



People's health seeking journeys were an important unit of analysis in Project ARC. The inflection points in these journeys helped the team understand the sources of frustrations (and at times, satisfaction) of health seekers. These frustrations and failures were identified, categorized and clustered. These clusters were then labeled and connections between them were explored. What emerged was essentially a set of **Frictions** - gaps between health seeker expectations from the healthcare system, and what providers (primarily public health but even other types of providers such as private healthcare providers or traditional practitioners) were willing and able to provide them. Apart from being barriers, these frictions, perhaps more importantly, are also opportunities for interventions and innovations. These frictions fall within two broad and interrelated buckets of the typical **health journey** and the **[lack of] enabling factors** that contribute to the success **[failure]** of the health journey. They are briefly described below.

- The health journey:
 - **Awareness & Knowledge**
The health system is often equipped to recognise a patient only after a successful diagnosis and patients are left to navigate the initial stages of their journey with minimal formal guidance.

“I used to have pain here (throat) at the end of December. My throat was swollen a lot; I didn't pay much attention (to begin with)...I went to Faraji Hospital. After going to the hospital, he (the doctor) gave many tests... After the tests, he didn't really tell me what had happened to me. He gave me a lot of medicine. I took it for about 1-2 months. Additionally, we had to pay him 500 taka as visiting fees. It was getting tough for us... Then I thought I

should go to Jashore (a smaller town and her maternal home). Everything is much cheaper in Jashore. I visited the doctor there and he said that I need a biopsy. After the biopsy he said that I had TB.”

A young woman from Dhaka, Bangladesh recounted her arduous and expensive journey to a TB diagnosis.

- **Accessing the system**

Through a healthcare journey, a health seeker has to make important financial, emotional, social, and spiritual decisions and sacrifices that have consequences on their health and the health of their families. These decisions take the form of ‘tradeoffs’, where certain strands are prioritized over others. While seekers are expected to make multiple trade-offs in favor of their physical health, they may perceive risk differently than their health providers.

“It was in Rangpur. After giving some treatment to her (his wife), they told me that they had to do an operation. They couldn’t tell me for sure that she could have a baby after that operation. I came back from there.”

A man from Bogura, Bangladesh spoke of a potential tradeoff (between his wife’s health and her ability to have children) that he and his wife were asked to make. Eventually, they successfully sought treatment elsewhere where they were not asked to make this tradeoff.

- **Adherence & Maintenance**

Upon diagnosis, seekers with serious ailments embark on an emotional transition from seeker to long-term patient, which is often a daunting experience for the seeker because of the trauma they experience from the diagnosis. Despite this, they are required to make this transition swiftly and without time and support.

"I have been on treatment for the past 8 years. It was not easy at all. I could not accept my status when I first found out. I wondered where I got the virus because I was very careful. I was in denial about my status. It took me 3 years to accept and start with the treatment. What made things worse was that at the time I was working at Love Life and my duty was to encourage people to take treatment and live a healthy lifestyle, yet I couldn’t talk to anyone about my status"

A 34 year old health seeker from Gauteng, South Africa who used to work at a NGO running HIV awareness campaigns. He spoke about his own difficulties during the first three years of his diagnosis.

- [Lack of] enabling factors:
 - **Dialogue/Trust/Understanding**

The absence of dialogue can lead to an understanding gap, which over time can result in reduced trust in the health system. This becomes a vicious cycle that compounds over time. As a consequence, seekers may be left feeling confused, disempowered, ill-equipped in managing their own health journey, and unable to deal with their side effects.

Nafisa, a staff nurse in Dhaka, Bangladesh stressed on the value of discussions with health seekers in the Korail slum. As a part of the Compassionate Korail project, she has been working with this community of health seekers for over five years. In slums, private space is often difficult to find and conversations happen in public squares. Nafisa talked about courtyard meetings, where health seekers were informed about the covid-19 pandemic and the steps they needed to take to prevent infection. In these discussions health seekers would ask questions and get their doubts clarified. Many of the “why” questions associated with recommended behaviors were discussed. As a result of these efforts, Nafisa says that her patients are much more aware and a real behavior change has been seen when it comes to mask wearing, hand washing and raising awareness within their families.

- **Social Networks**

Patients are part of an expansive social network, which includes family, friends, neighbors and non-formal health providers among others. By failing to leverage this network of care in a patient’s treatment, the system does not equip existing care-givers with information and skills that could improve a seeker’s health journey.

“My children were telling me that I was getting thin. I had pains in my heart. I was at first denying that I was sick... I started first at the pharmacy, but the medication I got did not help. Eventually the children insisted I go for help, so I went to the clinic. My children insisted I go to the clinic for TB testing and Covid testing. My clinic is within walking distance for me.”

A 60 year old man from Western Cape, South Africa who was struggling with unemployment required nudges from his family to seek healthcare and was diagnosed with TB.

- **Intermediaries**

Seekers need various forms of support to physically, emotionally and financially navigate a complex, at times bureaucratic public health system. While there is a large demand for this, the lack of formalized roles or solutions means that this support is provided largely by unregulated actors,

such as touts or pharmacists, who are accountable neither to the seekers nor the system.

“I went to Bogura, there was a doctor my friend knew, Jolly, who recommended me to a chest doctor at Ibne-Sinah hospital. After going there, the doctor changed the medicines. He again gave me so many medicines and injections. I took those for fifteen days but I didn’t improve a bit. Nothing was working. So, my friend called Jolly again and said that nothing was working and asked what we should do. Then she told us about a senior chest disease doctor to go to.”

A sixty year-old TB patient in Bangladesh benefitted by having intermediaries who helped him navigate the health system and advocate for his needs.