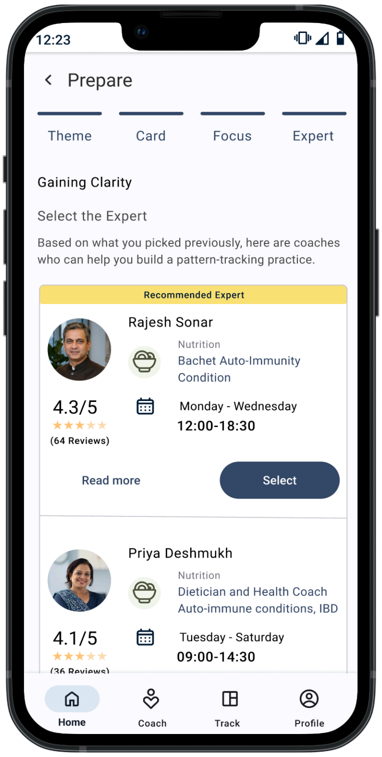


Gaining Clarity

What part of my treatment plan still feels confusing?

**Which step of the plan feels unclear or unrealistic?**

*Fig 23.3: Co-Care application - Prepare - Card*



Gaining Clarity

Select the Expert

Based on what you picked previously, here are coaches who can help you build a pattern-tracking practice.

Rajesh Sonar
Nutrition
Bachet Auto-Immunity Condition
4.3/5 (64 Reviews)
Monday - Wednesday
12:00-18:30

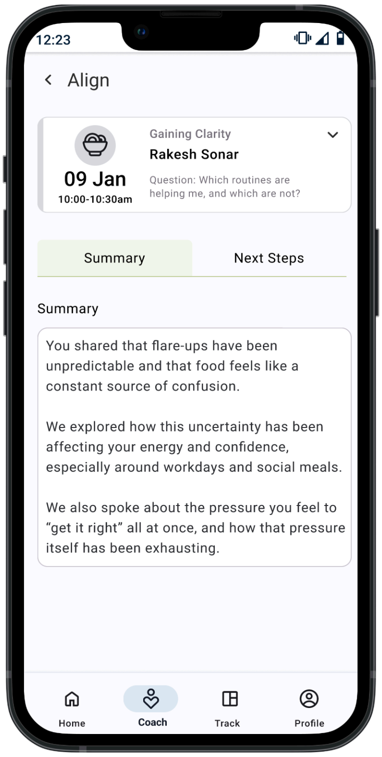
Priya Deshmukh
Nutrition
Dietician and Health Coach
Auto-immune conditions, IBD
4.1/5 (36 Reviews)
Tuesday - Saturday
09:00-14:30

*Fig 23.4: Co-Care application - Prepare - Coach*

## 9.1.2 Align

Align responds to the finding that patients and caregivers consistently struggled to find the right expert. Based on the topic and focus they selected in ‘Prepare’, the platform presents a curated list of matched coaches. The user reviews coach profiles, name, specialisation, approach, reviews, and verified credentials, before selecting and booking a session.

The session itself is a 30 minute coaching conversation, virtual or in person, that aligns the user’s expectations and goals with realistic, expert-informed direction. Following the session, the coach writes a summary and assigns personalised tracker modules to the user’s app profile, creating a documented and shared understanding of the care plan going forward.



Gaining Clarity
Rakesh Sonar
09 Jan
10:00-10:30am
Question: Which routines are helping me, and which are not?

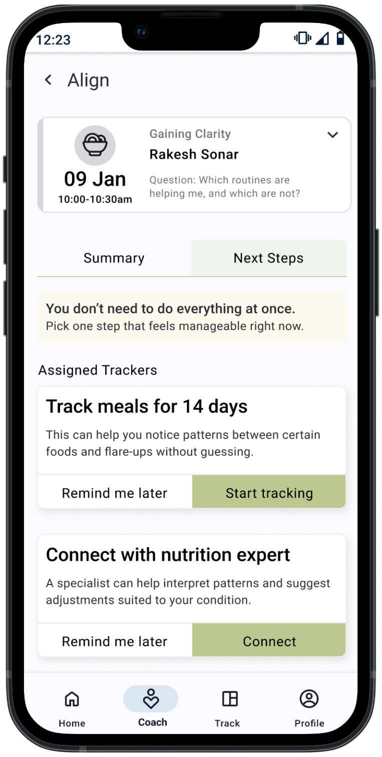
Summary

You shared that flare-ups have been unpredictable and that food feels like a constant source of confusion.

We explored how this uncertainty has been affecting your energy and confidence, especially around workdays and social meals.

We also spoke about the pressure you feel to “get it right” all at once, and how that pressure itself has been exhausting.

*Fig 24.1: Co-Care application - Align - Summary*



Gaining Clarity
Rakesh Sonar
09 Jan
10:00-10:30am
Question: Which routines are helping me, and which are not?

You don’t need to do everything at once.
Pick one step that feels manageable right now.

Assigned Trackers

Track meals for 14 days

This can help you notice patterns between certain foods and flare-ups without guessing.

Connect with nutrition expert

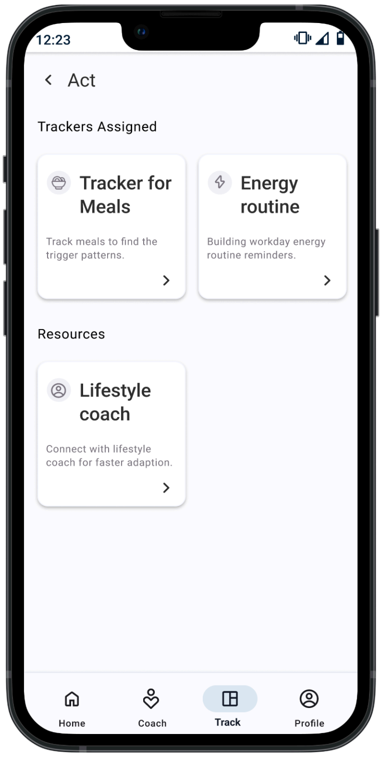
A specialist can help interpret patterns and suggest adjustments suited to your condition.

*Fig 24.2: Co-Care application - Align - Next Steps*

### 9.1.3 Act

Act is where the rehabilitation plan becomes a daily practice. Personalised trackers, covering diet, exercise, sleep, mood, symptoms, and medication, are activated in the app based on the ‘Align’ summary. System nudges maintain adherence when patterns break or engagement drops, escalating from a prompt to a follow-up via coach is initiated.

When the current plan is no longer working, due to a flare-up, a life change, or a shift in goals, the user or coach initiates a replan session, restructuring the care plan around the new reality. This re-entry logic is what interrupts the spiral the research identified, there is always a way back in, and the platform holds the continuity of the journey even when the user cannot.

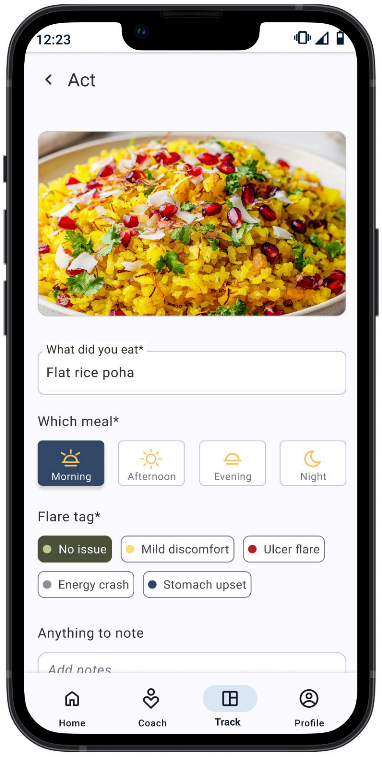


Track meals to find the trigger patterns.

Building workday energy routine reminders.

Connect with lifestyle coach for faster adaption.

Fig 25.1: Co-Care application - Act - Trackers



What did you eat*: Flat rice poha

Fig 25.2: Co-Care application - Act - Meal Tracker

## 9.2 For Care Coaches

The care coach in Co-Care is a verified, non-clinical support person who accompanies patients and informal caregivers through the rehabilitation dimensions that fall outside the scope of clinical care. The coach does not diagnose, prescribe, or override medical decisions. Their role is to make the rehabilitation journey more navigable, helping users make sense of information, set realistic goals, access the right resources, and sustain the emotional resilience required for long-term adaptation.

Three coach typologies form the current supply side of the platform.

- **Clinical experts** - including dieticians, physiotherapists, rehabilitation therapists, psychologists, and occupational therapists, bring domain-specific knowledge to condition management and lifestyle adjustment.
- **Domain experts** - health coaches, fitness trainers, behaviour change coaches, and lifestyle coaches, support habit formation, adherence, and the practical dimensions of building a new normal.
- **Senior and Retired Professionals** - retired doctors, scientists, and researchers, offer advisory support, case consultation, and mentorship for complex or difficult cases.
- **Lived experience coaches (Phase 2)** - former patients, caregivers, and patient advocacy members, is identified as a future expansion of the supply side, pending the development of a dedicated screening and training framework.

All coaches are verified through a three-tier legitimacy framework before appearing on the platform.

- **Institutional legitimacy** is established through affiliation with hospitals, clinics, rehabilitation centres, or NGOs.
- **Professional legitimacy** is established through degrees, certifications, registration council numbers, and practicing licenses.
- **Experiential legitimacy**, applicable to the future Lived Experience typology, is established through screening, service-specific training, and an ethical code of practice.

Verification is not one-time, coaches build trust over time through a post-session rating system across four dimensions: clarity, empathy, practical guidance, and confidence building (see figure 27,28).

**During Onboarding verification**

| Coach typology | Verification criteria |
|---|---|
| Clinical experts<br>dieticians, physiotherapists, rehabilitation therapists, psychologists, and occupational therapists | Professional + Institutional legitimacy |
| Domain Experts<br>health coaches, fitness trainers, behaviour change coaches, and lifestyle coaches | Professional legitimacy |
| Senior experts / retired professionals<br>retired doctors, scientists, and researchers | Professional + Institutional legitimacy |
| PHASE 2<br>Lived experience coaches<br>former patients, caregivers, and patient advocacy members | Experiential legitimacy |

*Fig 26: Coach onboarding verification criteria based on the coach typology*

**Post session rating system**

**Rating system**

★ ★ ★ ☆ ☆

**Dimensions**

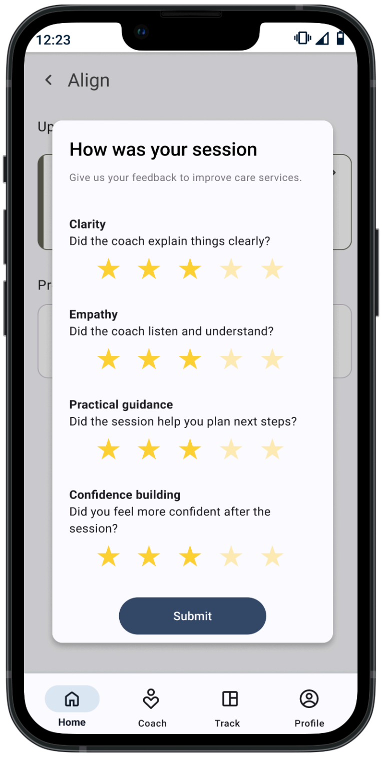
**Clarity**
Did the coach explain things clearly?

**Empathy**
Did the coach listen and understand?

**Practical guidance**
Did the session help you plan next steps?

**Confidence building**
Did you feel more confident after the session?

*Fig 27: Feedback - Post session rating system*



How was your session

Give us your feedback to improve care services.

Clarity
Did the coach explain things clearly?

Empathy
Did the coach listen and understand?

Practical guidance
Did the session help you plan next steps?

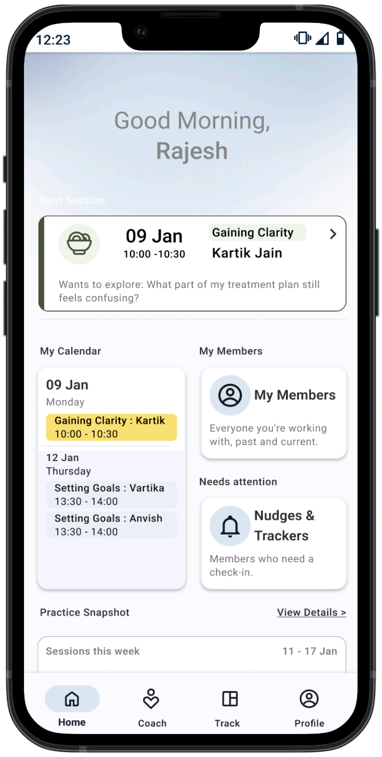
Confidence building
Did you feel more confident after the session?

*Fig 28: Co-Care - Post session rating*

The coach-side experience of the platform is structured around three parallel actions: Review, Assign, and Guide.

### 9.2.1 Review

Before a session, the coach reviews a consolidated profile of the patient or caregiver, their condition history, the topics selected during Prepare, and any previous session notes, arriving prepared rather than starting from zero.



12:23

Good Morning,
Rajesh

Next Session

09 Jan
10:00 -10:30
Gaining Clarity
Kartik Jain

Wants to explore: What part of my treatment plan still feels confusing?

My Calendar

09 Jan
Monday
Gaining Clarity : Kartik
10:00 - 10:30

12 Jan
Thursday
Setting Goals : Vartika
13:30 - 14:00
Setting Goals : Anvish
13:30 - 14:00

My Members

My Members
Everyone you're working with, past and current.

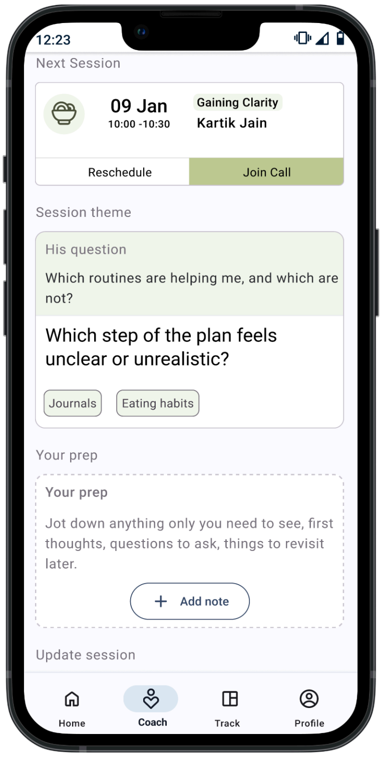
Needs attention

Nudges & Trackers
Members who need a check-in.

Practice Snapshot

Sessions this week
11 - 17 Jan

Fig 29.1: Co-Care - Coach - Dashboard



12:23

Next Session

09 Jan
10:00 -10:30
Gaining Clarity
Kartik Jain

Session theme

His question
Which routines are helping me, and which are not?

Which step of the plan feels unclear or unrealistic?

Journals
Eating habits

Your prep

Your prep
Jot down anything only you need to see, first thoughts, questions to ask, things to revisit later.

Update session

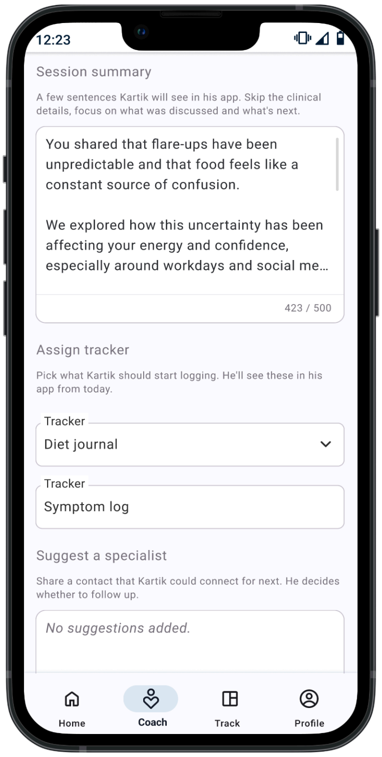
Fig 29.2: Co-Care - Coach - Review

## 9.2.2 Assign

During and after the session, the coach assigns the right resources, contacts, and tracker modules to the user's profile, building a personalised and documented care plan.

## 9.2.3 Guide

Between sessions, the coach guides through the platform's messaging and nudge system, monitoring engagement, identifying patterns, and initiating re-entry when disengagement or regression is detected.
The platform handles all administrative work, scheduling, reminders, and quality monitoring, so the coach can focus entirely on care.



Session summary

A few sentences Kartik will see in his app. Skip the clinical details, focus on what was discussed and what's next.

You shared that flare-ups have been unpredictable and that food feels like a constant source of confusion.

We explored how this uncertainty has been affecting your energy and confidence, especially around workdays and social me…

423 / 500

Assign tracker

Pick what Kartik should start logging. He'll see these in his app from today.

Tracker: Diet journal

Tracker: Symptom log

Suggest a specialist

Share a contact that Kartik could connect for next. He decides whether to follow up.

No suggestions added.

Fig 30.1: Co-Care - Coach - Assign

CC. Is something not working? 1h ago
Your coach can help personalise your routine.

Fig 30.2: Co-Care - Coach - Nudge

# 10. Service framing

Co-Care is a service framework that acts as a mediator between an overburdened healthcare system and patients and informal caregivers who are left navigating rehabilitation through repeated cycles of trial and error without structured support.

## 10.1 Value Proposition

**For Patients and Informal Caregivers**
Co-Care exists for patients and informal caregivers who have been discharged from clinical care and left to navigate rehabilitation alone, through trial and error, fragmented information, and no structured support. The service reduces the time it reduces time to insight, shortens the cycle of confusion and relapse, and builds lasting confidence in managing care independently. By connecting the dyad to a verified care coach matched to their specific needs, Co-Care bridges the gap between hospital care and care at home, creating a guided, structured pathway through rehabilitation that does not currently exist in the Indian healthcare landscape.

**For Care Coaches**
Co-Care exists for care coaches who are currently operating in a fragmented, privatised, and largely invisible system, without institutional infrastructure, without a reliable patient pipeline, and with analogue tools to track and document their impact. The platform gives coaches visibility within the healthcare system, consolidating patient history, session notes, and progress data into one structured space. It enables coaches to provide informed, evidence-based guidance. And by handling all administrative work, Co-Care allows coaches to focus entirely on the work of care.

## 10.2 Business Model

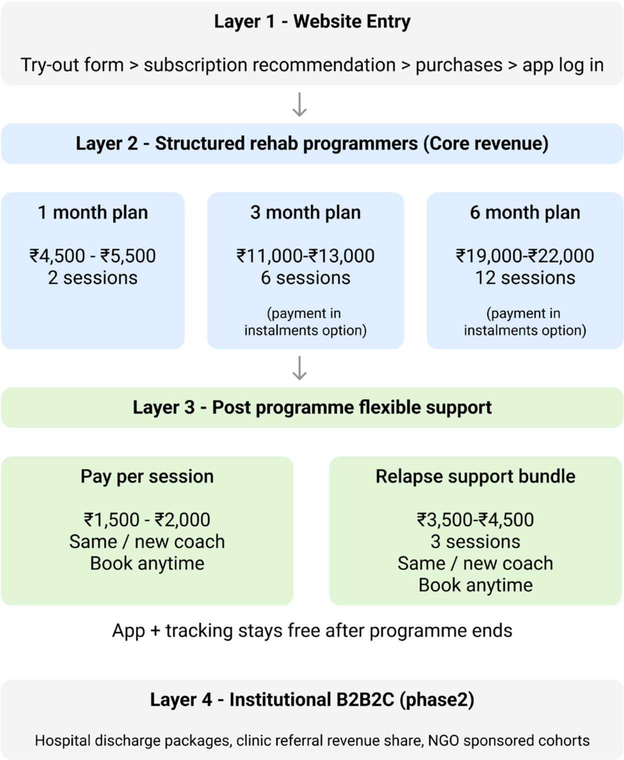
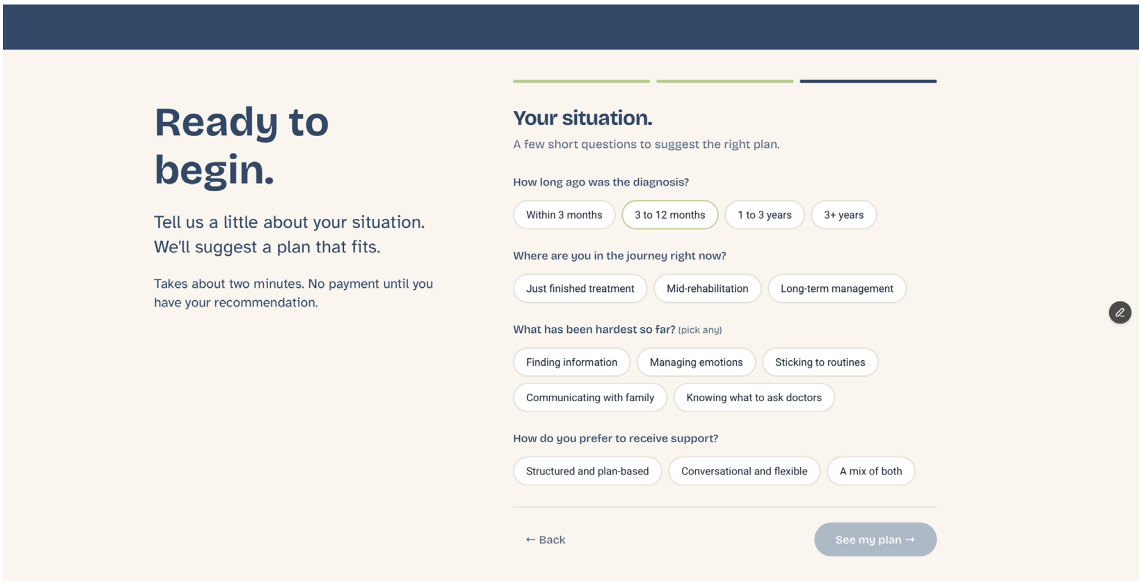


*Fig 31: Co-Care Business model*

The Co-Care business model is designed around the Indian healthcare context, based on insights from field and desk research, where out-of-pocket spending is high and institutional trust is built through known channels. The model progresses across four layers, each responding to a different stage of the user's rehabilitation journey and a different level of platform maturity. The model is illustrated in Figure 31.

Layer 1 is the pre-purchase entry point, hosted on the Co-Care website. A prospective user completes a short try-out form (see figure 32) that captures their condition, caregiving situation, and support needs and goals. Based on their responses, the platform recommends the most appropriate subscription plan. The user reviews and makes a purchase decision by completing payment online and at the end receiving the login credentials to access the app immediately after. This flow reduces the time between discovery and first use, and ensures users enter the platform already matched to the right programme rather than having to navigate options independently.



Ready to begin.

Tell us a little about your situation.
We'll suggest a plan that fits.

Takes about two minutes. No payment until you have your recommendation.

Your situation.

A few short questions to suggest the right plan.

How long ago was the diagnosis?
Within 3 months | [✓ 3 to 12 months] | 1 to 3 years | 3+ years

Where are you in the journey right now?
Just finished treatment | Mid-rehabilitation | Long-term management

What has been hardest so far? (pick any)
Finding information | Managing emotions | Sticking to routines | Communicating with family | Knowing what to ask doctors

How do you prefer to receive support?
Structured and plan-based | Conversational and flexible | A mix of both

Fig 32: Co-Care - Try Out form on website

Layer 2, the structured rehabilitation programme, is the core revenue engine. Three plan options respond to different rehabilitation timelines and financial capacities, a 1-month plan at ₹4,500 to ₹5,500 covering 2 coach sessions, a 3-month plan at ₹11,000 to ₹13,000 covering 6 sessions (approximately 10% saving against monthly pricing), and a 6-month plan at ₹19,000 to ₹22,000 covering 12 sessions (approximately 18% saving).
All plans include app and tracking access, async coach messaging, and peer community access. Instalment options are available for the 3 and 6 month plans, reducing the upfront commitment barrier without penalising users for choosing affordability.

Layer 3, post-programme flexible support, retains users after the structured programme concludes through two options. Pay-per-session access at ₹1,500 to ₹2,000 allows users to book a single session with the same or a new coach whenever needed. The relapse support bundle at ₹3,500 to ₹4,500 provides 3 sessions plus priority coach availability, triggered by a relapse or crisis moment. App access, tracking tools, and peer community remain free after the programme ends, keeping users connected to the platform and lowering the barrier to re-entry when support is needed again.

Layer 4, institutional B2B2C, is deferred to Phase 2. Three mechanisms are identified: hospital discharge packages providing bulk programme access for referred patients at a negotiated per-head fee, clinic referral revenue share where physiotherapy or specialist clinics refer patients in exchange for a platform referral fee, and NGO-sponsored cohorts where patient advocacy organisations fund subsidised programme access through grant or CSR funding. These partnerships require institutional credibility and platform track record that take time to establish, this layer is the scale play, not the day-one revenue model.

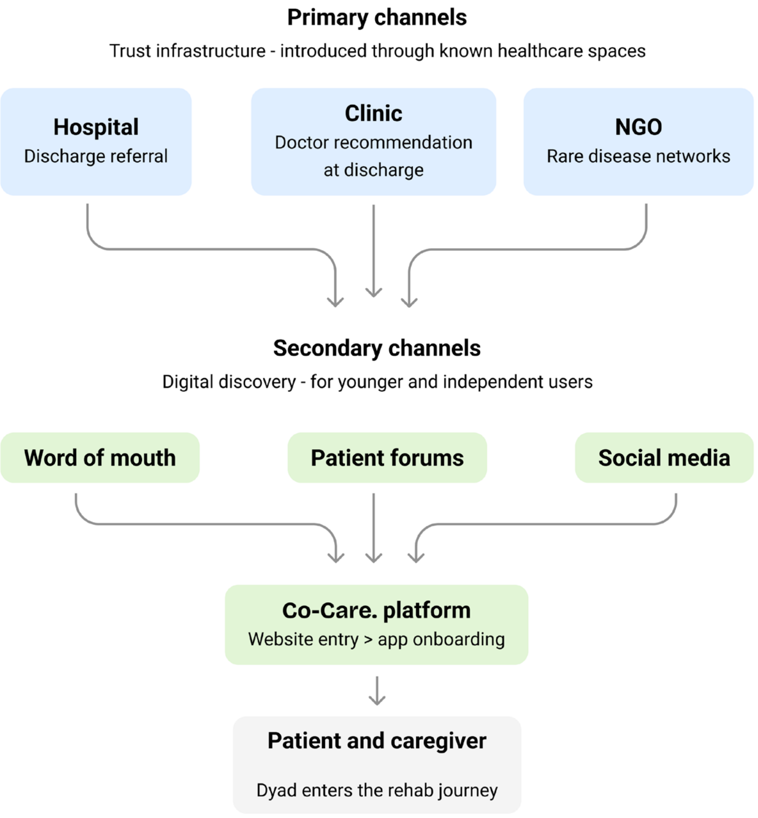


*Fig 33: Co-Care - Channel logic*

### Channel Logic

The primary channels, hospital and clinic referral at discharge, physiotherapist referral, and rare disease NGO networks, are not chosen for reach alone. They are chosen because they trust infrastructure. The Workshop 2 finding confirmed that family decision-makers, who are frequently the primary caregivers in India, will engage if a doctor, hospital, or known healthcare touchpoint introduces it. The channel is therefore inseparable from the value proposition, how Co-Care reaches people determines whether they will trust it enough to use it.

Word of mouth, patient community forums, and app store discovery serve as secondary channels, primarily reaching younger and more digitally confident users who are comfortable initiating the service independently.

# 11. Impact

**Impact Assessment**

Co-Care is a proposed service and its impact at this stage is projected and potential rather than measured. The following claims are grounded in two evidence sources, direct participant responses from workshop testing and research findings from the primary interviews in Part 1, across three tiers: individual, social, and systemic.

## 11.1 Individual

Co-Care's most immediate projected impact is the reduction of time to insight for patients and caregivers entering rehabilitation. The research showed consistently that patients could not articulate their needs, could not structure their questions, and could not identify which support would help them, resulting in extended cycles of trial and error that delayed meaningful rehabilitation and compounded emotional exhaustion. Workshop participants confirmed this directly. One reflected that the service would have been most useful in their initial 1-2 years of their exploratory phase. Another noted that access to a care coach would have helped identify the right specialist faster, reducing both time, emotional and financial cost.

The second individual impact is the projected reduction of cognitive and emotional burden on informal caregivers. The research found caregivers managing physiotherapy, nutrition, medication, and emotional support simultaneously without training, without guidance, and at significant cost to their own lives. Co-Care treats the caregiver as a co-equal participant dedicated caregiver sessions within every subscription plan, and a platform that acknowledges their needs independently of the patient's. Workshop 1 confirmed that the caregiver responded strongly to having their own dedicated cards, describing it as the first time the service felt like it was also for them.

## 11.2 Social

Co-Care is projected to strengthen the patient-caregiver relationship by providing both parties with a shared structure and language for navigating rehabilitation together. The research revealed that patients and caregivers frequently experienced misalignment, caregivers over-caring out of anxiety, patients feeling guilt, both struggling to communicate their experience to each other. Co-Care's dyad-centred design creates the conditions for collaboration rather than parallel suffering, with the care coach positioned explicitly as a communication bridge between patient and family.

The second social impact is the projected rebuilding of social confidence and participation for patients who have withdrawn from professional and personal life during rehabilitation. Insights 19, 20, and 22 documented how the invisibility of rare chronic conditions and the loss of previous life goals produced social withdrawal and diminished self-efficacy. As patients gain clarity, set achievable goals, and begin to see patterns in their condition, the research suggests confidence follows, replacing the isolation of self-navigation with a sense of guided progression.

## 11.3 Systemic

Co-Care’s most significant projected systemic contribution is the definition and legitimisation of an emerging professional role, the verified care coach, within the Indian healthcare landscape. Care coaching in India exists but is fragmented, unverified, and largely invisible, with no institutional framework, no standardised training, and no defined scope of practice. Co-Care addresses this by orchestrating an emerging role rather than inventing a new one. It introduces a three-tier legitimacy framework verified through institutional affiliation, professional credentials, and experiential knowledge, with quality monitored across four evidence-grounded dimensions: clarity, empathy, practical guidance, and confidence building.

The second systemic contribution is the creation of coordination infrastructure that makes coaching legible, matchable, and trustworthy across Tier 1 cities, a platform logic that scales without proportional human cost and that could serve as a replicable model for verified care coaching in India.

The third is the projected reduction of pressure on the clinical system by extending structured support beyond discharge. Every patient who navigates rehabilitation more independently represents reduced demand on an overburdened system. Workshop 3 also observed potential to scale beyond rare chronic conditions to psychological conditions, further extending this systemic contribution.

# 12. Discussion

The design process produced knowledge that the research phase alone could not specifically, that the service logic of Co-Care is legible, impactful, and trusted by the people it is designed for.

Three things were confirmed through prototyping that were not assumed at the start. First, dyad framing, treating the patient and caregiver as a co-equal unit of care rather than a primary and secondary user, was not just a design principle but something participants recognised and responded to emotionally. The caregiver feeling seen by the service was not incidental. It was a signal that the framing was accurate to lived experience. Second, the care coach role was welcomed consistently across all four workshops, provided it was positioned correctly, as a facilitator and navigator rather than a medical professional. This confirms that the role has a genuine place in the rehabilitation journey and that the boundary framing is not just ethically important but commercially necessary. Third, the platform-as-mediator logic resolved a need that participants had not been able to name before the workshops surfaced. The finding from Workshop 3, that users needed help prioritising before they could select, validated the core architecture of Co-Care as a coordination infrastructure rather than a directory or booking tool.

What remains to be tested is not the logic of the service but its execution at scale. The pricing model is informed by affordability reasoning but requires market validation. The coach verification framework is logically sound but has not been piloted with real coaches moving through onboarding. The nudge and re-entry logic in Act is designed in principle but not yet tested against the specific triggers that real rehabilitation journeys produce.

These are the natural boundaries of a thesis-stage prototype, they define the next phase of work rather than undermining the current one. The next design problem is a live pilot: a small cohort of patients, caregivers, and coaches over a three to six month rehabilitation period, testing whether the Prepare, Align, Act loop holds under real conditions.

# 13. Reflection

The research phase began without a fixed assumption about what the solution would look like. What the fieldwork revealed was not an absence of resourcefulness in patients and caregivers but an absence of structure to direct it. Participants had designed their own trigger-tracking systems, built pin-up boards, and assembled informal support networks, not because they lacked initiative but because no structured pathway existed. This was the first significant shift in perspective: the problem was not that patients were passive, but that the system offered no scaffolding for the resourcefulness that already existed. Co-Care emerged from that reframe.

The second unexpected finding was the care coach as an emerging role. The research did not set out to define a new professional category. But across the care coach interview, the literature review, and the recurring pattern of patients seeking guidance through informal networks, the same gap surfaced repeatedly, a role that existed in fragmented, privatised, and invisible form. Recognising this as a design opportunity became one of the defining moves of the project. Co-Care is, in part, an argument that orchestrating what already exists is as valuable a design act as inventing something new.

The hardest design decisions were experiential rather than conceptual, moments where a touchpoint that seemed logical in design failed in practice. QR code scanning appeared in early iterations as a natural bridge between the physical card deck and the digital platform. In testing it broke the flow, users lost momentum and the connection felt like friction rather than integration. Letting go of considered design decisions requires accepting that the user's experience of a touchpoint is not the same as the designer's intention for it.

From a broader perspective, this project surfaced something important about service design in healthcare contexts. The gap Co-Care addresses is not a gap in clinical knowledge or capacity, it is a gap in the connective network between clinical episodes. Service design is well-suited to this kind of problem because it concerns exactly those transitions and touchpoints that fall between institutional moments. The opportunity was to stitch existing infrastructure rather than build from scratch.

Scale remains the most significant open question, how a quality-dependent, coach-led service maintains integrity as it grows, and how feedback loops catch degradation before it affects users. These are not questions this thesis resolves, but opens the door for the next design problem.

# 14. Conclusion

This thesis set out to understand how patients with rare chronic conditions and their informal caregivers navigate the transition from treatment to rehabilitation in urban India, and what structured support could look like at that critical and currently unsupported moment. The research confirmed that this transition is marked not by a single gap but by a compounding series of them: absence of structured offboarding at discharge, fragmented access to expertise, self-constructed care tools built through trial and error, and emotional strain carried largely without acknowledgement by both patients and caregivers. The answer to the first research question is that patients and caregivers navigate post-treatment rehabilitation largely alone, through informal networks, improvised structures, and repeated cycles of confusion and relapse. The answer to the second is that what they need is not more information but a structure that helps them make sense of what they already know, connect to the right expertise at the right moment, and sustain adherence through the long and non-linear process of building a new normal.

Co-Care is a proposed response to those findings. But beyond the service itself, this thesis contributes something more transferable, a method for addressing rehabilitation gaps through the orchestration of existing roles, infrastructure, and knowledge rather than the invention of new ones. The care coach role existed before this thesis. The rehabilitation dimensions existed in the literature. The informal support networks existed in people's lives. What was missing was the connective infrastructure to make them work together. This is where service design has a specific and underutilised contribution to make in healthcare contexts, not in replacing clinical systems but in building the connective tissue between them.

This thesis also proposes a way of seeing rare chronic condition patients that the current healthcare system does not yet consistently apply, as people whose needs extend far beyond the clinical, whose informal caregivers are co-equal participants in their rehabilitation, and whose resilience and resourcefulness are assets that a well-designed service can scaffold rather than substitute. The dyad as the unit of care is not just a design decision. It is an argument about how rehabilitation support should be structured.

Co-Care is a thesis-stage prototype and its impact remains projected rather than demonstrated. What this work establishes is the logic, the framing, and the evidence base for a service that could meaningfully reduce the spiral of confusion and relapse that currently defines rehabilitation for rare chronic conditions in India.

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Interviews
1 Patient and Informal Caregiver
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1.3 Patient 3
1.4 Patient 4

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2.1 Care Coach
2.2 Physiotherapist

3 Workshop
Workshop 1
Workshop 2
Workshop 3
Workshop 4

Patient and informal caregiver interview
Patient 1, Caregiver 1
2:10
I: Awareness part of the phases of care - When he had the brain stroke and his accident happened, how did you get to know about this and what did you do and how did you manage to navigate and was the care accessible?
2:40
C1: His friend who was with him, who was a doctor, called me and said it was a minor accident and provided the location and recommended he come over. I was unaware of the gravity of his situation. But, before this incident there were few illnesses / sicknesses that we had faced in this house so I was aware about his health policies and where his medical reports are located. As the medical reports were placed all over the house I had to find them first, so I grabbed the medical reports that I could find at that moment and I left with my son who was a young teenager. So as I reached the location of the accident, the hospital nearby was Pioneer Hospital. Being a small hospital there was no patient lift. As I reached
his room I saw him on the ICU bed. As his ribs were broken, the drain to collect blood was in place. I was so confused about what had happened, I tried to communicate and called for his name. The doctor present there took me aside to explain his health situation but by then the friends he was with came and explained the whole incident. I felt anger and shock, like what had happened. Meanwhile their son was kept away and distracted by one of his friends. Meanwhile in my head I was wondering should I even produce my reports or submit them here. Then I was thinking of calling his office as there are departments who can support and handle this situation. After reporting this incident to his office who will handle the situation as they had their hospital. And called her sister in law for help. As she reached the Pioneer hospital I felt relaxed. She had so many contacts with doctors and after recommendations of contact doctors she knew they decided to shift him from a small hospital to a big hospital(one linked to his office). At this time it was risky to shift him without patient lift. And my sister in law took responsibility and called an ambulance to shift him. We made a makeshift stretcher and took him downstairs. Kept him in an ambulance and in the next 15 minutes we reached Aditya Birla hospital. As it was linked to his office, the ICU room was prepared for him and as we reached the location his treatment began right away. I am feeling a bit sad and I need some break from talking about this.
after few minutes of break
C1: As I am speaking about this all of the incident is coming in front of my eyes and normally we never discussed this or tried to recall these moments as my kids were very small at that time and we wanted to just get out of these moments.
11:23
I: Let’s do one thing now and not think of the past moments. Let’s change everything and talk about parts where things were better and development and lifestyle adaptation. Where you were able to see the growth and what all was done in that stage.
12:15
C1: I can continue if you want. But I also want to incorporate that Aditya Birla is a multi-speciality hospital which really helped us and all the facilities provided too. We needed orthopaedics, ophthalmologists, cardiologist and nutritionist and many more specialists. He had a stent placed in the same hospital so it became easy to pull the previous records and give the treatment accordingly. Every day the doctors used to update his status to me and not just that but also took in consideration all the previous health conditions.
13:14
P1: We also got to know that they used to have daily stand up meetings with all doctors and they had asked one of us to become a single point of contact to provide the updates. They said we will only talk to one of you. That was good management like that. One of my colleagues had created a group for support, who would take turns to accompany my

wife in
the hospital. For this they used a WhatsApp group and it had a schedule. The hospital had a sleeping area which helped.
15:08
P1: I am not sure if you can get such support abroad, but I am glad I could get this here. I got strong support from all these people who I had no idea about. Many people I have no idea about or met before, those people used to ask for any assistance needed at hospital duty or any help.
15:56
C1: Everyone had faith in god, they used to bring Bhagwadgeeta, other books like The Secret. These actions made me strong.
16:30
P1: People used to come and read Bhagwadgeeta and I had no idea about her and never met her before. My uncle when he saw the support I received from my colleagues, he wrote a letter to the office saying, 'I have never witnessed this in my office, or anywhere else'. But from this incident onwards one of things I have started doing is asking everyone about your financial planning. I did that and thus was able to not worry and retire early from work.
18:35
C1: The financial advisor came to me one day and told me that, 'you don't need to worry he has done the provision and has purchased the insurance policy.'
18:55
P1: My financial advisor operates in Mumbai and this time they came to Pune to get signatures.
19:15
C1: We have one flaw in our culture is the husband does not tell his wife about the financial planning and that is disconnect. We do not know the policies he has bought or planning he has done. And knowing it is important
19:31
P1: My advisor gave me a 10-12 page questionnaire that had my life goals and also brought your wife along with you. As it is a couple work, and mark the goals for which you need to work towards your finance. One of the goals I had was to have a trip across India with a Caravan, but now it is parked after my accident. Fundamentally health is your own responsibility and unless you take care of your health nothing else matters. The accident happened 8 years ago, and for the past 6 - 7 years I have been looking after some or the other activity. I started hydroponics, to learn how to keep yourself positive. In this hydroponics, you grow plants without soil and it was something new and trending is what my colleague told me. So I set up for hydroponics farming. So basically I was trying to keep myself positively occupied. Somehow I kept myself occupied doing interesting things all the time. But the one who introduced me to it relocated for personal reasons and thus the hydroponics farming also slowly died. But later I started reading books using google lens or some reading app.
25:00
I : As you started engaging yourself with some or the other activity, like finding the new trend of farming. So like this did you find anything online or was it friends who introduced it to you.
25:22
P1: My presence online became very low post accident. I had a Facebook group that promoted one day trips near Pune, now no one is taking charge of it and I cannot update anything due to partial vision and reduced travel. Whatever posts are there on Facebook groups are there and I wished someone took it over and continued.
26:13
C1 : During all of this, my daughter used to also go bike riding but she stopped.
26:20
P1: My daughter used to go one day bike rides before this incident, but now she got phobic to it or got some trauma around biking that she has stopped. But now I cannot drive or go biking so I rely on my family members.
27:00
C1: We love to travel and like to travel by road and wildlife.
27:48
P1: I like wildlife photography and used to click birds. I used to also record my travel journeys on bike.
28:10
C1: The period before the accident, all of it went in traveling, photography and reading books, which created a treasure of memories. Thus, we keep revisiting those days and stay happy.
28:35
C1: As soon as he started recovering we were happy to see that now we can continue traveling. We also took the letter from the hospital for his fitness and medical condition for further security check-ins. Like we started preparing ourselves for a better future and working towards it.
28:50
P1: When we went to Goa (first trip), I could not sit properly or even see. I had diplopia at that time and was seeing two things. But we managed the whole trip. For my eyesight, we went to an eye specialist later, and they were the only ones who could diagnose my condition and give me treatment. The specialists were in Chennai, we found it when we went to the ophthalmologist in Pune and explained to them the signs and symptoms. Looking at me it felt like I am fit and fine. So that clinic gave me some exercises at home. This could improve the muscles of the eye and improve the state of eye health and vision.
31:00
C1: The eye medications were hopeless, the exercises actually helped and we saw improvement.

31:10
I: So when you were not seeing improvement in some treatments, did you change the doctor or how did you navigate in this time.
31:19
P1: We kept on meeting different doctors, and thus we got led to the specialist in Chennai. Advised to stay over and give them the time and get treatment. That specialist prescribed the exercises, plan of action and a pair of eyewear that would help him with his vision. It would help him with improving his field of vision. I have outgrown that vision and improved now. The tests that they performed to diagnose me were various and they actually seemed to be knowing their methods. As the diagnosis was done through the physical examinations, the doctor gave me a proper explanation and provided me clear information on my vision status. That is where I learnt about neuroplasticity and I started trusting it. I also read it in one of the books and got to learn more about it by reading. Now that gave me confidence in how we can reverse my physical condition and the exercises now have helped me with motor functions and I am preparing myself for a trek in the Himalayas next year. Now my gym trainer has modified exercises and is focusing more on strengthening the leg and increasing balance.
34:55
I: This happened with support from an ophthalmologist, and while you were at home adjusting to the new normal, how did you find the caregiver at home?
35:15
C1: For 6 months, we had to find a caregiver and we were glad that we found this caregiver from contact. We got a male nurse for him who used to come and take care of him. We also had a physiotherapist.
35:56
P1: The caregiver used to stay at home for the whole day and night.
36:02
C1: We had given one of the rooms to the caregiver and it was also the room for his physio exercises. It was rearranged and had equipment for his care. It also had posters of exercises and had an attached bathroom for ease. As we hired this caregiver from a buro service, there were no issues as there was no need to train someone again and again. When we go with the services, they will provide another caregiver or change the caregiver depending on the availability. At times we did change the caregiver as they were not able to provide the help as they were old and had no strength to take care.
38:25
I: And how about physiotherapy, where did that happen?
38:33
C1: They would come home and conduct the sessions and it was very helpful. We were lucky to find and have him. He used to motivate him and make sure he does the exercises. He used to distract him from pain by talking about so many different topics like politics, recent events and other news. And thus he kept him occupied and engaged in conversation. We never changed the physiotherapist and as said we were lucky to have him. He made them practice exercises and made sure about it.
40:30
I: While in this recovery phase, did you make any structure or diary to see the growth. Or to note down exercises and schedules prescribed by the doctor.
40:40
C1: The exercises were partly noted down for reference by the physiotherapist. As there was a soft board in the room all the notes were pinned there. The medication like insulin and other notes of it was also pinned on the board. Also the acupressure points information was pinned too. We also explored Chinese medicine and pressure points and the traditional
approach. It is also a holistic way of cure.
43:23
To our last question before we do the next activity. In the recovery stage, did you feel that while you were explaining your issues and pains your wife was not able to understand you or empathise with you and your emotions and likewise same with you(wife)? Was there a phase where you felt like there could be some way to explain what is happening but not directly.
44:22
P1: I felt eureka, that she talked to some therapist to bring the incident up again because right now I felt her emotions are bottled up and she should talk it out. We have never had these conversations and I have no idea what impact that has created on her.
44:58
I: That is my last question about whether there can be any intervention that could be in place. Like in here, maybe you can express without directly talking about your emotions. Or maybe you could have got a direction like spending time while doing a family activity. And probably help in loosening the tension.
45:40
C1: In the condition which I was in, I could hardly think of anything. My focus was onlyhim. My energy was in practicing and managing these practices, yoga, pranayam, tratak exercises and handling the schedules. I used to be busy in this and never had got time to think of anything else apart from handling these duties. And he was busy handling his health. I was always occupied with these thoughts, what else can I do, can I read something for him. My whole day was occupied with these duties. Yes I could have some trauma or while trying to remember those days it might get difficult. And I always wanted to make sure I tried my best.

46:38
P1: And one of the main nurses which we had, he used to take care of my hand which had mobility issues and was aware of my partial vision. For this he made sure in the evenings we played carrom games.
47:18
C1: We got such supportive people around us that they were aware about how much effort I as his wife have to put in. There has been no time or event where we have never involved him in the activities.
47:35
P1: For my right hand's mobility, even the doctor made me do some simple exercise. Now that I remember these exercises I feel how simple they were, but they did make a huge impact and I can see the growth. Mobility exercises like crumbling the paper with one hand or spreading the gel around the table.
48:28
C1: In the initial days at times he used to get aggressive and hyper. I was going out and it irritated me and I got angry. Because I myself am an independent woman and I am doing my best.
49:02
P1: No actually in the initial period I was having very psychotic behaviour. Like I have heard the stories from my family, I do not remember the stories.
49:20
C1: But one good thing was though he was negative, he used to still do the exercises, practice the movements and was strong during that period. I could see minor improvements day by day.
49:45
P1: Actually we did go through this story for the first time and it was because of this interview. I do not think that we ever had this conversation before, probably once or two but not in this detail.
50:08
C1: But the most funny incident was when he was in hospital for a month or two. He used to speak and give all the information about things which he has never used or tried before. It was shocking for us initially but later we became used to it. But at times he used to even forget names, addresses or information about personal life.
54:00
P1: I had photography as a hobby and now since I cannot continue it I cannot keep sulking on the fact that I cannot do it anymore. Now I have given all of my equipment to my nephew.

Summary of Interview 2 – Patient 2, Caregiver 2

P2 (Patient 2) had early signs of Behçet's autoimmune condition since childhood, experiencing occasional ulcers and fatigue, but dismissed them as minor issues. P2's family also never suspected anything serious, assuming the symptoms were temporary. However, over a span of 20+ years, flare-ups worsened, leading to frequent discomfort. The issue started flaring up in 2019. Since it was related to the throat and ulcer spots there, P2 decided to consult an ENT specialist. A heavy dose of medicine was prescribed, but even after medication the ulcer did not calm down. After visiting a couple of other ENT doctors, the ulcers still persisted. At this point, P2 decided to avoid spicy food and switched to eating softer, non-spicy, fermented foods like idly (common in India).

Frustrated with the recurring ulcers, P2 visited a multi-specialty hospital and was prescribed a heavy dose of steroids. Even then, the flare-ups did not come under control. In the follow-up visit, P2 was referred to a larger specialty hospital for better diagnosis. During this long process of changing doctors and clinics, P2 described the journey as frustrating and exhausting, with moments of hopelessness. At the larger hospital, a series of examinations and tests were recommended, including checks for cancer, skin diseases, blood work, and other physical assessments. While waiting for results, P2 felt scared and helpless, and C2 (Caregiver 2) felt deeply worried.

Most tests returned negative, leaving doctors uncertain about the next steps. By this time, P2 and C2 had spent significant amounts of time and money since the early signs appeared, leaving them confused and gradually losing trust in the healthcare system. Alongside this, P2's work and professional life were heavily affected due to constant hospital visits and the toll of the condition on both physical and mental health.

Finally, in a follow-up consultation with new test results, P2 was diagnosed with a rare autoimmune condition Behçet's disease. Both P2 and C2 felt an initial sense of relief at finally having clarity. P2 was prescribed a lifelong heavy steroid dose, with instructions to return for follow-ups to assess possible adjustments. The medication initially worked, ulcers stopped flaring, and P2 began feeling better.

A few months later, the doctor reduced the dose to a milder level. However, within days, the ulcers returned. P2 again lost trust in the medication, while C2 became worried. The heavier dose was reinstated, which helped, but the constant cycle of trial and error with treatments, doctors, and examinations left P2 drained.

Noticing P2's struggles, a friend suggested consulting an Ayurvedic doctor. P2 appreciated that the Ayurvedic consultation was holistic, with a genuine effort to understand the full health history and identify root causes. P2 was advised to avoid foods such as milk, fermented items, and spicy dishes. Within 2–3 weeks, P2 reported feeling better, and both P2 and C2 felt renewed hope. However, the treatment required significant time commitment, and due to frequent work travel, P2 could not continue it. What remained consistent was dietary adjustment. Together, P2 and C2 noticed clear food-related triggers for flare-ups. C2 started maintaining a diet journal to track patterns. At one point, P2 deliberately consumed restricted food, which caused the ulcers to flare, reinforcing the connection and making P2 feel that answers were finally becoming clear.

In parallel, P2 turned to online resources and communities. Many individuals described the need for individuals to figure things out for themselves. P2 also experimented with AI tools to better understand the condition and was surprised at how informative and empowering this felt, giving a greater sense of control. After nearly 1.5 years of cycling through different doctors and treatments, P2 felt more in control balancing prescribed steroids with self-guided dietary management.

However, the condition unexpectedly relapsed one day, sending P2 back to the emergency room. The ulcers were severe, and no clear trigger could be identified. Doctors admitted they had no definitive answers. This episode left the family shaken, and C2 especially felt shocked and worried that, despite all their efforts, the condition could still relapse without warning.

Both P2 and C2 went through a negative spiral, but within a few weeks, structured journaling of diet and activities helped them regain some sense of control. They have now accepted the condition and are gradually learning to adjust to their new normal.

Interview 3 – Patient 3
4:47
I: Lets, begin with introducing yourself and knowing who you are, what are you doing right now and where are you located right now and what is your condition.
5:10
P3: I am currently located in Delhi for work, but my hometown is Mumbai. I was diagnosed in the second half of 2023 and it took half a year to 9 months to get diagnosed. In this to just get diagnosed for my condition it took 6 months to 9 months. But there also was a period in initial days where in those 2 months I was visiting a general physician, our family doctor. The doctor used to give me antibiotics for my stomach and thought it was some bacterial infection or food poisoning. But medications never used to work. During that time some lapses or ups and downs in my mental health as well which I did not understand or prior to that never felt or thought why am I thinking in such a way or why am I thinking this is not me. When I used to convey it to the doctors they used to think I have hypertension or stress. And a few doctors prescribed heavy medications which they usually prescribe for I would not call it depressed or depressive patients, which I took about one or less course of it like just for a few days. Then I stopped using it because when I consulted another doctor he said no, I do not need to continue as that is not your condition. Then another doctor started me on antibiotics for stomach aches, as in bacterial or food poisoning. And these antibiotics used to help me for a few hours in a day but their effect used to wear off. But then that constant pain used to start. And during that period there was no change in my diet and I was not eating outside food but one cooked at home. But it was daily cooked food like the Indian diet - a balanced diet, a roti, curry, rice everything. And I had no idea what I was eating was also causing me a lot of pain. Then after one month of visiting different general physicians, I decided to visit a specialist in this, it was gastroenterologist. On the first visit itself or consultation itself, he guessed what I was going through. I mean he did a physical check up on me, showed it to me and explained to me what he thought I might be going through. And his first guess was correct actually so that process was structured. First of all he made me feel comfortable, he said that whatever questions you might be feeling as you have already spent 2-3 months in pain. Then he drew a diagram and showed me where exactly the issue might be located, which is the junction of the small intestine and large intestine. And just to confirm his guess, he prescribed a CT scan as soon as possible. Because by that time my weight was also lost. I lost around 8-10 kgs. Then he put me on a liquid diet to reduce the pain, and went on until the pain subsided. Until the CT scan is done and his guess is correct, but he said just to be sure there might be two conditions. To confirm it you will have to get done with a biopsy. He prescribed an endoscopy. His guess was either its tuberculosis and it has targeted my intestines. It is also one of the major diseases faced in India. If I was not in India it would not be a guess. And another one was Crohn.
11:45
P3: during this period other than physical and mental turmoil I was going through, I was also facing a lot of doubt and prejudice from my family and friends. They thought I was an addict or something and I was consuming too much alcohol like an alcoholic. And my past decisions were costing me. During this period my emotions were very confused, directionless and at the same time I was angry and frustrated. And at times I used to lash out at others for not understanding me. Though they were trying to understand me, I felt that people were being very ignorant or they were blaming me for my own condition in a way. But after visiting the specialist, he cleared my confusion which made me feel a bit calmer. At least I was not lost. Also in India there are superstitious beliefs that are a bigger part of culture. At times people used to come to me and still they do, and say things like they have done black magic on you. But my personal opinion is that I do not focus on those things but do face them till date. Meanwhile I was put on tuberculosis medication for the next 6 months because once you start it you have to complete the course. And while on that medication, I was given other steroids and each medicine had their own side effects. The steroids that I was prescribed, there was a 5% chance that I could get glaucoma. And during this period my eye sight weakened and I got spectacles. Due to this I had to now have my eye check ups every month while I was taking that medication. And the main tuberculosis medicine

caused extreme decline in my liver health. So I had to get blood tests done every week for the first 2-3 weeks and then it was every 2 weeks. But though I was on both medications, the pain subsided but it was not such that I am able to function completely 24 hours. I still could not get complete sleep, as it used to hurt a lot. Apart from medications, just to keep myself feeling better I used to sleep with a hot water bag.
17:07
I: And did yourself remedies help you? And for how long did you keep trying yourself help remedies ?
17:10
P3: I tried this hot water bag for a month. Since I was put on a complete liquid diet, my weight was further reduced from 60kgs to 47 kgs. The liquid diet included boiled veggies and water. Boiling the veggies in water, I would only drink the left water and not the boiled veggies. Along with this water based protein powder. And no curd and nothing. After a month I started with some form of solid diet, it started with simple khichadi, *pej* and porridge. It started from pej, then I started semi-solid khichadi and also ate some jaggery. And then later I started drinking boiled veggies soup. And later when I started eating solid food again, it used to start paining. As I was on tuberculosis medications and did not target the Crohn's issues. When I used to take medicines I used to feel better, but at times I used to wake up in the middle of the night. And then I used to just keep walking in the house so that I could exhaust myself and maybe it would put me to sleep. And even my parents and relatives, everyone wanted to know what was happening since they had no idea. Just to clear some things and their doubts, that I have not caused this myself but its an auto immunity condition. I recorded the voice message as the doctor explained it during consultation and then I forwarded to whoever's asking. This helped in explaining what I am going through to everyone and at the same time completely shut up their misinterpretation or thoughts. During the endoscopy they found the main cause of intestinal problems were found. In the doctor's consultation I got to know that there are two ways to handle this, none of which can guarantee you a solution. One was surgery which would save a lot of pain but would be costly and losing that patch of intestine. Another was to put me in course of medication, which would avoid me going under the knife. So after 3 months in medication when I started eating solid food again, I was having pain and was constipated. The bloating and pain was so unbearable that I had to rush to the hospital twice. Then he used to prescribe me another medication against constipation. During this time I was in discomfort and in pain. After 5 months of treatment the pain started to subside. And I started feeling better, and eating normally. I could not eat everything even today I don't, but I started eating many foods. Today, whenever I start feeling issues I cut down on bread, spicy and oily. Could not completely cut down on gluten as its part of the main diet. In Mumbai, I could eat bhakris (millet bread), or breads based on other millets. And rice was also one of the main staple food. And protein as well, egg, chicken and fish.
26:20
P3: Just to make lifestyle changes has been difficult. Whenever I feel normal, since this was in remission, I started eating normally. Only when I feel that my stomach is getting upset or feels burning sensation or acidity or bloating I cut down my food and go back to eating simple food for a week or two depending on how things go. What I am hearing is more of you are the expert of your own self-diagnosis and you keep working on yourself. Yes and during the treatment the doctor also said that you will have to observe what you are eating and keep a check on it and what is causing troubles. He said there is no specific course of action. The only one we can do is to completely take out solid food from the equation. First, start having some liquid food first and get liquid nutrition. And then introduce simple food and protein to help with the healing process and some pre and pro biotic. At times what was recommended for others was not suiting me, since there is no broad thing and it was needed to have a personalised approach. While starting solid food I used to slowly introduce two to three ingredients a week. So simple foods like fruits with no skin and less sugar. Many types of lentils were a no go for diet. For this process it was more trial and process of elimination. It was a slow process, it was a somewhat painful process but once I got to know about what condition that I was facing it became easier for me to get direction that I could cater my own diet. Also Indian foods include lots of spices and oil and during this period I had a sort of aversion to smell and sight of the food that was spicy and oily. Things that I was enjoying before I was totally averse.
31:24
I: In the process of elimination do you have any particular structure, where you can see these are things I have tried and found patterns that triggered.
31:43
P3: Whenever I used to start getting stomach pains I would first cut down on bread, oily and spicy food.
32:20
I: And how did you find it out that these are the triggers. Like a food journal or diary. How did you find the patterns?
32:24
P3: I had a food journal, I don't maintain it now but during those initial four months I did maintain a food journal. To know what I have eaten for the week and to see what caused me the issue. And later try not to eat that food for the next week. As my condition started getting better and better then I introduced that food again to check if that causes the trouble. Some foods that caused me bloating made the pain worse at times.
33:50
I: Talking about different aspects of treatment like access, affordability and finance. I would like to go back in the timeline and know where all you face these issues as it is a bit unclear of when and where it all started.
34:16
P3: It all started in Ahmedabad. First of all I was taking tablets for indigestion. It did not start suddenly as such, and later I started with vomiting. And later the irregular bowel movements. And then one night pain hit me like a truck. But after a couple of days I went to the doctor in Ahmedabad. Since I was confused about what exactly was going wrong, he gave me medication for the stomach and a medication to put me to sleep. Even that sleeping pill used to be ineffective after

3-4 hours and I used to wake up with pain. And later when I could not manage this pain anymore I decided to move to Mumbai, my hometown. In Mumbai, my parents thought it was just a problem of common food poisoning but my reaction was extreme for food poisoning. So they were not understanding. So after that I went to the general physician who prescribed me with hypertension and depression medication. Even the chemist was shocked to see the prescription with a heavy dose of medication. And that is the same medication that I took for a few courses.
Recording 2 (restarted due to technical issue)
00:10
I: Continuing further, how did you manage to find the doctors?
00:18
P3: Through practo.
00:20
I: And the first few doctors were not working.
00:23
P3: Yes, after the first doctor I went to the second doctor who is our family doctor and gave me some food poisoning medication.
00:46
I: And then later you went to the specialist doctor.
00:49
P3: Since my parents were also not aware, they thought either it is food poisoning or alcohol poisoning or something else. And they put me on a proper balanced diet and forced me to eat more. Even the general physician said that if you give him a lot to eat when his stomach is upset.
01:35
I: How did that workout? Were you able to communicate?
01:37
P3: No, it did not work out. But it gave me more pain.
01:45
I: So then after a few weeks you went to the specialist? And you found them on practo as well?
01:55
P3: Basically I was looking for someone who is very close to my house, readily available. It was actually my sister who checked for it on some website. And she recommended it as the hospital was within walking distance.
02:36
I: Did you at any point feel that the access to the doctors was very difficult?
02:52
P3: I would not call it difficult as such, but I guess me and my family's mindset to not opt for specialist at start was an issue. Even though I changed doctors in between but did not opt for specialist doctor.
03:16
I: And how about the finance challenges?
03:24
P3: No challenges as such, but finance wise it was pricey. It was pricey because my condition was such that if I had opted for a government institution there would be a lot of waiting and I was not in that state that I could wait. In those days I used to get easily frustrated and angry and used to be in constant pain. Even at a good time there used to be mild pain. Now that my flare up has started a bit I can constantly feel a dull sensation.
04:20
I: And does your insurance cover your condition?
04:22
P3: It covered all the medical expenses which included a stay at the hospital, endoscopy, CT scan. And all of that cost me around a lakh of Indian rupees and the insurance covered it.
05:00
I: And do you have any expenditures right now? Or is it self-managed?
05:07
P3: It is prominently self-managed but when the flare up starts, there are certain prescribed medications I take. Apart from this I also tried a holistic medication approach to just manage the pain. I used to go to yoga classes and that actually helped me. Like I feel it helped me. The stretching and the physical activity kind of alleviated the pain I was facing and also made me recover some strength.
06:07
I: And talking about post treatment and self-management. When you were diagnosed and your treatment was going on what sort of support did you opt for like was it family or people around you with the same condition or any support groups or anything?
06:50
P3: I did not follow any support group or actively look out for people who are sharing information online. Then articles and news articles, those kinds of things I looked for.
07:13
I: And did you also like to look for the condition information constantly on any sort of health platform?
07:28
P3: Not just Web MD but many other platforms which I cannot recall all. But yes, YouTube was one thing, here I followed

a few TedX talks on this condition that let me gain a bit of perspective. Then there were articles about not just my condition but also how to look at life or things after you're diagnosed and what kind of medicinal approaches that I might take. And more holistic approaches where I learnt about how I can look for my care and treatment. Because even allopathic medicines which were prescribed by my gastroenterologist were harming my body as well. I mean they had their own side effects. So it was helping me but also creating other problems.
08:49
I: And how about the accountability part on both ends? Were there any follow ups? And if so, did you manage to have those follow ups?
09:05
P3: For now, I am not following up or anything. I am only following whatever course of actions that I was told to follow. But I have contacts even in Delhi which I managed to get like if there is an SOS/ emergency situation I can contact people. But since finance is an issue for me I am not keeping in touch or following up.
09:48
I: And what was the impact of all of this on your private and social and professional life?
10:07
P3: Private and social life I guess whoever is in close circle is very understanding about this. And right now they are understanding and managing whatever they have power to do. But in my professional life I am currently facing issues because there is a performance card. And during flare up episodes I am not able to focus on anything and go to work. And then explaining it is also difficult. People do not consider my situation as serious, even I do not consider it as serious. But it is very detrimental to my day to day life. Like I can not perform like a normal person. I mean I get sick very easily, because my immune system is hyperactive. Like when my immune system acts I start getting fever and other issues. My immune system starts fighting against things not causing problems.
11:40
I: Even if it is not physical, but the constant hammered pain and mental fatigue.
11:52
P3: whenever I am explaining it to others they feel like I am making something up or like I am bloating up a very minor issue like indigestion. Especially in India, I faced this a lot, where they say why are you complaining on a small issue. But if that small issue is happening everyday then it spins my head. I have kind of formed a thick shell around it, now I do not try to explain myself too much. I will only say this is what I am facing and this is what I was diagnosed with, if you want to clarify anything so come ask me personally or google it. There are people who understand it as well, but you can not expect everyone to understand what you are going through and be okay with it.
13:12
I: For the closing question, if you could change one or three things about this whole journey that you shared with me
13:24
P3: I would change my genetics first. Like I know it is an impossible ask. Even the second one I am thinking is impossible. Like living a very AQI friendly and environmentally good life and having a well nutritional diet.
14:16
I: Yes but if that is what your condition is making you feel like you need those changes.
14:22
P3: A different living condition would be much more peaceful and healthier. Society should be less ignorant.
14:40
I: And is there anything else you wish from the healthcare system, the government or the community?
14:55
P3: From the healthcare system, whoever I connected with like specialised doctors, because I went to a better and good hospital like a nice well established and pricey hospital, everyone that I had contact with was very understanding and very calm. That made me feel safe, as it was a private hospital whoever I was in contact with it was helpful and the experience was fine. Actually that was the one place other than the environment that would make me feel calm. When I was going through a lot of anger that place gave me clarity about my situation which made me calm. It is just that it is very pricey and not viable for me. Looking at my financial background, it is not a viable thing for me for over a long period of time. And I have watched my uncle die in a government institution so it is a very scary and anger inducing place for me. That is why I do not even comment on government policy and services. Also that it is overburdened.
17:13
I: And did you find that when you went to the hospital or clinic and any doctors, that they gave you enough and ample amount of time and information that you required at that stage?
17:24
P3: Yes
17:27
I: And what would your ideal support system look like? Like how should it be?
18:12
P3: As I look at it, I have not thought about it. But the allopathic that I went to were very supportive and did not judge my life. They gave me all the information that I needed, especially the specialist. But I would expect my family or my parents to be that understanding as well. Since my food palette is now very specific, I don't expect my colleague to understand that and I am not even bothered that they are not aware about it. But I would expect that from my close family members and that is what I expect. Ideally I would say something that would be accepted that would be from my parents and my close friends. As I live in a joint family, they cannot cater to an individual with a special diet. How can this be practical

is what I am aware of. But in ideal case, I would like them to understand me but I am not expecting them to satisfy the requirements of my condition and diet.
20:40
I: Thanks for sharing your story and your story gave me so many insights into this condition and how one perceives the treatment and you receive the treatment and how you are handling it. That's interesting and very strong of you to do all of this on your own and tell people about it
21:13
P3: Yes there was a time I had to fight with my family to just eat eggs. They were asking me to leave non vegetarian food. So then I had to involve my doctor who had to mention that eggs are one of the easiest sources of protein for your body to digest and his body needs it to heal itself. There were deeper level struggles on a day to day basis. I guess not everyone faces it, maybe there are other factors that other individuals might face like religious beliefs and culture.
22:10
I: Thank you for sharing. Let's move to the activities, it would take another 15-20 minutes.

Interview 4 – Patient 4
00:05
I : To begin with, let's start with a small introduction. Tell me about you, your healthcare journey and how did you find it ?
00:16
P4: I was a swimmer back then, I played national swimming competitions and won medals for the state. In one of the swimming matches, I was leading the board. In the last 15 meters I lost my pace. From leading the board, I was then swimming in 7th place. My parents kept wondering what went wrong. But then I was continuously complaining to my mom that my hand is in pain and it is going numb, I cannot feel my own hand. My hands were also turning blue while swimming. Everyone started thinking that I am giving nonsense reasons because I do not want to swim. But then my signs were highlighted by my coach and family as well. One day my coach came to my family and told them that he is genuinely suffering from this condition. My dad works in a hospital in management. Normally we go to his hospital to get treatment as we know all the doctors. Like a normal family does, we went to the hospital. We showed it to the general physician at the hospital. He said that I have some problem with the brachial plexus. But that time we were unaware, and then thought to take a second opinion. So we went to a neurosurgeon, and this specialist made me do multiple tests and perform physical examinations. As the reports were negative so they started another test which included needles pricking in my hand to see the graph of why I am having such numbness in my hand. In this, they pinched 4-5 needles in my hand, and the graph used to generate. At first, the assistant did the examination with needles and printed a report, but when the doctor arrived and said, ' I want to do it again as I was not there'. As I am afraid of needles, I started crying as I did not want to go through the pain again. In this examination, they put 4-5 needles on my palm and they used to pass electric shock to get the graph. After this at the doctor's consultation, my family and I were told that I have some mental disorder. And there is no physical issue, he is getting depressed by his work and you are forcing him to play for nationals and he is mentally abused. I did tell her that it is not true. Later we shifted to another doctor, he was a vascular surgeon. He referred me to the brachial plexus specialist practising at another hospital. There we waited for 4 hours to get his appointment and time. In the first meeting, he said to get the surgery done and thus we were scared. But it went well, because he said, 'I do not know if the operation will be successful or unsuccessful before doing it. All I know is I can only tell the success after I go to his room post surgery. And if it is unsuccessful there are a lot of chances for him to get paralysed'. This was because I was in the last stage of the condition. The thoracic outlet was getting pinched by a lot of forces when I was doing swimming and other physical activities.
06:48
I: Thank you for sharing this. But how did you get to know all this information? Now I can see that you went to so many doctors beforehand. At this point did you feel like I should change the doctor because I have already changed my doctor so many times, or was this more like confirmation and trust on this doctor. What made you decide or finalize the doctor.
07:12
P4: I had almost changed 9-10 doctors in this journey of 4 months. But then every doctor was concerned about some reports and some papers but the final doctor (brachial plexus) was only concerned about, what I am thinking, what I am saying. He was not concerned about any MRIs and scans and other. He just did some physical examinations. So my family and I were satisfied with his diagnosis. He said that I have to undergo surgery, as this is something which cannot be cured by medicines. So we were satisfied by his answer.
08:05
I: And were you informed about the whole procedure, the condition in that same meeting or was there a follow up?
08:16
P4: No, actually we got all the information in one meeting. We had 7 days to think and come up with a decision in the next follow up. But in those days, he was constantly there for us on the call. In the first meeting, it was just me and my mom so my dad once called the doctor and tried to get the information of procedure, insurance and other things. In this call the doctor was communicating and it went well. When my operation was supposed to happen, the papers got delayed from the insurance company and they will not reimburse for conditions that are by birth. As they denied the insurance, for a change when the doctor called the insurance company and requested to accept the papers. But that kind of made us anxious and wondered why a doctor would do this. Why would he care about this? At first it was kind of fishy for us, like why would a doctor do it for a patient by calling an insurance company, and all of this when he is so busy. But then we got to know from contacts that he is retiring and he is not looking for money or any other benefits. So later, I got admitted as planned and got an operation in the morning. And I got discharged in 2 days post operation.

10:56
I: And in that first meeting that you got informed about this condition, did you get all the information on the surgery and regarding your health and what caused it.
11:14
P4: Yes
11:19
I: As we came to the journey where you were admitted and discharged. Post that what all the activities happened when it came about care management. Was that transition from hospital to home enough information provided to you by the hospital services? How was the support provided by the hospital?
12:02
P4: After discharge, they provided contact to the physiotherapy. But it was far from my house, I guess it was 25-30 kms away. We only went once to the physiotherapist, and later she was not there in the city due to personal reasons. We only did one session though it went well, but then she asked my mom to do the rest of the physiotherapy at home. This included massage on my surgery scar and stitches, that made me scared of this. But then, being a doctor she can do it, but being a mom she cannot do it as I am her son.
13:12
I: True and she is not trained to do it as well.
13:18
P4: Exactly, and my mom tried her best but then I did not want to continue it and wanted to do something else. So then we did some other things. From the hospital's end it was clear for us with information and there were no issues. Like after the discharge stage.
13:46
I: Because you modified the exercises physiotherapist gave to you did you like find that information somewhere or figured it out yourself.
13:55
P4: As I told you, I am a swimmer. I had my own trainer and sports physiotherapist, he used to treat me when I got any sports injuries. So I went to him when I had to continue physiotherapy.
14:21
I: And did that help you out with physical issues.
14:29
P4: Now I will be completing 3 years and I do not have issues with the right hand.
14:38
I: Did you look for any particular information when you were going through recovery or trying to find some people who know about this?
14:53
He: I did not get any kind of good results from the web.
14:57
I: Like reliable or 'good' results?
14:58
P4: Reliable mainly. Whomever I read about were from north India a bit far away from me. And I also looked for doctors for brachial plexus, but then I could not find doctors in India but in Sweden. This is called the syndrome, it's not very common in our age. As doctors said that this is common to have but this is not common to get diagnosed at this age. By birth this condition exists, but this condition starts showing issues to people who are 60+ in age, when they stop doing physical activity. But locating the issue at age of 16 is not normal or common. I guess I was 16 when I got the operation.
16:39
I: All of this information coming to you, taking care of yourself. How have you managed your emotions? Like how it was when the physiotherapist was not there after a certain point and everything was on you and could not go back to hospital. What was the emotional state at that time?
17:04
P4: Actually I was not doing fine at that time. I missed my college for almost 2 months before and after the operation. So it was imbalanced because I was missing my lectures, swimming and also a national tournament. Plus I am not finding any kind of cure, I had tape on the stitches so I was completely on bed rest. So I was kind of thinking to myself about what I have done to me. And then I am not finding any kind of physiotherapist, but then my family stood for me. My grandmother was here to support me. I had to use a walker, I do not know why, my condition has nothing to do with my legs. I had that mental condition that I could not walk or move. Then it went well. I had a girlfriend of mine like she was always there. Even in the hospital she used to come after the college, and used to update me with the college and studies. Later, she used to also come home just to give a summary of the lectures and college. It was well.
18:46
I: As you were mentioning that there were people around you supporting you, did you realise a few things that they might be undergoing through any complications of not being able to relate to you and you not able to relate to them.
19:08
P4: Yes kind of, but I was not in that stage to think that deeply about it. But then as I started healing, those thoughts also started to vanish.
19:57
I: When it came to these emotions that you were going through, what have I done to me. At that stage did you feel like

nobody is able to understand me and my stage. Were there efforts or any other sort of activity you did to express each other's stage or zone.
20:26
P4: Actually these emotions were there before the operation, when I was trying to tell my parents and my coach that I am not making any excuses but it is really happening to me. It was really hard for my parents and coach to understand what I am going through. All they used to say is that I am not doing well. At one point, I was losing swimming laps against a 6 year old kid. It was a bad thing they said, but it was shameful for me, that being a national swimmer, I am getting defeated by a child. And all of this due to an issue which my parents are not understanding. Later after a few conversations, my parents accepted that he was telling the truth.
21:30
I: That is good that there were supportive people around you throughout the process. Good to hear that they hear you and you did not go unseen in this process. Now talking about accountability and how you managed to track your progress. Like did you have any particular tool for tracking your progress or where you want to reach, or was there any particular tool?
22:05
P4: I did not have any tools, but I just had one goal. The doctor said that you can resume swimming after 2-3 months of the operation. So that was my only goal to keep exercising and to keep myself strong so that at least I can resume swimming in 3-4 months. I even had my boards and prelims coming up. I had just set up a goal to swim in 3 months.
22:52
I: And did you manage to achieve it?
22:55
P4: Yeah, I do not know about studies, but I managed to achieve my goal of swimming. But now I have stopped swimming. That time I did start swimming (2022 to 2023). And till July 2024 I did continue to swim. And in that one year, I realised that I have lost my pace and now it is impossible for me to match it to the level where my competitors are. As my age was not more in the bracket of under 18 to open, so it was not great to continue swimming. So I have left swimming for nationals.
24:14
I: Do you still manage to go for a swim, but not for any competition?
24:18
P4: No, next month I am starting to go for normal swimming as a hobby but not to compete. Just like to have a regular fitness or routine. I actually got another medical condition, 4 months ago. I got cervical spondylosis. I do not know the reason, but the discs near my neck kind of moved from their original place. Doctors have suggested at least going for a swim. It has now healed from doing physiotherapy, and swimming will help now. And talking about the left side hand, I am having the same problems with my left arm. And this was one of the reasons why I left swimming completely. I am facing the same issues and pain. Professionally I am a photographer and I do have my own event management company. I started it 2 years back, I have been working for almost 12-14 hours a day for the events and photography shoots. I have to carry a camera of 3-4 kg on my neck and keep standing for almost 6-7 hours. So it is kind of a hectic job for me. And this is why the issue is flaring up. In these events, I realised that it is going again on the tracks which I left. I started fainting at events now, but it was not the case before.
26:50
I: And did you contact your doctor now?
26:54
P4: No, I have not yet contacted him.
26:57
I: And are you doing some physio or taking care at this stage?
27:04
P4: I am just waiting right now. I do not know if these signs are the same. As I mentioned I got cervical spondylosis. That time doctors said it was not in the serious stage, you need to start forgetting to get out of this. To have a normal lifestyle, you need to have better posture is what the doctor said. But then, I am not sure on my own that this is the same case I got operated for or it is something new. I am just kind of waiting for the right time. Actually, I am talking to a sports person who is also a coach for the Indian Kabbadi team and he has given contacts to the sports physicist. This sport physicist is expert and helps in avoiding 90% of surgeries and gives right treatment which is also doable and is curable. But to get his appointment the waiting is for 9-10 months. In the next 5 months I will get an appointment by contacts. Let's see how it happens. This flare up is affecting my business and my productivity time.
29:01
I: This is also one of the topics I wanted to talk about, where your personal and professional life gets affected because of this health condition. As we can see how it affected your professional life. Apart from this, has it affected your social life, like your mental health too?
29:25
P4: What do you mean by social life?
29:29
issues.
I: Like because of this condition, going out and meeting friends and losing confidence
29:38
P4: Yes, It was my last year of my senior schooling and I had lots of friends. They used to go around and bunk the

lectures. And everyone was going everywhere and I could not join them. But then at the same time, they sometimes used to visit me to cheer me up. It was kind of balanced at times for me.
31:20
I: How do you balance your personal and professional life with the new normal and condition? Whenever the flare ups happen or sometimes the pain is intense, how do you manage that?
31:39
P4: I always have a substitute at an event or shoot, and when I am feeling dizzy or my hand is getting numb by holding the camera for too long, then I get the substitute who will work for me.
32:18
I: And how do you note these flare ups, like do you journal or write any note on those days.
32:50
P4: No, I am so lazy that I do not do it. My mother says to do it on your own, but I do not do it.
32:44
I: Thank you for sharing your journey of care from start till date.

## Expert Interviews

### Summary of care coach interview

She is a cancer research scientist and used to work at Cancer research centre in Mumbai in the field of carcinogenesis. At the age of 36 she was diagnosed with ovarian cancer. She self-diagnosed herself as she was expert in this field and her colleagues and other cancer experts indicate the exposure to cancer due to her field of work.

Being in this field of cancer research and working in it for decades, she stated that she was mentally strong and knew that she had to accept it. She had read articles and was active in this field which made her journey of diagnosis and treatment better, where she knew she had to keep herself busy in a routine. As she was diagnosed with ovarian cancer she had to shift her professional career path and joined her husband's business in IT. Being in this field of work, it was easy for her to navigate and knew what could be the plan of action and had access to contacts of specialists. It became her duty to talk to her family and explain and give them information. Everyone in her family and her relatives were worried but constant communication and clear explanation of her status by herself helped them in understanding the situation.

Today, she is providing coaching for patients diagnosed with cancer and providing the required support to find resources like finance, specialist doctors and hospitals, she spreads awareness and educates patients of their condition. She has been doing this counselling for 10 years and free of charge.

She mentioned she likes to inform the patients and their families about the importance of mind and body connection and its relationship. She promotes positivity and links it to body hormones. She provides the patients and their families a routine and suggests them to reflect and think positively at night as the thoughts at night impact the start of the day and further links to the hormones that will keep you positive the whole day. She asks them to stay grateful and keep themselves engaged in some routine. She asks them to have 3 hobbies, this will help them to keep themselves distracted from negative thoughts. She advises them to keep saying positive words daily.

For the financial support, she provides them different plans and solutions that they can opt from government schemes or other NGOs and charitable trusts. She mentioned that it sometimes worries her that people have so many misconceptions about cancer and sometimes social media and certain applications provide a platform to spread false information.

She further emphasized a mix of mindset and cultural practices. In India traditional practices like ayurveda and yoga are followed by many. In these practices she mentioned how it follows the body, fitness and overall health. She mentioned how holistic care is required in managing care and to see improvements.

She mentioned how many times with the false information getting spread due to access to social media and the internet, individuals would follow random suggestions and thus would not get the positive results impacting their mental health.

During her counselling she gives different time slots to patients and their family members which allows them to open up. She advises them to have clear and open communication. She believes her role is more like a bridge to connect the patient and family member together and bring them on together and share their emotions, frustrations and problems and work as a team. She introduces the family members to how to not over care and yet still be supportive. She has observed that the patients at times are at a better stage than the family members. Family members feel irritated and burdened under the new responsibility and are clueless of how they can manage this and also take care with no medical background. While the patient's confidence level drops and is not sure of how to adapt to the new normal.

At times as a counsellor she has to give them the advice as a second opinion holder.

She emphasises on three main things :

1. Relation with your body - Keep an eye on your body and mind. Try to find the root cause and start acting towards it.
2. Start treatment - It is important to not just accept the condition but also to work towards it and adhere to the process of treatment and rehabilitation.
3. Keep yourself busy - Patients should keep themselves occupied with at least 3 hobbies

**Summary of Physiotherapist Interview**

The sports physiotherapy centre was a large one with Mult speciality services. It not only looked at physical exercises but also strength and conditioning, nutrition, psychology, bio-mechanics and recovery services. I spoke with the managing head of the centre.

Types of people who come there are people who have some injury or surgery or athletes who are undergoing muscle injury. And this could be chronic cases or cold cases. The scope in this field as mentioned by the head of management is that they are facing problems with marketing as they are not able to reach and be accessible, apart from this is the problem of spreading awareness that physiotherapy is equally important as medications. He said 50-60% of the informal caregivers, that is the family members, are involved in the process of physiotherapy and want to learn about how to take care.

He mentioned that it is work of patience, as to see the impact of sessions it requires 6-7 sessions thus it requires adherence to the treatment. They try to follow up through multiple ways Follow ups are done in multiple ways, At centre, Reminders through calls, Trackers at centres, At home service. They try their best to have a strong follow up as adherence to treatment is really important. But he has seen that as the pain reduces after a certain number of sessions, patients tend to leave the treatment in between causing a flare up or relapse in muscle pain.

When trying to give them exercise to do at home, he makes sure that they are not above 30 minutes as that might impact on adherence and they would not do it. Many times he has seen the family members record the exercise videos in their phones and they themselves support and promote taking videos as it ensures that they would have less doubts while doing so and build confidence.

Apart from that he mentioned that nutrition is equally important in muscle development. At times they also see that the patient is suffering through trauma of doing certain activities. They also prescribe massages in the recovery phase to help in rehabilitation to a new normal.

Things that he wants to spread awareness about is that to tell everyone walking is not an exercise, wants to spread awareness about the importance of physiotherapy and its adherence, and last thing is that surgeries can be avoided or prevented if you work on your body.

The physio centre also has their own application called Athlex it uses the font camera and scans the space and body. Post that it follows your body to see if your exercises are on point and doing right and mainly focuses on strength and conditioning. It also has the evaluation of personal goals to keep track of your development. And mainly that application is linked to Ayushman Bhart the policy that is looking forward to digitalise and consolidate the healthcare system in India.

Design thesis workshop summary

Workshop 1
Co-Care Service Prototype Testing Participant: P2 and C2 (Patient and Informal Caregiver)
Condition: Behçet’s disease (rare autoimmune condition) Phase: Rehabilitation- active self-management phase

Context
P2 and C2 were engaged in a prototype testing workshop for the Co-Care service. By the time of this workshop, P2 had developed a working understanding of their condition through dietary journalling, trigger tracking, and independent research. The session was conducted with both the patient and informal caregiver present.

Workshop Structure
The session opened with a brief framing of where Co-Care sits within the care ecosystem, positioned between home care and clinical visits, with the coach supporting patients and families in the intervals between hospital appointments. The coach role was clarified as non-clinical: coaches do not diagnose or replace doctors. Their function is to help users organise questions over time, prepare for care conversations, make sense of information and options, identify next steps and resources, and follow through on actions post-appointment.

The three service stages were then introduced using accessible language: Identify your question, Attend a session with a coach, and Act on the post-session summary.

Scenario Selection

Participants were offered scenarios inspired by real experiences from prior research interviews, or the option to propose their own. P2 selected the following scenario:
“I thought I had figured it out, then it relapsed.” Through diet tracking, journalling, and online research, the user had begun to understand their triggers and felt more in control. Then the condition relapsed severely without a clear cause, resulting in an emergency room visit. Despite sustained effort, doctors had no definitive answers, leaving both patient and caregiver without clarity.

Prototype Walkthrough
Working from this scenario, participants moved through the physical card set and selected: Which routines are helping me, and which are not? They then scanned the QR code on the card, which directed them to the app. Within the app, they reviewed and selected from a set of sub-prompts, topic categories relevant to their situation, and used these to identify the focus area for a coaching session. A session slot was then booked through the platform.
Following the booking, the post-session experience was explained: participants would receive a coach-written summary in the app alongside contextual calls-to-action. For example, a recommendation to track diet or exercise would link directly to the in-built tracker; a recommendation to consult a specialist would surface a connect or book option.

Summary
The workshop validated the core service logic for a participant who had already moved through the most difficult phase of rehabilitation independently. The primary value proposition resonated most in retrospect, both participants identified the service as most relevant to the earlier, more disorienting phase of their journey. Caregiver inclusion within the card set was a notable point of positive response. Open questions around subscription structure and coach assignment will be carried forward into service flow refinement.

Workshop 2
Co-Care Service Prototype Testing Participant: P4 (Patient)
Condition: Thoracic Outlet Syndrome- post-surgical, with emerging symptoms on the second hand
Phase: Rehabilitation- post-surgery, navigating recurrence of signs and weakness

Context
The second workshop followed the same structure as Workshop 1. P4 had undergone surgery in mid-2022 and was a national-level competitive swimmer prior to diagnosis. At the time of the workshop, he was no longer able to practice competitively and was experiencing early signs of the same condition developing in his other hand. The session was conducted with P4 individually.

Workshop Structure
The session framing, coach role definition, and three-stage service introduction followed the same structure as Workshop 1: positioning Co-Care between home care and clinical visits, clarifying the non-clinical nature of coaching, and walking through the Identify, Attend, and Act stages.

Scenario Selection
P4 selected the following scenario:
“This doctor believes me, but I have to decide quickly.” After months of uncertainty and repeated misdiagnoses, the user met a specialist who listened carefully and confirmed the diagnosis through physical examination alone. Surgery was presented as the only viable option, carrying significant risk, with only a few days to reach a decision. The period was marked by insurance delays, family discussions, and ongoing communication with the doctor, all happening simultaneously under time pressure.

Prototype Walkthrough
From this scenario, P4 selected the card: What part of my treatment still feels confusing?
He moved through the QR code, reviewed the sub-prompts within the app, selected topics relevant to his experience, and proceeded through the booking flow as in Workshop 1. The post-session summary and contextual calls-to-action were explained in the same sequence.

Summary
Workshop 2 reinforced the service’s relevance at a specific and underserved moment in the care journey: the period of high uncertainty and rapid decision-making that precedes major clinical intervention. P4’s reflection on generational trust differences surfaces a meaningful design and communication consideration, the service’s credibility with older informal caregivers is likely to depend on institutional endorsement rather than independent discovery. The open questions around payment structure and coach selection are consistent with those raised in Workshop 1 and will be carried forward as priority areas in the service flow and onboarding design.

Workshop 3

Co-Care Service Prototype Testing Participant: Care Coach (Expert)
Background: Retired cancer research scientist; currently provides informal care consultations to patients and families, offering guidance on navigation, contacts, and care decisions
Phase: Expert validation workshop

Context
The third workshop was conducted with a practicing care coach to test the service concept from the supply side. Unlike the patient and caregiver workshops, this session was oriented toward understanding how an experienced coach perceived the service logic, where she saw gaps, and what she would add or change based on her own practice. Her dual perspective, as both a scientist and a long-standing informal care consultant, made her feedback particularly relevant to the coach role definition and the pre-session design of Co-Care.

Workshop Structure
The same service framing was used: Co-Care's positioning between home and clinical care, the three-stage flow of Identify, Attend, and Act, and the non-clinical definition of the coach role. The session then moved into open discussion, with the participant responding to the prototype based on her own consultancy experience.

Summary
Workshop 3 provided expert-level validation of the service concept while surfacing two significant design implications. First, the pre-session preparation stage may need a prioritisation layer, a structured mechanism that helps users narrow down what they most need before they encounter the coach matching flow. Second, the suggestion of a mediator function points toward a triage or intake layer that sits earlier in the journey than the current Identify stage accounts for. The proposal for a 24/7 lightweight support touchpoint is consistent with the nudge and re-entry logic already defined in the service, and reinforces its importance as a safety net between scheduled sessions. The question of scope expansion and the recurring open questions around payment structure will be carried forward into the business model and service flow documentation.

Workshop 4
Co-Care Service Prototype Testing Participant: P3 (Patient)
Condition: Crohn's disease (autoimmune condition - dietary trigger tracking and allergen management)
Phase: Rehabilitation- active self-management phase
Format: Remote session; participant tested the app prototype through user task workflows

Context
The fourth workshop was conducted online with P3, who had been a research participant in the earlier interview phase. The session moved beyond concept explanation into hands-on prototype interaction, with P3 completing user task workflows within the app. This made the feedback more specific and interaction-level than the previous workshops, surfacing friction points that would not have been visible through discussion alone.

Workshop Structure
The session followed the same framing as previous workshops, Co-Care's positioning, the coach role definition, and the three-stage service flow. P3 then navigated the prototype independently through defined task flows, with observations and feedback collected during and after the interaction.

Closing Reflection
At the end of the session, P3 offered the following unprompted observation:
"Live service tracker provides credible advice, and not only AI service but beyond that, it builds human connection and people and community. It's bringing the learned knowledge and shared experience."

Summary
Workshop 4 produced the most interaction-specific feedback of the four workshops, surfacing two friction points requiring direct design resolution: coach visibility before payment, and the need for a co-created shared goal plan within the post-session experience. P3's preference for coach selection over coach assignment, and his concern about cards as a potential entry barrier, reinforce decisions already under consideration in the service flow. His closing reflection articulates the platform's underlying value proposition with clarity, the combination of structured tracking, human coaching, and shared community experience is what differentiates Co-Care from a purely digital or AI-driven tool. This framing is worth carrying explicitly into the thesis write-up.